S.I. : PARENTING CHILDREN WITH ASD

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Documenting and Understanding Parent's Intervention Choices for Their Child with Autism Spectrum Disorder

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Abstract

Understanding why parents choose some interventions but not others for their child with autism is important for a number of reasons. Estimating the proportion of evidence-based interventions engaged, identifying the agencies influencing parental decisions, and elucidating the barriers or reasons leading to intervention rejection or discontinuation can result in better service provision. New Zealand parents (n = 570) of a child with autism reported what interventions were being engaged, and why some interventions were engaged but not others. Funding was a major determinant of intervention engagement, while medical professionals exerted the most influence. Sources of support were not related to intervention engagement, but parental perceptions of their child's symptom severity were. Finally, non-engagement does not necessarily reflect parental opposition to an intervention, but rather the existence of barriers.

Keywords Autism · ASD · Parent decision making · Intervention choice

Introduction

The initial diagnosis of Autism Spectrum Disorder (ASD) is typically a traumatic event for parents, and feelings of shock, grief, fear, guilt, and/or uncertainty are common (Lutz et al. 2012). Following diagnosis parents typically progress through stages of mourning, adaptation and adjustment, while at the same time needing to focus on the interventions that their child will need to engage (Barak-Levy and Atzaba-Poria 2013). Compared to most other childhood-related disorders it is commonly parents, as opposed to medical professionals, who shoulder the burden of decision-making regarding ASD-related interventions (Valentine 2010). Though parents are given freedom of choice, these decisions are time critical and consequently parents may become overwhelmed and experience stress. Pressure to immediately engage with interventions is driven by decades of scientific research indicating that early intervention more effectively decreases core symptoms and problem behaviours (Warren et al. 2011). However, parents choosing interventions for their child are faced with a number of challenges (Hebert 2014), including the plethora of available interventions (Valentine 2010) and conflicting sources of information about the most effective treatments (Bowker et al. 2011; Matson and Williams 2015).

Although there is no cure for ASD nor a universal standard of care, studies worldwide have identified the most commonly utilised interventions (Bowker et al. 2011), and international variations are pronounced (Keenan et al. 2015). While the number and types of interventions vary, the child's age, symptom constellation, and symptom severity appear related to patterns of intervention uptake (Goin-Kochel et al. 2007). Though a subset of ASD interventions have been scientifically evaluated and shown to be useful (e.g., Speech Language Therapy, Applied Behavior Analysis), many have not, and parents may in fact be engaging interventions that

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are ineffective, expensive, time-consuming, or even harmful (Foxx and Mulick 2015). Thus, documenting the interventions that parents adopt (or avoid) and exploring the reasons for these decisions may inform service providers and/or lead to the better provision of information and support to parents.

Availability of (or accessibility to) interventions has been identified as an important factor in parental decision-making (Carlon et al. 2013, 2015). Availability may be an issue for those living in remote areas, and for those whose child has attained an age where the service is no longer offered. Furthermore, availability due to the geographical distance between the child and clinic may differ across intervention type (Matson and Williams 2015). For example, private clinics offering intensive behavioural interventions may not be as broadly distributed as other types of services.

Funding for an intervention has been identified as a further factor directing parental decision-making (Carlon et al. 2013; Smith and Antolovich 2000). Raising a child with ASD is expensive, and ASD has been estimated to double the cost of raising a child in the United States (Montes and Cianca 2014). Thus, financial hardship may drive parents towards interventions that are funded by external agencies such as the Government or charities. In the New Zealand context, intensive Applied Behavioural Analysis Therapy (iABA) is not typically funded by the Government nor covered by insurance, and so the cost falls upon the child's family. Travel expenses to-and-from specialists and clinics can likewise mount. Christon, Mackintosh and Myers (2010) reported that cost was the second most commonly cited reason for parents discontinuing complementary and alternative medicines with their child with ASD.

When selecting the best interventions for a child with ASD there are a multitude of sources from which parents can obtain information, including the internet, health and medical professionals, and other parents of children with ASD. Medical professionals believe that the dissemination of information from credible sources such as themselves will result in parents making better choices (Matson and Williams 2015). Research confirms that parents are likely to seek advice from medical professionals as they are perceived to be most knowledgeable about the interventions (Carlon et al. 2015; Green 2007), are often the professionals involved at the time of diagnosis (Romanczyk and Gillis 2005), or are themselves intervention providers (Hebert 2014). Consequently, when seeking advice from professionals, parents may be vulnerable to professional recommendations based on 'professional opinion' rather than guided by evidence-based practice (Elder 1994).

