

## Decision-Making Regarding Early Intervention by Parents of Children with Autism Spectrum Disorder

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Published online: 7 December 2014

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**Abstract** Seventy-five parents of preschool-age children with autism spectrum disorder (ASD) completed surveys designed to identify factors considered when selecting an intervention approach for their child and to elucidate the relative importance of those factors in the decision-making process. For decisions to use interventions, the most important factor related to the individual needs of the child. This factor and several others; including staff attributes, whether the intervention was ASD-specific, and intuition/gut feelings, were weighted more highly than research evidence in both decisions to use and to reject interventions. When the individual factors were grouped pragmatically, the category representing service characteristics, including staff attributes and whether the intervention was ASD-specific, was ranked significantly higher in importance than all other categories. Advice/recommendations from others have been reported in previous research as being frequently considered in parental decision-making. However, in the present study, advice and recommendations from others was rated significantly lower in importance than all other categories regardless of whether participants were considering using or rejecting an intervention.

**Keywords** ASD · Autism · Decision-making · Intervention · Parent · Treatment

There are a large number of intervention options to use with children with autism spectrum disorder (ASD). While some of these are supported by research evidence, there are many interventions that have either weak or no empirical support (National Autism Center 2009; Odom, Boyd, Hall, and Hume 2010; Prior, Roberts, Rodger, Williams, and Sutherland 2011). Parents have reported that they typically use several interventions simultaneously, including those with empirical support (such as interventions based on the principles of Applied Behavior Analysis [ABA]), those with little support (such as many Complementary and Alternative Medical [CAM] interventions), and those for which the efficacy is currently uncertain (such as Relationship Development Intervention [RDI]; Carter et al. 2011; Goin-Kochel, Myers, and Mackintosh

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2007; Green et al. 2006). Therefore, how they come to make decisions about which interventions to use is of interest.

A number of studies have examined factors considered in parental decision-making regarding interventions (e.g., Birkin, Anderson, Seymour, and Moore 2008; Bowker, D'Angelo, Hicks, & Wells, 2011; Christon, Mackintosh, and Myers 2010; Hanson et al. 2007; Miller, Schreck, Mulick, and Butter 2012; Smith and Antolovich 2000; Valentine 2010). In a recent review of research on the factors declared by parents of children with ASD to be related to their decision-making regarding the selection of and discontinuation of interventions, several factors were identified (Carlon, Carter, and Stephenson 2013). The factors most frequently reported across studies were recommendations or advice from others (e.g., other parents, medical professionals, friends or relatives), availability and/or accessibility of interventions, cost, the parents' satisfaction with the intervention, the use and perceived effectiveness of other interventions, the specific needs of the child, research evidence, and time constraints. Other factors that were less frequently reported included funding, the availability of alternative interventions, the child's resistance to or preference for the intervention, treatment side effects or adverse effects, and the compatibility of the intervention with other interventions.

Although a number of factors related to parental decision-making have been identified, there are very few data related to how much weight parents place on different factors (Carlon et al. 2013). An exception was the study of Hanson et al. (2007), where parents were asked to rate the importance of a number of statements in their decisions regarding the use of CAM interventions for their child with ASD, on a five-point scale from "not important" to "very important". The statements that were ranked as "important" or "very important" by 50 % or more of the participants were concerns about safety and/or side effects with prescribed medications, recommendations (from doctors, friends, family, or other parents), the preference for a scientifically-proven therapy, wanting more control over the treatment, and the hope for a cure (Hanson et al. 2007). Smith and Antolovich (2000) asked parents both about the source from which they first heard about an intervention, and the source that was most influential on their decision to use that intervention. The parent responses revealed that the initial source of information did not necessarily have the greatest influence on parent decisions to use the particular intervention, and other factors may have also influenced the decision-making.

The preceding findings highlight the importance of considering the weight that parents place on factors in decision-making. It cannot be assumed that because a factor is frequently considered by parents that it is necessarily highly influential on parent decision-making. It is possible that some frequently considered factors are given little weight by parents in their decision-making. Explicitly asking parents about how important different factors are in decision-making would enable researchers to gain a better understanding of the level of influence of different factors on parent decision-making.

Extant research has tended to focus on factors that parents have considered in their decision to use an intervention (Carlon et al. 2013). However, parents also make active decisions not to employ specific interventions. There are very few data on the factors that influence these rejection decisions and how they may differ from those involved in a decision to select a given intervention (Birkin et al. 2008; Valentine, Rajkovic, Dinning, and Thompson 2010).

The present study aimed to identify the relative importance placed by parents on different factors influencing their decision-making about interventions to use with their preschool-age children with ASD. Specifically, the following research questions were addressed:

1. Which factors are most important and unimportant in parents' decisions to use and to reject interventions?
2. Is there a difference in the factors considered important and unimportant by parents when choosing to use an intervention compared to when rejecting an intervention?

## Materials and Methods

### Participants

The sample for this study consisted of 75 parents of preschool-age children accessing autism-specific early intervention services in New South Wales (NSW), Australia. Participant characteristics are shown in Table 1. The majority of respondents were mothers (85.3 %). Eleven families (14.7 %) had more than one child who had been diagnosed with ASD (these participants completed the survey in regard to their oldest child with ASD who had not started school). All participants reported that their child had received a formal diagnosis of ASD (85.3 % autistic disorder). The children were aged between 34 and 73 months ( $M=51.2$ ) and had been diagnosed with an ASD between the ages of 18 and 58 months ( $M=34.8$ ). The time since diagnosis ranged from 2 to 36 months (mean=16.3).

