
Parent Perspectives on Sources of Information About Autism Spectrum Disorder Interventions in Australia

Sarah Carlon, Jennifer Stephenson and Mark Carter
Macquarie University Special Education Centre, Australia

Extant research on sources of information about interventions used by parents of children with autism spectrum disorder (ASD) has provided a general overview of sources used. However, it has provided little insight into why parents view certain sources as reliable or trustworthy, or how useful parents found the information provided to them by the sources and why. This paper provides a qualitative analysis of interviews conducted with 12 Australian parents of preschool-age children with ASD. Participants discussed the factors related to their perceptions of the reliability and trustworthiness of sources used, as well as the usefulness of the information provided. Parent ratings of the reliability of sources were influenced by factors including the firsthand experience of other parents, the parent's relationship with the source, and their beliefs about the sources' intentions. A number of parents reported that sources provided either information of limited use or an overwhelming amount of information. Considerable variation was reported in the usefulness of information provided to parents. Recommendations regarding research and practice are offered.

Keywords: autism spectrum disorder, decision-making, information sources, intervention, parent, treatment

After diagnosis, and often throughout their children's lives, parents of children with autism spectrum disorder (ASD) make decisions about intervention use. There are many interventions available to parents, including interventions that have sound empirical support, such as those based on the principles of applied behaviour analysis (ABA; National Autism Center, 2009; Odom, Boyd, Hall, & Hume, 2010; Prior, Roberts, Rodger, & Williams, 2011; Wong et al., 2013). There are also a number of interventions without such support, such as a range of complementary and alternative medicine (CAM) interventions, including some that have been identified as ineffective and controversial (Green et al., 2006; Metz, Mulick, & Butter, 2005; National Autism Center, 2009; Prior et al., 2011).

Sources used by parents to obtain information about interventions available for children with ASD have been reported in recent survey studies. These offer a general indication of how parents are finding out about interventions. Commonly reported sources include the internet, medical and other professionals, educators, autism

Correspondence: Sarah Carlon, Macquarie University Special Education Centre, Macquarie University, NSW 2109, Australia. E-mail: carlon.sj@gmail.com

associations or peak bodies, newsletters, other parents of children with ASD, friends, relatives, books, media sources, and research/journal articles (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Christon, Mackintosh, & Myers, 2010; Erba, 2000; Hanson et al., 2007; Miller, Schreck, Mulick, & Butter, 2012; Şenel, 2010; Smith & Antolovich, 2000). Although sources of information about ASD interventions were reported in numerous studies, few studies included data on the relative importance that parents give to information obtained from different sources. The data that were available simply provided an overview of the relative importance of recommendations from different sources in the decision-making of two groups of parents (Hanson et al., 2007; Smith & Antolovich, 2000). They did not provide insight into why parents perceive different sources to be more or less reliable or trustworthy. Nor did they address the issue of how useful parents find the information provided to them by the sources and why. Although data collected in survey studies may assist in identifying which sources are given more weight in decision-making, deeper qualitative investigation is necessary for the exploration of why parents perceive sources as reliable or trustworthy. Qualitative investigation would also facilitate the analysis of the type of information provided to parents and how useful they perceive it to be.

Much of the research related to sources of information used by parents has been conducted with populations in North America (Christon et al., 2010; Erba, 2000; Green, 2007; Hanson et al., 2007; Miller et al., 2012; Smith & Antolovich, 2000). In Australia, there has been only one study specifically addressing information sources and intervention decision-making, with a focus on dietary interventions and nutritional supplements (Lynch, 2004). Three other Australian studies addressing the issue of postdiagnostic support for parents included some data on information sources used and the usefulness of the information provided (Rajkovic, Thompson, & Valentine, 2010; Valentine, 2010; Valentine & Rajkovic, 2010).

In 2008, the Australian Federal Government introduced a program to support families with young children with ASD called the *Helping Children with Autism* (HCWA) package (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012). The package includes the provision of information for parents through *Early Days* family workshops and an ASD website, the provision of ASD-specific playgroups and ASD-specific learning and care centres, and funding for some early intervention services. Through the HCWA package, parents of children aged 6 and under may access A\$12,000 of funding (maximum of \$6,000/year) to pay for early intervention services from approved service providers. It is the parents' responsibility to allocate this funding towards their chosen intervention(s) (delivered by approved providers). State and territory autism associations in Australia provide an autism advisory service as part of the HCWA package. Autism advisors provide information about the package and, along with the *Early Days* workshops and the Raising Children Network ASD website, are likely to be common information sources that are specific to the Australian context (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012).