The influence of the internet on parental decision-making has yet to be fully explored, and though identified by Green (2007) as the paramount source of information for parents regarding ASD interventions, this finding was not replicated in Carlon et al.'s (2015) study. The internet is often seen to present conflicting information regarding intervention efficacy, even when presented by national autism associations (Stephenson et al. 2012), and can foster confusion and information overload. Unlike internet-sourced information, parents are not, unsurprisingly, likely to be seeking information about interventions from the scientific literature (Stephenson et al. 2012). This avoidance of scientific research is likely due to accessibility issues or difficulty in understanding the scientific lexicon. When making intervention choices, Carlon et al. (2015) report that parents were more likely to use "gut feeling" or "intuition" than consult research evidence.

It might be expected that intervention engagement might also be facilitated by informal sources of support, such as family, friends or spouses. Support from friends or family decreases parenting stress levels, negative emotional reactions, and mental health problems in parents of children with ASD (e.g., Ekas et al. 2010; Murphy et al. 2006; Zaidman-Zait et al. 2016). Additionally, studies show that 'neighbourhood social support' lowers risk of parental depressive symptoms in the ASD context (Zablotsky et al. 2013). Low levels of family and other sources of informal support, on the other hand, are associated with higher levels of psychological distress for mothers of children with ASD (e.g., Pozo and Sarriá 2014). A number of reasons for the positive effects of support have been proposed, including having a sense of being understood, support with daily schedules (Ludlow et al. 2011) and assistance in dealing with difficult behaviours (Plant and Sanders 2007). However, the impact of informal support (or lack of) on intervention choices has yet to be sufficiently explored.

Parent-rated ASD symptom severity likewise guides the intervention choices parents make for their children. Those interventions purporting to address the ASD-related symptoms perceived by parents to be most affecting their child's function and behaviour would be expected to be engaged (Carlon et al. 2013). For example, Speech Therapy would be selected to target communication difficulties, and dietary interventions to address gastrointestinal issues. In a qualitative study, Hebert (2014) reported that parents commonly chose interventions that target specific ASD-related deficits, such as communication or toileting skills, especially as the child gets older and developmental milestones are missed. Furthermore, if parents perceive the effects of traditional intervention approaches (e.g., Speech Therapy or Occupational Therapy) as lacking, then they may try untested alternatives over those being recommended by their doctors or other health professionals (Hebert 2014).

In relation to terminating an intervention, parental satisfaction with progress and perceived reduction of core symptoms may be important factors (Bowker et al. 2011). An intervention maybe terminated if the target symptom has been satisfactorily addressed, or else after a period of engagement the parents begin to doubt its impact.

Considering the latter, discontinuation may also occur even if the intervention is successful in the clinic but the benefits are not perceived to be generalising to the family home (Carlon et al. 2013).

Decision-making is also confounded by the parents' responsibility to protect their child from harm. Studies show that parents struggle to identify the interventions that are most appropriate and safe for their child (Call et al. 2015), and the risks and side effects may not be immediately apparent until the intervention has commenced. Predictably, parents will discontinue interventions if they perceive their child to be in pain or discomfort (Shyu et al. 2010). Thus it is not uncommon for parents to select both validated and non-validated interventions for their child (Call et al. 2015), as the potentially harmful effects of the latter have yet to be determined, and a 'try anything' approach adopted. Because of the time-critical nature of ASD interventions, it may be that some parents embrace and adopt unsupported interventions out of desperation or fear of missing out (Matson and Williams 2015).

The inability to effectively manage time given the demands of caring for a child with ASD can also lead parents to avoid particular interventions. Green (2007) noted that time-investment was an important consideration when parents are deciding to implement an untested intervention. Because parents are likely to shun time-consuming interventions, many purveyors of unsubstantiated ASD-related interventions market them as having profound positive effects without need of extensive time investment (Matson and Williams 2015).

The Current Study

Carlon et al. (2014) have noted within the ASD context that parental decision-making is becoming a topic of increasing interest. However, compared to other child disabilities and disorders, research into parents' intervention choices for their child with ASD is still relatively rare (Hebert 2014). Matson and Williams (2015) assert that "…intervention selection is a field unto itself." (p. 23), and appeal for more research on this topic. Furthermore, Bowker et al. (2011) emphasize an even greater gap in the current parent-related ASD literature: investigations into why parents discontinue their child's ASD-related interventions. Allied to this, Carlon et al. (2014) highlight that while a small number of existing studies focus on elucidating those factors driving intervention choices, little has been done to investigate why parents actively reject specific interventions. These omissions in our current understanding of parents caring for a child with ASD are regrettable for a number of reasons. A better understanding of the intervention decisions parents make in regard to their child with ASD will allow professionals to

better inform parents about optimal interventions that are effective and will not waste parents' time or money. Further exploration will also uncover the guidance and support that parents receive, and how credible these sources are.