### Distribution and Data Collection

Ethics approval for this study, including the use of an incentive prize draw, was obtained from the relevant ethics committees. Surveys were distributed to parents of preschool-age children with ASD using one of three autism-specific early intervention services in NSW. These were (a) the Building Blocks centre-based program (an autism-specific early intervention program delivered by Autism Spectrum Australia [Aspect]), (b) Autism Behavioural Intervention (ABI) "Footprints 'stepping into learning' program" (a home-based program based on the principles of ABA, delivered by ABI NSW), and (c) PlayConnect Playgroups. The first two services were chosen because they are the largest providers of autism-specific intervention services in NSW. In contrast, PlayConnect Playgroups are run by Playgroup NSW, which is a broad community-based organization, offering the potential to access a broad sample of children.

For the centre-based (group) services, where practical, the first author visited the groups and gave the parents a brief overview of the project before distributing the surveys to the parents. Parents wishing to participate later returned the surveys to the early intervention staff, who posted them back to the first author. For the centre-based groups where it was not practical for the first author to attend, and for the home-based services, early intervention staff distributed the surveys to

**Table 1** Participant characteristics

Characteristic	Number (%)	Months Mean (Range)
Respondent ( <i>n</i> =75)		
Mother	64 (85.3)	
Father	10 (13.3)	
Other (foster mother)	1 (1.3)	
Mother's Age ( <i>n</i> =75)		
<25 years	1 (1.3)	
25–34 years	18 (24.0)	
35–44 years	56 (74.7)	
>44 years	0 (0.0)	
Father's Age ( <i>n</i> =71)		
<25 years	0 (0.0)	
25–34 years	11 (15.5)	
35–44 years	49 (69.0)	
>44 years	11 (15.5)	
Mother's Education ( <i>n</i> =74)		
High school or equivalent	13 (17.6)	
TAFE*, college, or further training	23 (31.1)	
Undergraduate University degree	23 (31.1)	
Postgraduate University degree	15 (20.3)	
Father's Education ( <i>n</i> =70)		
High school or equivalent	10 (14.3)	
TAFE*, college, or further training	26 (37.1)	
Undergraduate University degree	22 (31.4)	
Postgraduate University degree	12 (17.1)	
Annual family income ( <i>n</i> =75)		
<\$40,000	10 (13.3)	
\$40,000–\$80,000	30 (40.0)	
\$80,000–\$120,000	22 (29.3)	
>\$120,000	13 (17.3)	
Primary decision-maker regarding intervention use ( <i>n</i> =75)		
Mother	33 (44.0)	
Father	2 (2.7)	
Both parents together	40 (53.3)	
Child's gender ( <i>n</i> =75)		
Male	69 (92)	
Female	6 (8)	
Child's age ( <i>n</i> =75)		51.2 (34–73)
Child's age at diagnosis ( <i>n</i> =72)		34.8 (18–58)
Time since diagnosis ( <i>n</i> =72)		16.3 (2–36)
Child's diagnosis ( <i>n</i> =75)		
Autistic Disorder	64 (85.3)	

**Table 1** (continued)

Characteristic	Number (%)	Months Mean (Range)
Asperger's Disorder	2 (2.7)	
PDD-NOS	8 (10.7)	
Other (high functioning autism)	1 (1.3)	
Additional diagnoses	8 (10.7)	
Parent rating of severity of ASD ( $n=74$ )		
Mild	29 (38.7)	
Moderate	35 (46.7)	
Severe	7 (9.3)	
Others		
Mild-to-moderate	2 (2.7)	
Moderate-to-severe	1 (1.3)	
Child with sibling with ASD	11 (14.7)	

\*TAFE (Technical and Further Education) is the largest provider of vocational training in Australia

parents, collected them from those who wished to participate, and sent them back to the first author.

Parents were asked if they had received the survey from a different service provider (as children may have been using more than one of the services) and surveys were only distributed to those who had not already received the survey. Two return envelopes were provided to each parent with the survey package (one for the survey and one for contact details), so that those wishing to enter the incentive prize draw and/or express interest in being involved in future research could provide their contact details without compromising the anonymity of the survey.

### Instrument

A five-section survey was developed. The first three sections provided background information. Section one included demographic information regarding the child and family, the child's diagnosis, the parent's perception of the severity of their child's ASD (mild, moderate, or severe), both parents' education levels, both parents' use of CAM treatments, their beliefs about the causes of ASD, and the primary intervention decision-maker in the household.

In the second section, participants identified sources of information used. A list of possibilities was provided, including sources identified in previous survey studies (Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean 2010; Christon et al. 2010; Hanson et al. 2007; Miller et al. 2012; Smith and Antolovich 2000) and in a recent qualitative study with Australian parents of children with ASD (Carlon, Stephenson, & Carter 2014). Participants were also invited to add additional sources. The third section addressed interventions considered and used by the parents.

The final two sections of the survey addressed factors that may have affected decision-making. In the fourth and fifth sections (respectively), parents were asked to

nominate (a) the most important intervention currently being used, and (b) an intervention the parent had considered but decided not to use. In contrast to much existing research, which has asked “in principle” questions about decision-making regarding interventions, parents were asked specifically to provide information on a particular intervention they used or had decided not to use. This proactive strategy was employed to aid parents in recalling what was actually important and unimportant in specific decisions, rather than requiring them to hypothesize about what may have been generally important or unimportant.

Section four listed factors that may have influenced parent decisions to use the nominated intervention and in section five participants identified factors that may have influenced decision-making regarding the intervention they had decided not to employ. These decision factors, shown in Table 2, were developed from those frequently reported in the literature (Carlon et al. 2013) and those identified by Australian parents in a recent qualitative study (Carlon et al. 2014). Participants were required to indicate how important each factor was in making their decision regarding the particular intervention they named, indicating on a Likert-type scale whether it was: (1) very unimportant, (2) somewhat unimportant, (3) neither important nor unimportant, (4) somewhat important, or (5) very important. A copy of the survey is available from the first author on request.