Given the range of interventions available to parents of children with ASD, including those available through the HCWA package, it is important to determine how parents decide which sources of information about interventions to use. There are very few data available regarding how parents assess the reliability and trustworthiness of information sources. Additionally, there are scarce data regarding how useful Australian parents find the information provided by different sources.

In response to this lack of data, an exploratory qualitative study was conducted to examine how Australian parents decide which interventions to use with their

preschool-aged children with ASD. In this paper, two specific aspects of parents' perspectives on interventions for preschool-aged children with ASD are reported using data collected in the study; namely, reliability and trustworthiness of sources of information and impressions of the usefulness of information provided. Specifically, the research questions addressed in this paper were:

- (1) What factors do parents consider in assessing the reliability and trustworthiness of sources?
- (2) How useful do parents find the information provided to them?

Method

Participants

Participants were parents of preschool-age children with ASD, and were recruited through Autism Spectrum Australia (Aspect). Aspect is the largest provider of ASD-specific early intervention services in Australia, and an ASD diagnosis (from a paediatrician or psychologist) is required to access these services. Aspect early intervention staff distributed email or hard copy recruitment notices to parents of children receiving early intervention services from Aspect in Sydney, regional New South Wales (NSW), and the Australian Capital Territory (ACT). Twenty-two parents expressed interest in participating, including 12 from a single centre-based service location. As the researchers wished to include participants from a variety of locations, three parents were chosen at random from the group of 12 from the single location and were invited to participate. In addition, one other parent was excluded when she advised that her child was attending school, thus giving 12 participants in total.

A demographic questionnaire (asking about the child's age and diagnosis, presence of siblings, both parents' ages and education levels, residential postcode, family income levels, and parental beliefs about the aetiology of ASD, and perceptions of their child's ASD) was developed by the authors. It was administered by the first author (via phone or in person) prior to the interviews, along with the Childhood Autism Rating Scale – Second Edition (CARS-2; Schopler, Van Bourgondien, Wellman, & Love, 2010), to obtain background information about the families and the level of functioning of the children.

The respondents were 11 mothers and one father. Four were aged between 25 and 34 years, seven between 35 and 44 years, and one over 44 years. Ten participants were from the Greater Sydney area, one from the Central Coast of NSW, and one from the ACT. They were from a range of service locations, including both centre-based and home-based services. All participants lived in areas classified as major cities in the Australian Standard Geographical Classification of Remoteness Structure (Australian Bureau of Statistics, 2006). Annual family income levels were reported in 11 cases. Five families had income levels between \$40,000 and \$80,000; three between \$80,000 and \$120,000; and three over \$120,000 per year.

Information was also requested about the highest education level of both the responding parent and the child's other parent. The highest education level obtained was high school for one mother; Technical and Further Education (TAFE), college, or further training for four mothers; an undergraduate university degree for six mothers; and a postgraduate university degree for one mother. There was a similar pattern for fathers. The highest education level obtained was high school for one father; TAFE, college, or further training for four fathers; an undergraduate university degree for five fathers; and a postgraduate university degree for two fathers.

The children had a mean age of 4.0 years (range: 3.0–4.9, $SD = 0.59$), and included eight boys and four girls. They had all received a confirmed diagnosis of an ASD from a paediatrician or psychologist (this was a requirement for accessing Aspect's early intervention services). These diagnoses were all received prior to the release of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013)*, in which criteria for the diagnosis of ASD under a single label are presented. Eleven children were diagnosed with autism and one with pervasive developmental disorder not otherwise specified (PDD-NOS). Parent ratings of severity of ASD symptoms ranged from mild to severe. The CARS-2 (Schopler et al., 2010) scores placed five of the children in the range of minimal-to-no symptoms of ASD, five in the range of mild-to-moderate symptoms of ASD, and two in the range of severe symptoms of ASD.