In New Zealand, the Autism Spectrum Disorder Guidelines developed by the Ministries of Health and Education (2008) direct service delivery for a child with ASD (Searing et al. 2015). Operationally, the most commonly utilised interventions in New Zealand for ASD include Behavioural Therapy (BT), iABA, Occupational Therapy (OT), Speech Language Therapy (SLT), and Dietary Interventions (DI). The present study will explore the views of parents that have engaged or rejected these five mainstream interventions with their children, and seek an understanding of what factors contribute to their decision making. In building on past research, the present study has three core objectives. Firstly, to provide descriptive data that documents parents' intervention choices and the reasons driving their engagement and, if applicable, their reasons for discontinuation. Secondly, further explore factors that are central to parent decision-making processes such as perceived child symptom severity, levels of support, and sources of recommendation. Thirdly, by using a New Zealand sample we can respond to calls for more international data to augment those data collected in the North American context (Bowker et al. 2011).

Method

Participants

The study involved a cross-sectional design utilising an online survey. Convenience sampling was employed to recruit 585 participants whose electronic contact details were held by Autism New Zealand, New Zealand's largest autism national association and a provider of support services to parents caring for a child with ASD. Table 1 describes the sociodemographic characteristics of the participants. Mean participant age was 44.9 years ($SD = 7.76$), which did not differ significantly [$t(565) = 1.407, p = .165$] between male ($n = 53$, $M_{age} = 46.73$, $SD = 9.55$) and female ($n = 529$, $M_{age} = 44.76$, $SD = 7.56$) participants. The age range of their child with ASD was 2 to 19 years ($M_{age} = 11.08$, $SD = 5.85$), with 82.4% of the children being male. About a quarter of the children were an only-child, while a small proportion ($\approx 3\%$) of children had four-or-more siblings. Approximately 37% of children ($n = 168$) possessed other medical or psychological conditions, with anxiety disorder ($n = 104$), Attention-Deficit/Hyperactivity Disorder ($n = 78$), and Global Developmental Delay ($n = 38$) being the most common. Approximately 97% of the parents reported that their child received a diagnosis of ASD from a qualified medical professional. For the purposes of the study, those

Table 1 Characteristics of participants and their child with ASD

Category	n (%)
Gender of parent	
Female	529 (90.4)
Male	53 (9.1)
Highest education level of parent	
Primary school	2 (0.3)
Secondary school	144 (24.6)
Technical college	94 (16.1)
University degree	274 (46.8)
Other	70 (12.0)
Relationship with child	
Parent	567 (96.9)
Legal guardian	7 (1.2)
Other	9 (1.5)
Number of children in family	
1	153 (26.2)
2	274 (46.8)
3	107 (18.3)
4	30 (5.1)
5 or more	17 (2.9)
Gender of child	
Female	103 (17.6)
Male	482 (82.4)
Source of diagnosis	
General practitioner/medical doctor	10 (1.7)
Paediatrician	398 (68.0)
Clinical psychologist	106 (18.1)
Never received formal diagnosis	15 (2.6)
Other medical specialist	55 (9.4)

indicating that their child had never received formal diagnosis ($n = 15$) were eliminated from the analyses.

Materials

Parent-Rated Child Symptoms

Parents were asked to rate the severity of their child's core ASD symptoms using the Autism Impact Measure (AIM: Kanne et al. 2014). The AIM is a 25 item parent-report measure based on a 2-week recall period. The AIM contains four primary domains targeting the core symptoms of ASD: Restricted/Ritualized Behaviours (8 items); Communication/Language Deficits (5 items); Social-Emotional Reciprocity (7 items), and; Odd/Atypical Behaviours (5 items). The AIM measures the impact of symptoms on an individual's daily functioning and utilises a 5-point Likert scale ranging from 1 (*not at all*) to 5 (*severely*). Kanne et al. (2014) report that the AIM possesses modest to moderate test–retest (0.53 to 0.85) and cross informant (0.46 to 0.73) reliability.