## Data Analysis

Initially, individual factors that parents rated were descriptively analyzed. Additionally, to assist in inferential analysis, factors were pragmatically grouped into the six categories shown in Table 2. These categories were advice/recommendations, child factors, emotion-based factors, pragmatic factors, research evidence, and service characteristics. The advice/recommendations category was developed primarily to include specific advice and recommendations from other individuals, such as other parents and medical doctors. The child factors category was intended to include factors related to child characteristics (e.g., age, individual needs, and preferences) as well as potential side effects or adverse effects on the child. The emotion-based factors category was developed to include parents’ emotional responses related to hope and intuition. The pragmatic category was developed to address factors related to practical considerations including availability, funding, and practical impact on the family. The service characteristics category included factors related to the characteristics of the intervention program and staff (e.g., professionalism and experience). Research evidence was included as a stand-alone category as our interest was in the extent to which evidence itself informed decision-making, rather than the specific source of the research evidence. The scores for each category were calculated by taking the mean of the scores for the constituent items.

Given the underlying ordinal measure and modest sample size, conservative non-parametric analyses were conducted. Friedman two-way analysis of variance tests (Stricker 2008) were conducted to determine whether categories were ranked differently by the participants for both the decision to use the most important current intervention and the decision to reject a nominated intervention. Where the results of this test indicated that there were significant differences in the rankings, Conover post hoc comparisons (Stricker 2008) were completed.

**Table 2** Factors included in the survey relating to decisions to use or reject interventions, grouped by category

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Factor as Grouped by Category
Advice/recommendations
Advice from friends/relatives
Advice from medical doctors
Advice from other parents
Advice from teachers
Advice from therapists
Information from service providers
Most people thought it was an (in)effective intervention
Child factors
Child's age
Child's individual needs
Side effects/adverse effects
Thought (did not think) child would enjoy it
Emotion-based factors
Feeling might need to try anything that might help <sup>b</sup>
Intuition/gut feelings
Hope for cure <sup>b</sup>
Hope that it will work <sup>b</sup>
Pragmatic factors
Availability of alternative interventions
Availability of the intervention
(Not) convenient time-wise/did (not) fit schedule
Cost
Effectiveness of other interventions being used <sup>a</sup>
Family impact
Funding available
Location or accessibility
Research evidence
Research evidence
Service characteristics
Compatibility with other interventions being used
Whether or not ASD specific
Whether staff appeared professional
Whether staff were experienced

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<sup>a</sup> Only asked about for intervention rejected

<sup>b</sup> Only asked about for most important intervention currently being used

## Results

Surveys were distributed to 175 parents and 75 were returned (return rate=42.9 %). Thirty-three (44 %) of the surveys were returned via Aspect, 21 (28 %) via ABI, 17

(22.7 %) via Playgroup NSW, and 4 (5.3 %) were posted directly to the researchers (due to the anonymous nature of the survey the service[s] from which these 4 parents received the surveys were unknown). A mean of 7.3 interventions was reported to be used currently (range=2–14 interventions) and 2.7 in the past (range=0–10).

### Sources of Information Used

Parents selected sources that they had used from a list of common sources of information about ASD interventions. The frequency of use of each source is shown in Table 3.

### Current Intervention

Participants were asked to provide the name of the most important currently used intervention before rating the importance of factors in their decision to use it. The interventions nominated, and the importance of different factors in deciding to use these interventions, are presented below.

*Interventions Nominated* The intervention nominated by the greatest number of participants as the most important currently used intervention was speech therapy/speech pathology (nominated by 16 participants). Other frequently nominated interventions included ABI (12), Building Blocks (10), occupational therapy (6), and ABA (5). The most important current intervention was not specified in two cases. Data regarding these two unknown interventions were included in the analysis.

*Importance of Individual Factors in Decision-Making* Table 4 shows the ratings of the factors asked about for the most important current intervention being used, ranked by mean. The numerical values (1–5) that were attached to the Likert-type scale were used to calculate means for each factor. All of the means were above 3.0, and between 48 and 100 % of participants indicated that the factors were considered somewhat or very important. The most important factor in choosing to use the nominated intervention was the child's individual needs (considered very important by 86.7 % of participants and somewhat important by the remaining participants, with a mean rating of 4.9, ( $SD=0.3$ ). Other factors considered very important were: staff experience ( $M=4.8$ ,  $SD=0.4$ ); that the staff appeared professional ( $M=4.7$ ,  $SD=0.5$ ); the hope that it would work ( $M=4.6$ ,  $SD=0.8$ ); intuition or “gut feelings” ( $M=4.6$ ,  $SD=0.8$ ); and availability ( $M=4.7$ ,  $SD=0.7$ ). There were 10 additional factors added by parents as ‘very important’. Four were related to the individual therapists' perceived intentions and relationship with the child (including two parents noting the child's bond/relationship with the therapist), and two parents noted the importance of access to a parent group. Other factors nominated by single participants were the recommendation of a particular therapist, knowing their own child, being realistic with goals, not listening to a ‘sales pitch’, and the effectiveness of the intervention with an older sibling.