Instruments

A structured interview schedule was developed by the authors based on available data about commonly reported information sources used and factors in decision-making (Carlon, Carter, & Stephenson, 2013). (A copy of the interview schedule is available from the authors on request.) It included both factual questions regarding interventions and sources used as well as open-ended questions designed to explore parental reasoning. Questions relating to decision-making were asked about specific interventions rather than asking about decision-making for interventions in general. This was to support parents to accurately recall what had influenced specific decisions rather than hypothesise about what may be important in decision-making.

Questions designed to explore parental reasoning were presented as leading questions with a number of probe questions, and asked about: (a) the three interventions currently being used that were considered the most important, (b) interventions that had been discontinued, (c) one intervention that the participant had seriously considered using, and (d) one intervention that the participant was least likely to use. For the present paper, answers to the following probe questions were of interest: (a) Where did you first hear about it? (b) Did you get information about it from anywhere else? (c) Did you receive information from friends or relatives, other parents, medical staff, the internet, magazines, teachers or service providers, books, conferences, research/journal articles, media programs, newsletters, or any other sources you can think of? (d) Did you receive conflicting information about this treatment/intervention? (e) How did you decide which information was the most accurate? In addition, parents were explicitly asked about the reliability of different sources. First, they were asked an open-ended question about which sources they believed offered the most reliable and accurate information. Second, they were provided with prompts of sources commonly identified in previous survey studies, and asked whether they believed any of those sources were reliable. Third, participants were asked to rate the reliability of the sources they had actually used (not reliable, not sure, somewhat reliable, or very reliable). Any additional comments about why they made these ratings were recorded.

It should be noted that the concepts 'intervention' and 'reliable' were not defined for parents in this study. This meant that rather than being confined to a restrictive definition of the terms, parents were able to interpret what they meant. This was to allow parents to identify what they believed to be interventions; that is, what they had decided to use or not to use with their children, and for them to state how reliable or trustworthy they believed sources to be. To facilitate the triangulation of data, parents' perceptions of the

reliability of sources were asked about in three ways. If a parent nominated a source as reliable, this was coded as reliable unless they qualified their answer, in which case it was coded as somewhat reliable. If a parent indicated they did not believe a suggested source was reliable, this was coded as unreliable. The same coding rules applied to responses to prompts of commonly used sources, and to responses given by parents when asked to rate the reliability of sources they had used. When asked whether a source was ‘not reliable, not sure, somewhat reliable, or very reliable?’ some parents replied ‘reliable’. Ratings of ‘very reliable’ or ‘reliable’ were coded as reliable.

Procedure

Ethics approval for conducting the interviews, including the use of an incentive for participation, was obtained from both the Macquarie University’s Human Research Ethics Committee and the Aspect Research Ethics Committee. Interviews were conducted by the first author using the interview schedule. Additional probe questions to clarify information provided by the interviewees were used as needed. Telephone interviews were conducted with 11 of the parents and a personal interview in one case at the participant’s request. All interviews were audiotaped and later transcribed by the first author. This provided an opportunity for emergent insights into the themes present in the data (Patton, 2002). Transcripts were sent to the study participants, to allow them to check the transcripts for accuracy and add further explanation if they thought appropriate. Some minor changes and additions were made to some of the transcripts, and the amended transcripts were used in the data analysis.

Data Analysis

Qualitative data analysis was undertaken. Initially, all data were coded for overarching major themes relevant to the larger study. The primary coder (first author) used open coding (Strauss & Corbin, 1998) to identify emergent themes in the data. All transcripts were examined and a preliminary list of major themes and subthemes was developed. Additionally, possible major themes and subthemes were also identified by the three authors through deductive analysis (Patton, 2002), using the interview questions as a framework. These were added to the list of preliminary major themes and subthemes developed from the first reading. The major themes were related to different aspects of decision-making as explored in the interviews, including themes both related to parental reasoning (e.g., reasons for trusting sources of information) and factual information (e.g., interventions and sources used). Data analysis was then undertaken using the qualitative data analysis computer program TAMS Analyzer Version 4.13b13h (Weinstein, 2011). Responses were analysed on a sentence-by-sentence basis, and sentences were segmented if more than one theme or subtheme was presented in a sentence. One transcript was initially coded independently by each of the first two authors using the preliminary list of major themes and subthemes.