Intervention Choices

A series of questions were developed in order to document the interventions parents were choosing for their child, why they were (or were not) engaged, who funded them, for how long the interventions were engaged, and finally if relevant, why they were discontinued. As data was collected in the New Zealand context, a total of five interventions were chosen based on the frequency of intervention use reported in recent literature (Shepherd et al. 2017). These interventions were iABA; BT; DI; OT, and; SLT. The selection of these interventions was determined in part by Bowker et al.'s (2011) appeal to use more refined and specific intervention categories than those used in their own study, and by the much smaller number of interventions available in the New Zealand context. According to the classification system outlined by Green et al. (2006) and adopted by Bowker et al. (2011), our five interventions would fall into the following categories: *Standard* (SLT); *Applied Behavioural Analysis* (iABA and BT); *Physiological* (OT), and; *Alternative Diets* (DI). Furthermore, Carlon et al. (2015) criticize the often umbrella-like use of the term "ABA" in the ASD literature. For the current study both iABA and BT were carefully differentiated, with iABA defined as intensive behavioural programmes and BT as less intensive interventions such as the Picture Exchange Communication (PEC) system.

For each intervention a standardised definition was presented, followed by an item asking if, in the past or present, their child had engaged with this intervention. Participants indicating that their child had engaged the intervention ('*Yes*') were asked at what age the intervention started and, if not ongoing, what age the child was when the intervention was discontinued. Next, who-or-what had chiefly influenced intervention choice was asked, and which primary ASD trait the intervention attempted to address (re: Table 2). Additionally, how the therapy was funded (i.e., Government or self-funded) and, if appropriate, the main reason for discontinuing the intervention were documented. Participants selecting '*No*' were required to state the main reason for not implementing the intervention by choosing from the following options: too expensive, scepticism in the intervention's efficacy or safety (i.e., risk), unaware as to its existence, or time pressures (re: Table 3). Additionally, these non-engagers were asked if they had a desire to engage the intervention if given the choice.

Support for Parents

Participants were asked to rate how much support they felt they received from their partner, family, friends and health professionals (e.g., doctor, therapist) using a 7 point Likert-scales ranging from 1 (*Not at all Supported*) to 7 (*Very Much*

Table 2 Number of participants having engaged their child in ASD-related interventions currently or in the past

N (%)	SLT	BT	iABA	OT	DI
	n=385 (65.8)	n=285 (48.6)	n=78 (13.3)	n=370 (63.1)	n=234 (40.6)
Mean age start[a]	3.70 (1.97)	6.69 (3.91)	4.49 (3.11)	5.11 (3.12)	5.41 (3.14)
Funding					
Self-funded	84 (25.3)	64 (25.0)	62 (89.9)	53 (16.3)	147 (71.4)
Government	248 (74.7)	192 (75.0)	7 (10.1)	272 (83.7)	59 (28.6)
Target trait					
Language	286 (74.3)	24 (8.4)	36 (46.2)	17 (4.6)	23 (9.8)
Behaviour	6 (1.7)	41 (14.4)	10 (12.8)	32 (8.6)	20 (8.5)
Odd behaviour	3 (<1.0)	9 (3.2)	0 (0.0)	7 (1.9)	8 (3.4)
Social deficits	35 (9.1)	92 (32.3)	12 (15.4)	54 (14.6)	15 (6.4)
Sleep	2 (<1.0)	4 (1.4)	0 (0.0)	3 (<1.0)	7 (3.0)
Sensory issues	7 (1.8)	24 (8.4)	0 (0.0)	91 (24.6)	10 (4.3)
Eating	5(1.3)	6 (2.1)	0 (0.0)	10 (2.7)	48 (20.5)
Toileting	2 (<1.0)	3 (1.1)	1 (1.3)	16 (4.3)	16 (6.8)
Motor deficits	3 (<1.0)	24 (8.4)	2 (2.6)	92 (24.9)	2 (<1.0)
Other	33 (8.6)	86 (30.2)	15 (19.2)	46 (12.4)	81 (34.6)
Influence					
Doctor	16 (4.2)	9 (3.2)	0 (0.0)	13 (3.5)	19 (8.1)
Psychologist	18 (4.7)	46 (16.1)	9 (11.5)	31 (8.4)	6 (2.6)
Internet	13 (3.4)	7 (2.5)	19 (24.4)	3 (<1.0)	43 (18.4)
Other parent	14 (3.6)	11 (3.9)	11 (14.1)	8 (2.2)	13 (5.6)
Friend	9 (2.3)	5 (1.8)	6 (7.7)	4 (1.1)	6 (2.6)
ASD books	10 (2.6)	7 (2.46)	5 (6.4)	6 (1.6)	21 (9.0)
Teacher	46 (11.9)	22 (7.7)	2 (2.6)	32 (8.6)	0 (0.0)
MoE	143 (37.1)	46 (16.1)	2 (2.6)	95 (25.7)	2 (<1.0)
Paediatrician	93 (24.2)	66 (23.2)	1 (1.3)	108 (29.2)	61 (26.1)

The table indicates the mean age the intervention commenced, the source of funding, the trait being primarily addressed, and the dominant source of influence