Factors with the lowest means, indicating that they were generally considered less important by the participants, were advice from friends/relatives ( $M=3.2$ ,  $SD=1.2$ ), the



**Table 3** Sources of information about interventions used

Source	Number (%)
Autism Advisor <sup>a</sup>	61 (81.3)
Therapists	58 (77.3)
Medical Doctors	50 (66.7)
Friends or relatives	39 (52.0)
Autism Associations	38 (50.7)
Other parents	37 (49.3)
Teachers/educators	34 (45.3)
The Raising Children Network website <sup>b</sup>	32 (42.7)
Parent training programs/conferences/workshops	29 (38.7)
Autism association websites	29 (38.7)
Books	28 (37.3)
Service providers	27 (36.0)
Government websites	25 (33.3)
Websites of service providers	20 (26.7)
Newsletters	18 (24.0)
Parent forums/blogs/online support groups	15 (20.0)
Research literature	13 (17.3)
Print media/TV/radio/movies	10 (13.3)
Social workers/counsellors	10 (13.3)
Alternative medical staff	9 (12.0)
Other sources listed by parents	
An autism consultancy business	1 (1.3)
Lifestart <sup>c</sup>	1 (1.3)
Childcare centers	1 (1.3)
Psychologists	1 (1.3)
Diagnostic services	1 (1.3)
Autism handbook <sup>d</sup>	1 (1.3)

<sup>a</sup> Autism Advisors provide information to parents about the Australian Federal Government's "Helping Children with Autism (HCWA)" package

<sup>b</sup> A website sponsored by the Australian Federal Government which includes a section that provides information to parents of children with ASD, as part of the HCWA package

<sup>c</sup> An early intervention provider

<sup>d</sup> "The Australian Autism Handbook" is a book written for parents by two parents of children with ASD

hope for a cure ( $M=3.3$ ,  $SD=1.5$ ), the availability of alternative interventions ( $M=3.5$ ,  $SD=1.1$ ), and that it was convenient within the family's schedule ( $M=3.6$ ,  $SD=1.4$ ).

*Importance of Categories in Decision-Making* A Friedman two-way analysis of variance (Stricker 2008) was conducted to determine whether different categories (as noted in Table 2) were ranked differently by the participants. The results of this test indicated that there were significant differences in the rankings,  $\chi^2(5, N=73)=47.69$ ,  $p<0.001$ , so Conover post hoc comparisons (Stricker 2008) were completed. The results of these

**Table 4** Factors in decision-making for the most important intervention currently used, ranked by mean

Factor	Mean	Number of responses (%)					
		5. Very important	4. Somewhat important	3. Neither important nor unimportant	2. Somewhat unimportant	1. Very unimportant	No response
Child's individual needs	4.9	65 (86.7)	10 (13.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Whether staff were experienced	4.8	61 (81.3)	14 (18.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Whether staff appeared professional	4.7	57 (76.0)	15 (20.0)	2 (2.7)	0 (0.0)	0 (0.0)	1 (1.3)
Hope that it will work	4.6	57 (76.0)	9 (12.0)	5 (6.7)	2 (2.7)	1 (1.3)	1 (1.3)
Intuition/gut feelings	4.6	54 (72.0)	14 (18.7)	6 (8.0)	0 (0.0)	1 (1.3)	0 (0.0)
Availability of the intervention	4.6	52 (69.3)	20 (26.7)	1 (1.3)	0 (0.0)	1 (1.3)	1 (1.3)
Family impact	4.5	46 (61.3)	22 (29.3)	3 (4.0)	3 (4.0)	1 (1.3)	0 (0.0)
Whether or not ASD specific	4.5	46 (61.3)	20 (26.7)	6 (8.0)	1 (1.3)	1 (1.3)	1 (1.3)
Advice from therapists	4.5	44 (58.7)	24 (32.0)	4 (5.3)	0 (0.0)	2 (2.7)	1 (1.3)
Funding available	4.4	49 (65.3)	14 (18.7)	5 (6.7)	3 (4.0)	3 (4.0)	1 (1.3)
Information from service providers	4.4	37 (49.3)	31 (41.3)	3 (4.0)	1 (1.3)	2 (2.7)	1 (1.3)
Side effects/adverse effects	4.3	46 (61.3)	13 (17.3)	7 (9.3)	1 (1.3)	5 (6.7)	3 (4.0)
Research evidence	4.3	34 (45.3)	25 (33.3)	12 (16.0)	0 (0.0)	1 (1.3)	3 (4.0)
Cost	4.2	39 (52.0)	22 (29.3)	6 (8.0)	5 (6.7)	3 (4.0)	0 (0.0)
Feeling might need to try anything that might help	4.2	35 (46.7)	20 (26.7)	14 (18.7)	2 (2.7)	2 (2.7)	2 (2.7)
Child's age	4.2	35 (46.7)	23 (30.7)	12 (16.0)	4 (5.3)	1 (1.3)	0 (0.0)
Location or accessibility	4.2	34 (45.3)	29 (38.7)	5 (6.7)	7 (9.3)	0 (0.0)	0 (0.0)
Compatibility with other interventions being used	4.1	30 (40.0)	29 (38.7)	11 (14.7)	3 (4.0)	1 (1.3)	1 (1.3)
Advice from teachers	4.1	26 (34.7)	37 (49.3)	5 (6.7)	1 (1.3)	4 (5.3)	2 (2.7)
Advice from medical doctors	4.0	29 (38.7)	25 (33.3)	12 (16.0)	5 (6.7)	2 (2.7)	2 (2.7)
Thought child would enjoy it	3.9	32 (42.7)	20 (26.7)	12 (16.0)	9 (12.0)	2 (2.7)	0 (0.0)
Advice from other parents	3.9	24 (32.0)	33 (44.0)	7 (9.3)	4 (5.3)	6 (8.0)	1 (1.3)
Most people thought it was an effective intervention	3.8	23 (30.7)	29 (38.7)	12 (16.0)	6 (8.0)	5 (6.7)	0 (0.0)

**Table 4** (continued)

Factor	Mean	Number of responses (%)					
		5. Very important	4. Somewhat important	3. Neither important nor unimportant	2. Somewhat unimportant	1. Very unimportant	No response
Convenient time-wise/fit schedule	3.6	24 (32.0)	22 (29.3)	12 (16.0)	8 (10.7)	9 (12.0)	0 (0.0)
Availability of alternative interventions	3.5	16 (21.3)	23 (30.7)	19 (25.3)	9 (12.0)	4 (5.3)	4 (5.3)
Hope for cure	3.3	23 (30.7)	12 (16.0)	16 (21.3)	8 (10.7)	13 (17.3)	3 (4.0)
Advice from friends/relatives	3.2	6 (8.0)	31 (41.3)	23 (30.7)	2 (2.7)	12 (16.0)	1 (1.3)

paired comparisons and mean ranking differences between categories are presented in Table 5 (in the table the positive rank difference favors the categories listed in the first column).