Disagreements in coding were resolved through discussion, and this included the addition of themes and subthemes not originally identified. Subsequently, three transcripts were independently coded by each of the coders. An agreement was considered to have occurred when text was coded in the same way by both coders, and a disagreement occurred when there was no overlapping of coding of a certain theme or subtheme. The coders reached agreement of an average of 80.1% across the three transcripts and resolved all disagreements through discussion. The remaining nine transcripts were coded by the first author.

In the present paper, only data related to the interventions used, sources used, and the perceived reliability, trustworthiness, and usefulness of sources are presented. During the analysis of transcripts that had not been jointly coded, the first author detected a small number of subthemes related to the research questions explored in the present paper that were not on the original list. These new subthemes were added and all transcripts were checked by the first author for related data. The data as coded for each of the additional subthemes were extracted from the transcripts by the first author, and consensus was reached between all three authors that the data were coded appropriately. Finally, major themes related to the research questions for the present study were identified, and subthemes were grouped according to these major themes (as shown in [Table 1](#)).

Additionally, factual data coded according to the following major themes were also used in the presentation of results: currently used intervention, intervention used in the past, type of intervention used, source used, and reliability of source.

Results

Participants listed the interventions they were currently using and those they had used in the past. The researchers did not try to restrict parents' responses and accepted any intervention the parent identified, from broad programs, such as childcare, preschool, or kindergarten, and occupational therapy, through to very specific techniques or tools for delivery, such as the Picture Exchange Communication System[®] (PECS), and an iPad[®]. Twenty-two different types of interventions were identified as currently being used by participants, with each participant using an average of 4.7 interventions (range: 1–10, *SD* = 2.5). Eleven interventions in total had been used in the past. On average, participants had used 2.4 interventions in the past (range: 1–6, *SD* = 1.4).

For the three most important interventions currently used, the interventions tried but discontinued, and for two interventions the parents had heard about but rejected, parents identified the source from which they first heard about the intervention and any additional sources of information. In total, 26 different types of sources were used by the participants. The internet in general was the most frequently identified source, and some parents also specifically stated that they used online groups and the Raising Children Network website. The internet was followed in frequency by other parents, the autism advisor or a list of approved providers for HCWA package funding, service providers, and paediatricians. Seven parents identified that they had previously used the intervention or service provider providing the intervention. This had occurred either before the child's ASD diagnosis, with the child's sibling, or with a staff member or service provider offering a different intervention.

Sources consistently identified as reliable by parents included service providers, teachers, conferences, research or journal articles, and nonmedical professionals. Other sources that were generally considered to be reliable by a majority of those rating them included parents of other children with ASD, autism advisors or a list of approved providers for HCWA package funding, and newsletters. Participants offered mixed opinions about the reliability of medical sources, books, media sources, and friends or relatives. Nine participants considered the internet to be somewhat reliable, and two unreliable.

A number of subthemes relating to factors influencing parents' impressions of the reliability and trustworthiness of sources, and to parents' impressions of the usefulness of sources emerged from the qualitative analysis. These are shown in [Table 1](#) and presented as follows.

TABLE 1

Major Themes and Subthemes Related to the Research Questions and Examples of Quotes Demonstrating the Subthemes

Major theme	Subthemes	Examples
Factors related to perceived trustworthiness of sources	Trusting other parents (including the perception of firsthand experience and the role of emotions)	'... because they have tried therapies and they can say what's working for their child and what's not' (Parent D) 'I was so desperate for someone to tell me something about what they had done and if they had had a positive experience' (Parent H)
	The parent's 'gut feelings' or intuition	'I took my gut instinct as a mother' (Parent I)
	Knowledge of the local area	'She's been living in the Illawarra for quite a few years so she knows what is happening' (Parent A)
	The perceived intentions of the source	'She does more than most, she's an amazing lady, not about the money, and I think that's where the trust comes in' (Parent I)
	Relationship with the source	'I knew the lady from a connection a long, long time ago, and she recommended ...' (Parent H)
	Verification of the information provided	'... when they told me their opinion I then jumped on the internet and researched as to why they said that, and whether they could be right or wrong' (Parent I)
	The parent's own beliefs about whether the information being provided was feasible	'So she may have come and done a big spiel and given me a great story but what she actually said I truly believe it was right as well ... that she was on the right track' (Parent J) 'Some parents were saying that they saw great changes in their children, but I don't believe it' (Parent G)
Reliability of service providers as sources and the presentation of information	Marketing	'And they had some really good marketing. I think that's what sold us' (Parent H)
	The perceived intentions of the service provider	'... I think "well, you're not really here for the interest of my daughter if you're asking me about money"' (Parent J)
Usefulness of sources	The information provided was of limited use	'... there's more needed, better explanations of what services do what' (Parent C) 'I think the lack of information they give is not very good. I think they tell you what they think you need to know but not what you should know' (Parent I)
	The amount of information provided was overwhelming	'... you're swamped with that information, and you kind of feel like it's too much to choose' (Parent B)
	The importance of the source acting as a guide in decision-making	'I didn't know what the difference was, they had all sorts of programs that they were providing, and funding, it was very confusing. Thank goodness I had the [service provider] counsellor to answer all my queries because if I didn't have her I wouldn't have known whether I ought to accept them or not, whether to apply for them in the first place' (Parent L)
	The source connecting parents to other sources of information was useful	'... she's fantastic because she gave all of the initial contacts' (Parent L)

Factors Related to Impressions of Reliability and Trustworthiness of Sources

Firsthand experiences of other parents of children with ASD. A number of parents identified the fact that sources were parents of children with ASD who had firsthand experiences of interventions as reasons for trusting or believing them. Parent L explained that other parents were reliable sources of information: ‘... simply because they have tried it, and if they say that it’s worked for their child it might work for my child, and they have actually tried it so that rates quite high for me’. Parent A identified the fact that her service provider was also a parent of children with ASD as a reason for trusting the information she provided about other interventions and services.

Firsthand experience appeared to be related to trust on an emotional level. Parent H explained how the firsthand experience of another parent was connected directly to her feeling reassured:

So I found that the most reassuring advice, it was something that I was willing to trust because she’d been there and done that and had some results. On an emotional level it was good advice ... I was so desperate for someone to tell me something about what they had done and if they had had a positive experience.

Not all parents, however, appeared to trust a source simply because they were a parent of a child with ASD. When asked to rate the reliability of other parents, Parent G commented: ‘... people like to talk a lot and they like to believe in some imaginary things’. Nonetheless, she considered a friend with a child with ASD who had provided information about an ASD-specific early intervention program to be a reliable source.

Parents’ perceptions of the intentions of the source. Parents identified that their perception of the intentions of the person providing the information were important in establishing trust. When Parent L was asked to identify reliable sources she stressed the importance of the source not appearing biased towards a particular approach or type of intervention:

The specialist, but not biased, so it wouldn’t be the specialist in that particular field, or in that particular approach or theory. So for instance [Service Provider X] is quite unbiased because they don’t just deal with autism but across the special needs children, and they don’t have a particular approach as such — they are not really into ABA or really into RDI as the private therapist would be, because a private therapist would adopt a certain approach and they would praise their own approach, of course, because they believe in it.

Parent I explained that she trusted the information provided by an occupational therapist about new interventions because of her beliefs about the occupational therapist’s intentions:

She does more than most, she’s an amazing lady, not about the money, and I think that’s where the trust comes in. If she thinks it will work for [my child], not just because of the program but specifically for him and the problems that he has, then I’ll give it a go.

Parents’ beliefs about the reliability of the prospective service providers also related to perceptions of the service provider’s intentions. For example, Parent J explained that when seeking information from service providers about the interventions they offered their perceived intentions were important:

Because a lot of people, the first thing they ask you is, ‘Oh, how much FaHCSIA [Australian Government Department of Families, Housing, Community Services and Indigenous Affairs] money [HCWA package funding] do you have?’, and when I hear that I think ‘well, you’re not really here for the interest of my daughter if you’re asking me about money’. You know they should be asking me, ‘Exactly what has your daughter got, have you been diagnosed, what do

the reports say?’ That’s what I want to hear, and then afterwards they can ask me about FaHCSIA money.