The category relating to service characteristics had the highest mean ranking ( $M=4.43$ ). As shown in Table 5, it was ranked significantly higher than all other categories. Following service characteristics, research evidence ( $M=3.77$ ) and child factors ( $M=3.75$ ) had the highest mean rankings of the remaining categories. As shown in Table 5, they were both ranked significantly higher than pragmatic factors and advice/recommendations. Emotion-based factors, with a mean rank of 3.41, and pragmatic factors, with a mean rank of 3.15 were, along with the other categories, ranked significantly higher than advice/recommendations.

### Interventions Rejected

Participants were also asked to provide the name of an intervention they decided not to use before rating the importance of factors in their decision to reject it (participant ratings of factors for decisions to reject an intervention were made separately from ratings about factors to use an intervention). Sixty-two participants provided answers for this section of the survey. The interventions nominated, and the importance of factors in deciding to reject these interventions, are presented below.

*Interventions Nominated* ABA was nominated as the intervention that parents rejected in 21 cases. Other frequently nominated interventions were dietary restrictions (12), Floortime (3), and RDI (3).

*Importance of Individual Factors in Decision-Making* The factors in decision-making regarding an intervention that was rejected, ranked by mean response, are shown in Table 6. The factors most frequently selected as important were the child's individual needs ( $M=4.4$ ,  $SD=1.0$ ), that the staff were not experienced

**Table 5** Friedman analysis and mean rank differences for importance of categories for the most important intervention currently used

	Advice/ recommendations	Child factors	Emotion- based	Pragmatic	Research evidence
Child factors	1.26***				
Emotion-based	0.92**	-0.34			
Pragmatic	0.66*	-0.60*	-0.26		
Research evidence	1.29***	0.03	0.36	0.62*	
Service characteristics	1.95***	0.68*	1.02***	1.28***	0.66*

\*  $p < 0.05$ . \*\*  $p < 0.01$ . \*\*\*  $p < 0.001$

( $M=4.3$ ,  $SD=1.0$ ), intuition/gut feelings ( $M=4.2$ ,  $SD=1.1$ ), and the perceived effectiveness of other interventions being used ( $M=4.2$ ,  $SD=0.9$ ). Eleven ‘other factors’ were nominated as very important by single participants. Four of these were related to parents’ impressions of the service providers that would have delivered the intervention, and four related to the parents’ beliefs about the intervention, their own values, and how their child would respond. Parents also added that there was a long waitlist and their child did not ‘get in’, that they were offered a Government sponsored alternative intervention, and that they felt overwhelmed.

The factors least frequently rated as important were advice from friends/relatives ( $M=2.9$ ,  $SD=1.1$ ), advice from other parents ( $M=3.3$ ,  $SD=1.1$ ), that most people thought it was an ineffective intervention ( $M=3.3$ ,  $SD=1.1$ ), advice from teachers ( $M=3.5$ ,  $SD=1.0$ ), and advice from medical doctors ( $M=3.5$ ,  $SD=1.1$ ).

*Importance of Categories in Decision-Making* A Friedman two-way analysis of variance (Stricker 2008) was conducted to determine whether different categories (as noted in Table 2) were ranked differently by the participants. The results of this test indicated that there were significant differences in the rankings,  $\chi^2(5, N=61)=45.15$ ,  $p < 0.001$ , so Conover post hoc comparisons (Stricker 2008) were completed. The results of these paired comparisons and mean ranking differences between categories is presented in Table 7 (in the table the positive rank difference favors the categories listed in the first column).

The emotion-based category had the highest mean rank ( $M=4.13$ ) and, as shown in Table 7, was ranked significantly higher than the pragmatic category and research evidence. Service characteristics had a mean rank of 3.93 and child factors a mean rank of 3.76. The pragmatic category and research evidence had the same mean ranking of 3.48. The category of advice/recommendations had the lowest mean ranking, of 2.22 and, as shown in Table 7, was ranked significantly lower than all other categories.