Relationship with the source. If parents had an existing relationship with a source, they appeared to be more likely to regard them as reliable. For example, Parent I explained that she was considering using ‘audio treatment’ with her child because the speech therapist working with her child told her about it: ‘I heard about it from my speech therapist . . . and I trust her’. Additionally, other parents identified friends or other parents of children with ASD as reliable sources of information because they had established relationships with them. For example, Parent G stated that her friend who had a child with ASD was a reliable source despite identifying other parents as only somewhat reliable.

Presentation of information. Parent H described how she was influenced by the way a prospective service provider presented information about an intervention. What she considered clever marketing led her to see the service provider as a reliable source and to commence using the intervention (which she later discontinued due to finding it ineffective): ‘. . . they had some really good marketing. I think that’s what sold us, they had a whole set of seven DVDs for you to watch, and I think she was very cleverly marketed’.

Usefulness of Information

Information was of limited use. Many parents commented on the limited use of information provided by sources, particularly autism advisors and medical sources. Parent C, for example, described that the information provided by autism advisors, while accurate, lacked the detail to make it useful:

. . . they give you all of this information and it’s like, ok, you’ve got to go and pick what the best treatment is for your child and there’s not really enough help to tell you ‘this treatment does this’, ‘this treatment does that’ . . . you’ve got to do a lot of the research yourself, and it’s really lacking in that area. It’s like, ‘Here’s your FaHCSIA money, you just go and spend it’, but they don’t tell you, ‘This would suit your child’ or ‘That would suit your child’.

Parent E held a similar opinion: ‘I think they gave us very broad information. The information they gave us definitely is correct, but then you can go further and find out some is not helpful, some is helpful’.

Some parents also reported that medical sources provided information of limited use. Parents F and I both stated that they needed to advise their doctors about what to do. Parent I saw this as related to the nature of general practice, noting ‘You need a specialist now days for anything that’s wrong with you’. Other sources that were identified by parents as providing information of limited use were media programs (Parent F), service providers (Parent J), and the Raising Children Network website (Parent L).

Connecting parents to other sources. Parent L described how even though the information given to her by her child’s paediatrician, although reliable, was limited in terms of detail about interventions, it did provide her with other reliable and useful sources of information: ‘. . . she’s fantastic because she gave all of the initial contacts, but because, of course, she doesn’t specialise in autism she wouldn’t be able to advise on the different approaches’. Other sources were also considered useful because they provided a connection to additional sources. For example, when Parent J stated that she believed conferences were a reliable source she added:

I’ve learned a lot, but also I’ve learned a lot more from parents who go there. You have your intermission; you have your morning tea or afternoon tea, and generally you hear a lot of things from parents as well. So that all works together.

This indicated that she found the conference useful not only as a source of information in itself, but also as a means for connecting her with other parents as additional sources of information.

An overwhelming amount of information. Although a number of parents had identified that the information provided by the autism advisor was limited, Parent B, for example, noted that the amount of information provided was overwhelming.

The usefulness of a guide in decision-making. How useful parents found the information provided by sources also appeared to be related to whether the parent saw the source as a guide, explaining the options, and how they related to their child. Both Parents B and L identified that they had a source acting as a guide for them that was helpful, and that they used the information provided by this guide in their decision-making. Parent B explained how her child's paediatrician helped her:

She drew me a graph, and she drew me three columns — this year, next year and the year after that — what you should do, and she wrote that for me. And I think that's a pretty good summary of what you should look into And it actually made life a little bit more structured and easier to find out.

Other parents described the frustration of being presented with information alone and not having someone to guide them through the information and how it related to their child. For example, Parent I explained:

My biggest gripe about when you get a diagnosis is that you're a parent — you're not a doctor, you're not a speech therapist, you're not an occupational therapist, but you're given a pack and given the FaHCSIA money and told to make the decision as to how you are going to treat your own child. It all depends on, possibly it all depends on, the first person you see and their opinion that they give you, or you just educate yourself and then try to figure out what your child needs — but it's a bit like a doctor saying, 'You've got cancer. How would you like to treat it?'

Discussion

The present paper included data from parents regarding how they assessed the trustworthiness and reliability of sources, and how useful they found the information provided. These issues are discussed in the sections that follow, including limitations and recommendations for further research and practice.

How Parents Assessed the Reliability and Trustworthiness of Sources

Themes emerged regarding why parents trusted certain sources more than others. This topic has not been explicitly examined in previous research on parent decision-making regarding ASD interventions.

In the present study, parents who had firsthand experience with interventions were seen as trustworthy sources by a number of participants. This appeared to be linked to the feeling of reassurance offered to participants by knowing that somebody else had been in a similar situation to them, which may have provided a sense of hope for the future outcomes for their child. It may also be related to the power of anecdotal stories over scientific evidence, which was described by Newman (2003) in reference to decision-making in general. Newman (2003) described the power of stories as being related to a number of factors. Specifically, it appears that (a) humans apparently process stories better than other forms of input, (b) estimates of probability differ when presented with an anecdote rather than other data, and (c) the passion conveyed by the storyteller gives the listener an emotional connection to the story beyond that possible for information

presented in other forms. For example, a parent hearing from another parent that their child's ASD symptoms had improved after using dietary interventions may remember this story more readily than data they may have read regarding the scientific efficacy of dietary interventions. Another subtheme that was related to parents' emotions was that parents trusted sources because of a prior professional or personal relationship. This is not surprising given that trust and relationships are concepts that are often linked in day-to-day life, so parents may feel that they can trust information provided by someone with whom they have a relationship.

The perception of the intentions of the source was also a significant factor related to trust. This indicates that some parents are sceptical of service providers or professionals who they see as 'selling' a product or particular approach in which they have a vested interest, rather than caring for their child as an individual and genuinely wanting to help their child. Given the commercial environment now surrounding a number of interventions that are marketed to parents of children with ASD, particularly in Australia where parents are given access to government funding to spend on interventions, it is not surprising that some parents were sceptical of the intentions of some sources. This was also the reported case in a review of parents' decision support needs when making health decisions (e.g., regarding acute illness, breastfeeding, immunisation, and oncology) for children (Jackson, Cheater, & Reid, 2008). It was reported in the review that parents lacked confidence in the reliability of the information provided by sources who may profit from the parents' decision to use a particular intervention. When parents are influenced by the presentation of information or marketing they may invest time and energy into ineffective interventions, as was the case for Parent H in the present study.

The Usefulness of Sources

Parents' views of the usefulness of sources, again, are an issue not commonly explored in previous research. Some parents reported that, particularly in relation to autism advisors and medical doctors, they saw the information provided as accurate but of limited use because it lacked detail about how the interventions would relate to their child. This was consistent with the data collected in the recent evaluation of the HCWA package, where it was reported that although the majority of families were satisfied overall with the advice and support provided by the autism advisor service, a large proportion of families also reported that even with advice from the autism advisor it was difficult to understand what service would be best for their child/children (ARTD Consultants, 2012). This indicates that the information provided to parents regarding interventions may be too general and lacking specific guidance. With regard to information provided by medical practitioners, Lynch (2004) and Loomis (2007) both reported that parents felt frustrated that some medical professionals did not provide them with information about CAM interventions for ASD. This is one possible reason that the information provided by medical professionals may be seen as limited in its usefulness.

Parents described feeling that they had inadequate information to make decisions, yet were expected to do so. Valentine (2010), in a study focusing on choice and engagement of parents in the intervention decision-making process and the postdiagnostic support they were provided, also identified that parents in her study felt that they were forced to make decisions. Another theme common to both the present study and Valentine (2010) was that some parents felt overwhelmed with the amount of information provided to them. This has implications for professionals and autism advisors who provide support to parents of children with ASD.

Two parents in the present study described the usefulness of an information source who actually acted as a guide regarding the information provided. They offered some structure in assisting the parents to understand the different interventions and how they would relate to their children. For example, Parent B described her child's paediatrician writing down specific interventions that she should consider using with her child for the present year and the following 2 years, and how helpful this was in her decision-making. This guidance may be something that is missing in many cases and may lead to parents turning to sources such as the internet where unfiltered information is widely disseminated.