**Table 6** Factors in decision-making for an intervention considered but not used, ranked by mean

Factor	Mean	Number of responses (%), <i>n</i> =62					
		5. Very important	4. Somewhat important	3. Neither important nor unimportant	2. Somewhat unimportant	1. Very unimportant	No response
Child's individual needs	4.4	38 (61.3)	10 (16.1)	8 (12.9)	3 (4.8)	1 (1.6)	2 (3.2)
Whether staff were experienced	4.3	35 (56.5)	14 (22.6)	10 (16.1)	0 (0.0)	2 (3.2)	1 (1.6)
Intuition/gut feelings	4.2	29 (46.8)	20 (32.3)	8 (12.9)	1 (1.6)	3 (4.8)	1 (1.6)
Effectiveness of other interventions being used	4.2	26 (41.9)	23 (37.1)	9 (14.5)	2 (3.2)	1 (1.6)	1 (1.6)
Cost	4.1	35 (56.5)	10 (16.1)	9 (14.5)	3 (4.8)	4 (6.5)	1 (1.6)
Availability of the intervention	4.1	30 (48.4)	11 (17.7)	17 (27.4)	0 (0.0)	3 (4.8)	1 (1.6)
Side effects/adverse effects	4.1	27 (43.5)	16 (25.8)	14 (22.6)	2 (3.2)	2 (3.2)	1 (1.6)
Whether or not ASD specific	4.1	25 (40.3)	21 (33.9)	9 (14.5)	3 (4.8)	2 (3.2)	2 (3.2)
Whether staff appeared professional	4.1	24 (38.7)	19 (30.6)	15 (24.2)	0 (0.0)	2 (3.2)	2 (3.2)
Funding available	4.0	32 (51.6)	9 (14.5)	11 (17.7)	3 (4.8)	5 (8.1)	2 (3.2)
Compatibility with other interventions being used	4.0	27 (43.5)	16 (25.8)	14 (22.6)	2 (3.2)	2 (3.2)	1 (1.6)
Research evidence	3.9	20 (32.3)	23 (37.1)	14 (22.6)	2 (3.2)	2 (3.2)	1 (1.6)
Availability of alternative interventions	3.9	18 (29.0)	20 (32.3)	17 (27.4)	3 (4.8)	1 (1.6)	3 (4.8)
Did not think child would enjoy it	3.8	22 (35.5)	17 (27.4)	15 (24.2)	3 (4.8)	4 (6.5)	1 (1.6)
Location or accessibility	3.8	20 (32.3)	18 (29.0)	14 (22.6)	6 (9.7)	3 (4.8)	1 (1.6)
Advice from therapists	3.8	17 (27.4)	24 (38.7)	12 (19.4)	7 (11.3)	2 (3.2)	0 (0.0)
Information from service providers	3.8	16 (25.8)	22 (35.5)	16 (25.8)	4 (6.5)	2 (3.2)	2 (3.2)
Child's age	3.8	16 (25.8)	24 (38.7)	18 (29.0)	1 (1.6)	2 (3.2)	1 (1.6)
Not convenient time-wise/did not fit schedule	3.7	22 (35.5)	14 (22.6)	15 (24.2)	5 (8.1)	5 (8.1)	1 (1.6)
Family impact	3.7	17 (27.4)	14 (22.6)	24 (38.7)	2 (3.2)	3 (4.8)	2 (3.2)
Advice from medical doctors	3.5	13 (21.0)	16 (25.8)	22 (35.5)	6 (9.7)	3 (4.8)	2 (3.2)
Advice from teachers	3.5	8 (12.9)	24 (38.7)	22 (35.5)	3 (4.8)	3 (4.8)	2 (3.2)
Most people thought it was an	3.3	8 (12.9)	18 (29.0)	25 (40.3)	4 (6.5)	6 (9.7)	1 (1.6)

**Table 6** (continued)

Factor	Mean	Number of responses (%), <i>n</i> =62					
		5. Very important	4. Somewhat important	3. Neither important nor unimportant	2. Somewhat unimportant	1. Very unimportant	No response
ineffective intervention							
Advice from other parents	3.3	7 (11.3)	24 (38.7)	18 (29.0)	9 (14.5)	4 (6.5)	0 (0.0)
Advice from friends/relatives	2.9	3 (4.8)	15 (24.2)	27 (43.5)	8 (12.9)	9 (14.5)	0 (0.0)

## Discussion

In the present study, data were collected regarding the relative importance of different factors in the decisions of parents of children with ASD to select or reject interventions. These shall be addressed in turn, followed by comparisons of the importance of factors for different decision outcomes (the choice to use an intervention compared to the choice to reject an intervention), and limitations of the study.

### Importance of Factors in Decisions to Use Interventions

The individual factor with the highest mean ranking (4.9, *SD*=0.3) was the child's individual needs. This indicates that parents are considering what is important for their particular child when making decisions. It may also reflect the widely held belief that all children with ASD are individuals who will each respond to interventions differently, and that therefore what works for one child may not work for another. This belief may be encouraged by the information published on websites such as the Australian Federal Government supported "Raising Children Network" website which states:

**Table 7** Friedman analysis and mean rank differences for importance of categories for an intervention considered but not used

	Advice/ recommendations	Child factors	Emotion- based	Pragmatic	Research evidence
Child factors	1.54***				
Emotion-based	1.91***	0.37			
Pragmatic	1.25***	-0.29	-0.66*		
Research evidence	1.25***	-0.29	-0.66*	0.00	
Service characteristics	1.71***	0.17	-0.20	0.46	0.46

\*  $p < 0.05$ . \*\*  $p < 0.01$ . \*\*\*  $p < 0.001$

...it's important to remember that just as every child on the spectrum behaves differently, every child will respond to interventions and therapy differently too.... Many parents find they have to try a few different treatment or intervention approaches to find what works best for their child and their family (Raising Children Network 2011).

Additionally, websites of national autism associations also promote such beliefs by containing disclaimers stating that they do not recommend any interventions for individuals with ASD because individuals may respond differently to interventions (Stephenson, Carter, and Kemp 2012). Although this may be the case, there is certainly evidence regarding the differential effectiveness of interventions (National Autism Center 2009; Odom et al. 2010; Prior et al. 2011), suggesting that some interventions have a higher probability of success than others.

When the individual factors were grouped pragmatically, the service characteristics category was ranked significantly higher than all other categories. Within the service characteristics category, attributes of staff delivering the intervention, namely whether the staff were perceived by parents as experienced and whether the staff appeared professional, were very important factors in the decisions of the majority of the participants. It should also be noted that a number of the factors added by parents as being very important in their decision-making were also related to staff attributes, such as the impression that the staff member had bonded with their child or that they went "above and beyond". This is consistent with the findings of Hebert (2014), who reported that most of the parents identified the attributes of teachers and staff (such as interpersonal style, training, and experience) as the most important factor in their decision-making. Similarly, Auert, Trembath, Arciuli, and Thomas (2012), in an Australian study, reported that personal attributes of the staff, as well as knowledge and experience of working with children with ASD, were key considerations for the parents regarding the use of speech pathology services.