Limitations

Some limitations of the present study should be acknowledged. The sample of participants was recruited through Aspect and therefore they were using Aspect early intervention services. This allowed for the confirmation of an ASD diagnosis without the requirement of the participants to provide documentation to the researchers. However, it also meant that all participants were using ASD-specific early intervention delivered by Aspect. Aspect is the largest provider of ASD-specific early intervention services in Australia, covering a wide range of families using ASD-specific early intervention. In recruiting participants, the researchers ensured that they were from a variety of service locations and included both those using centre-based and home-based services. The wide range of other interventions reported to be used by parents in the sample also allayed concerns regarding the possible homogeneity of the sample. Furthermore, as with all qualitative research, one of the inherent limitations is that one cannot assume that the results may be generalised to other populations (Lichtman, 2014; Schofield, 2002). Rather than examine a large representative sample, the intent of the present study was to gain some preliminary insight into the sources of information that parents used and their impressions of the reliability of the sources, and of the usefulness of the information provided. The qualitative approach was taken in the present study to allow for in-depth examination of factors related to parents' impressions of trust and reliability of sources and their usefulness in decision-making. However, the themes and subthemes that emerged will need to be examined in the future using other methods that would facilitate the generalisation of results, such as survey studies with larger and more representative samples.

Summary of Recommendations for Research and Practice

For research. Consistent with larger survey research, in the present study the internet was a widely used source of information, although other sources, such as professionals and research evidence, were generally rated by parents as more reliable than the internet. Parent A explained that certain websites may be more reliable than others, and that she could make this judgement based on recommendations from other parents. Considering these findings, future research could include systematic investigation of the types of resources Australian parents are accessing on the internet, including the extent of the use of the Raising Children Network website. Although the veracity of much of the information on the internet is debatable, there are some sites that appear to provide accurate information about the efficacy of interventions (e.g., Raising Children Network, 2006–2014; Research Autism, 2006–2014). Given that the Raising Children Network website is sponsored by the Australian Government as part of the HCWA package and that there is already some evidence to suggest it is not being utilised by many parents (ARTD Consultants, 2012), it would be useful to assess whether increasing parents' awareness of this website, and other reliable online sources, would increase their use.

Parents reported using medical and other professional information sources, including autism advisors who are specific to the Australian context. Some parents also reported that the information being provided to them by these sources was not useful because they found it either too general or overwhelming. As the sources apparently being used are offering varying levels of assistance, the research base would benefit from investigation of the type of information being provided by these sources to parents. This could include both the extent to which the information is (or is not) reflective of current research findings, and how useful parents consider it to be in their decision-making. This would also help to clarify whether some concerns of parents are indeed justified; for example, those related to the assumed lack of specific knowledge of ASD held by GPs.

For practice. Parents reported that even when sources were considered reliable to some degree, the information that they provided was not always useful. In contrast, some parents reported that when a professional provided guidance by linking information to their individual child's needs, this was particularly useful to their decision-making. Based on these findings, once the information being provided to parents by medical and other professionals has been investigated on a larger scale, guidelines could be provided to these professionals for improving the information provided where necessary. Although it would be useful for professionals and others to offer guidance regarding specific interventions, some problems are that there is limited research on many interventions and that the status of a number of interventions is indeterminate. Recently, the Australian Government updated guidelines on interventions eligible for funding through the HCWA package, based on a review of research evidence to identify effective early intervention practices for ASD (Prior et al., 2011). These guidelines may help professionals and autism advisors to offer accurate advice. They clearly differentiate levels of evidence for interventions and identify unsupported interventions. As such, they would be a useful tool for those offering advice and guidance to parents of children with ASD, or for parents to access themselves.

Finally, given that parents use a wide range of sources of information, they would benefit from the provision of guidelines for interpreting information presented by sources. This may help parents to identify reliable and useful sources more easily and assist them in making informed decisions about the interventions that they use with their children.

Conclusion

The parents in this study used a range of information sources in their decision-making, which was consistent with previous studies. The strength of this study, however, is that unlike previous research, parents described factors related to their perceptions of the reliability and trustworthiness of the sources, and the usefulness of the information provided. Factors related to the perceived trustworthiness and reliability of sources included whether the source had firsthand experience as a parent of a child with ASD, the parent's perceptions of the intentions of the source, whether they had a relationship with the source, and how the information was presented. Parents reported sources such as medical doctors and autism advisors as having provided limited information and/or an overwhelming amount of information. Systematic investigation of the type of information currently being provided to parents by professionals could lead to the development of guidelines for providing accurate and useful information in the future.

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