In the present study considerably more participants indicated that staff attributes were very important in their decision to use the intervention than indicated that research evidence was very important, although a mean rating of importance of 4.3 for research evidence indicated that most parents considered it important. Similarly, Auert et al. (2012) reported that parents had mixed opinions about the importance of research evidence. Furthermore, they reported that some parents prioritized staff knowledge, experience, and skills over research support for the intervention being provided by the staff. These findings have implications for staff working with families. Staff who display strong interpersonal skills and present as knowledgeable, experienced, and professional may be more likely to influence parent decision-making. Thus, it is important for professionals who may be in the position to advise parents about evidence-based intervention decisions to be aware that parents may place importance on their own impressions of staff when selecting interventions. Professionals should actively consider advising parents about possible warning signs of interventions that may not be effective, such as unsubstantiated claims, reliance on anecdotal accounts, or strong "marketing" that reflects commercial interest.

In a recent review of factors declared by parents as influencing their intervention decision-making, the most frequently identified factor was advice from others, which was identified in twelve of the sixteen examined studies (Christon et al. 2010; Hanson

et al. 2007; Le Grice and McMenamin 2001; Loomis 2007; Lynch 2004; Miller et al. 2012; Senel 2010; Shyu, Tsai, and Tsai 2010; Smith and Antolovich 2000; Valentine 2010; Valentine et al. 2010; Wong and Smith 2006). This finding may lead to the conclusion that advice/recommendations are one of the most important factors in parent decision-making (Carlon et al. 2013). In the present study, however, the category of advice/recommendations was ranked significantly lower than all other categories. This highlights the difference between those factors that are frequently considered in decision-making and those that carry the most weight in the parents' final decisions. The frequency with which factors are reported may not reflect the importance of the factors in parent decision-making. When considering the scores of individual factors within the advice/recommendations category, only advice from therapists ( $M=4.5$ ,  $SD=0.8$ ) was relatively highly ranked, although eight other factors had equal or higher mean importance ratings. Advice from other sources had means ranging from 3.2 to 4.1, which placed them in the lower half of the factors as ranked by mean importance. Thus, on balance, although advice from others may be a frequently identified factor in parental decision-making, the results of the study reported here would suggest that parents place greater weight on a range of other factors when making their decisions.

The above finding was also reflected in the sources of advice/recommendation frequently examined and used by parents, and those considered the most important in decision-making. Based on the frequency of reports of the influence of advice/recommendations in the literature, the conclusion may be reached that other parents would be the source of recommendation with the greatest influence on parent decision-making (Carlon et al. 2013). However, in the present study, professional advice (from therapists, medical doctors, and teachers/educators) had higher mean importance ratings than either that from friends/relatives or from other parents. Both friends and relatives, and other parents were used more frequently as sources of information about interventions than teachers/educators, indicating that the difference is unlikely to be purely due to more contact with professional sources. Rather, as suggested by Green (2007), this may indicate that parents perceive that information provided by professionals is more valid than that provided by other sources. Professionals working with children with ASD should, therefore, keep up-to-date with research regarding interventions so that they can provide accurate information to parents to assist them in making informed decisions about intervention use.

### Importance of Factors in Decisions to Reject Interventions

There is a limited research base of studies related to parents deciding to reject interventions, and within this research base, reports of professionals advising against the use of interventions are rare (Carlon et al. 2013; Loomis 2007; Valentine et al. 2010). In the present study, the advice/recommendations category was ranked significantly lower than all of the other categories. One possible explanation for this is that the parents may not have received any advice against the use of the nominated intervention. A recent review of information provided on the websites of national autism associations also revealed that advice against the use of interventions was rare, even in cases where empirical support for an intervention presented was weak (Stephenson et al. 2012). Future research regarding the type of advice (if any) parents are provided with regarding interventions would be useful in clarifying whether advice is



unimportant in decisions to reject interventions because parents dismiss such advice, or because they have not actually received advice.

### Relative Importance of Factors in Decisions to Use or Reject Interventions

For the individual factors presented in the survey there were generally higher means for the importance of factors related to the decision to use an intervention (range=3.2–4.9), than the decision to reject one (range=2.9–4.4). This pattern was also reflected in the mean ranks of the categories. The mean ranks for the categories for the decisions to use an intervention ranged from 2.5 to 4.4, and from 2.2 to 4.1 for the decisions to reject interventions. The slightly higher means for the decision to use interventions may in part be reflective of the strategy used in the survey. Parents were asked to select what they considered to be the most important intervention that they were currently using with their child, and any intervention that they had rejected, and to rate the importance of specific factors in arriving at the decision to use or reject the approach suggested. The parents are likely to look back on the decision to use the intervention, which they now consider to be the most important to their child, as a significant one, and perhaps this contributed to the majority of participants rating most of the factors as more important than they rated the factors related to the decision to reject a different intervention.

In addition to having generally higher means there was also more consistency in the ratings for the importance of categories for the decisions to use interventions. In contrast, there was a lack of differentiation on categories for the decisions to reject interventions. The advice/recommendations category was ranked significantly lower than all other categories and the only other significant difference between categories was that the emotion-based category (in this case a single factor: intuition/gut feelings) was ranked higher than pragmatic factors and research evidence. Unlike the ratings for the decisions to use interventions, there was not a pattern of prominent categories.

One might expect less consistency in the importance ratings of factors if there was a much greater diversity of nominated interventions, as it is possible that parents place greater weight on different factors when considering different interventions. Although 21 of the 62 participants answering this question nominated “ABA” as the intervention rejected they did not indicate the specific type of ABA program that they considered. ABA is a term commonly and non-technically used to refer to intensive behavioral programs but it more accurately describes the scientific discipline upon which a number of interventions (such as the Picture Exchange Communication System [PECS] and discrete trial training) are based (Sigafoos and Schlosser 2008). In Australia, the term “ABA” is commonly used by providers and parents to describe intensive intervention programs. As such, “ABA” has been reported by parents as an intervention used in previous Australian studies (e.g., Carter et al. 2011). Nevertheless, it is possible that when different parents nominated ABA in the current study, they were reflecting on decisions about different types of interventions based on the principles of ABA, which may have led to the diversity of responses, despite one third of the participants nominating this “intervention”. The anonymous nature of the current study prevented further exploration of exactly what parents meant when they nominated “ABA” as an intervention.

Despite the lower means for the factors in the decisions to reject interventions, there was some consistency in the rankings of individual factors across the two decision outcomes. The factor, child's individual needs, was the highest ranked factor for both the decision to use a nominated intervention ( $M=4.9$ ) and the decision to reject a nominated intervention ( $M=4.4$ ). Additionally, research evidence was ranked lower than a number of individual factors, including staff characteristics, whether the intervention was ASD-specific, and intuition/gut feelings, for both types of decisions. It is not clear whether parents are prioritizing other factors over research evidence because they are unaware of the importance of research, or if they are dismissing its importance in favor of other factors, including emotion-based factors such as 'gut feelings'. Future researchers may investigate whether the provision of information about evidence-based practice would influence the weighting that parents place on research evidence in their decision-making. The role of service providers and teachers in sharing this information with parents may also be examined. There is some evidence that pre-service teachers, for example, may not be aware of the level of research support for different interventions for ASD, but that despite being unaware of the efficacy of interventions they tend to endorse them (Bain, Brown, and Jordan 2009). It may therefore be useful to include information about evidence-based practice and where to find information about the efficacy of different interventions in preparation programs for service providers who may be in a position to advise parents.

### Limitations

Some limitations of the current research should be acknowledged. Two autism-specific early intervention service providers (ABI NSW and Aspect) assisted with the recruitment of participants. Whilst these are the two largest autism-specific service providers in NSW the sample may not be representative of parents of young children with ASD who either choose not to use early intervention services or choose to use generic rather than autism-specific services. Participants reported currently using between one and thirteen additional interventions along with the service from which they were recruited ( $M=7.3$  interventions in total). This allays some concerns regarding the representativeness of the sample.

The sample size of 75 is modest, but comparable with other studies in the area (e.g., Dardennes et al. 2011,  $N=78$ ; Patten, Baranek, Watson, and Schultz 2013,  $N=70$ ; Senel 2010,  $N=38$ ). Although some larger survey studies have been conducted (e.g., Bowker et al. 2011; Miller et al. 2012; Christon et al. 2010) it should be noted that these were distributed widely through a number of sources to an unknown number of potential participants and thus return rates could not be calculated.

The design of the survey required parents to respond regarding specific nominated interventions, and there was the possibility that the importance of factors might vary widely with the intervention being considered. However, asking parents to nominate specific interventions has the advantage of allowing them to reflect on factors that were important in their actual decision-making rather than hypothesize about what may be important. The interventions nominated included both specific interventions, such as Floortime; more generic ones that may incorporate a range of approaches and techniques, such as occupational therapy; and some that can also be used to describe specific programs as well as broad

methodology, such as ABA. Thus, it could be argued that parents were rating qualitatively different types of intervention. Parents in the present study, however, nominated the interventions and, as such, they were presumably consistent with their understanding of the options available. Further, the interventions nominated were consistent with the range of self-nominated “interventions” reported by parents in previous research (Bowker et al. 2011; Carter et al. 2011). In the future possible differences in factors considered important in decisions to use and reject different interventions may be examined with a larger sample by asking about specific and clearly defined interventions, rather than instructing participants to nominate interventions.

Although the participants were asked about the importance of “research evidence”, this term was not defined for the parents. It is possible that parents interpreted “research evidence” to include, for example, their own search efforts to find information or anecdotal evidence. In the future researchers collecting data about the importance of research evidence would benefit from defining this term for the participants.

The data are reliant on retrospective reports of decision-making and on parental perceptions of the influence of different decision-making factors. There may have been other factors that influenced their decisions that the parents did not necessarily recall, or factors of which they were not necessarily aware. Additionally, implicit factors, such as parent education levels (Hanson et al. 2007; Wong and Smith 2006) or causal beliefs about ASD (Dardennes et al. 2011), may have influenced their decisions.

Finally, the individual factors addressed in the survey were grouped pragmatically into categories to assist in inferential analyses. Due to the pragmatic nature of the groupings of factors the reader should use some caution when interpreting the results. The data regarding, and descriptive analyses of, the individual factors have also been presented to assist the reader in their interpretation of the full results.

## Conclusion

There is limited extant research related to the weight that parents place on different factors in their decisions to use or reject interventions for ASD. In the present study the factors considered important by parents in decisions to use nominated interventions received slightly higher ratings of importance than those in decisions to reject nominated interventions. There was also more differentiation between categories in the decisions to use interventions, with service characteristics ranked as the most important, followed by research evidence and child factors, emotion-based factors, pragmatic factors, and advice/recommendations. In both decisions to use and to reject interventions, individual factors such as staff characteristics, whether the intervention was ASD-specific, child needs, and intuition/gut feelings were more important than research evidence. The least important category in parental decision-making about interventions for both decision outcomes, advice/recommendations, has been frequently identified in the previous literature on influences on parent decision-making. This highlights the difference between frequently identified decision-making factors, and those that are of the greatest importance to parents.

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