SLT speech language therapy, *BT* behavioural therapy, *ABA* applied behavioural analysis, *OT* occupational therapy, *DI* dietary interventions

[a]Parentheses contain standard deviations

Table 3 Number of participants having not engaged a specific ASD-related intervention for their child, and the reasons for not engaging

N	SLT	BT	iABA	OT	DI
	n=200 (34.1%)	n=299 (51.2%)	n=505 (86.2%)	n=211 (36.3%)	n=343 (58.5%)
Expense	15 (7.5)	32 (10.7)	106 (21.0)	20 (9.5)	27 (7.9)
Scepticism	3 (1.5)	13 (4.3)	30 (5.9)	16 (7.6)	111 (32.4)
Availability	43 (21.5)	81 (27.1)	77 (15.2)	86 (40.8)	53 (15.5)
Unawareness	20 (10)	83 (27.8)	206 (40.8)	28 (13.3)	58 (16.9)
Too risky	1 (<1.0)	4 (<1.0)	15 (3.0)	1 (0.0)	8 (2.3)
Time pressure	2 (1.0)	12 (4.0)	29 (5.7)	3 (1.4)	12 (3.5)
Not relevant	103 (51.5)	37 (12.4)	36 (7.1)	35 (16.6)	41 (12.0)
Other	13 (6.5)	37 (12.4)	6 (1.2)	22 (10.4)	33 (9.6)
Desire to engage	90 (45)	198 (66.2)	273 (54.1)	137 (64.9)	152 (44.3)

The table also indicates the number of individuals who would be willing to engage the intervention were it not for barriers

SLT speech language therapy, *BT* behavioural therapy, *ABA* applied behavioural analysis, *OT* occupational therapy, *DI* dietary interventions

Supported). A 'not applicable' option was also available for non-existent sources of support.

Procedure

The Author's institutional ethics committee reviewed and approved the study. Participation was voluntary, both anonymity and confidentially were guaranteed, and completion of the questionnaire was taken as informed consent. Participants received an invitation to partake in the study via an email from Autism New Zealand. Parents completed the survey online and received no financial incentive for its completion. Parents initially responded to sociodemographic questions and then rated their child's ASD symptoms using the AIM. After indicating their sources (and degree thereof) of support, they indicated their engagement (or not) of the five interventions.

Data Analysis

For each of the five interventions, participants were classified as either *engagers* or *rejecters*. From those who engaged an additional subgroup was created, *discontinuers*, consisting of those whose child had received the intervention in the past but were no longer so. Data were then tabulated to display frequency counts and percentages of intervention-related variables as a function of intervention type. When variables were continuous (e.g., age), independent samples ANOVAs with Bonferroni adjustments were used to compare means across the five interventions. If variables were categorical then Pearson's Chi square tests (χ^2) were employed, with Yates' correction for continuity used when cell counts were less than five, and alpha adjustments made for multiple comparisons. Finally, five binary logistic regression models were created to further explore variables that predict intervention engagement. Here the predicted variable was intervention engagement (0 = yes, 1 = no), and the predictor variables were parent age and education (dummy coded), child age and gender, the four subscales of the AIM and the four sources of support scale items. Additionally, number of siblings was included as larger families will likely be associated with greater levels of parenting stress that in turn may impact a parent's ability to engage interventions.

Results

Preliminary Analyses

Mean score and Cronbach's alphas (α_c) for the four AIM subscales were as follows: Restricted/Ritualized Behaviours ($M = 24.51$, $SD = 6.83$, $\alpha_c = 0.834$); Communication/Language Deficits ($M = 14.06$, $SD = 5.99$, $\alpha_c = 0.884$);

Social-Emotional Reciprocity ($M = 19.31$, $SD = 6.45$, $\alpha_c = 0.868$), and; Odd/Atypical Behaviours ($M = 15.03$, $SD = 4.66$, $\alpha_c = 0.784$). By dividing the mean total scores by number of items, the mean scale score for each of the AIM subscales can be determined. This operation reveals that, on average, parents rated their child's Restricted/Ritualized Behaviours as most impacted by ASD, and Social/Emotional Reciprocity function as the least. Cronbach's alphas are all over 0.75, the cut-off generally considered to represent sufficient scale consistency.

Engagement of Interventions

Parents were asked to report which of the five frontline ASD interventions offered in New Zealand they had used, or were using, with their child. Of the 585 responses, only 3.9% of the sample indicated that they had never accessed an intervention, while 13.2% indicated that their child had engaged one of the five. Most had engaged two (26.8%), three (29.5%), or four (17.7%) of the mainstream interventions, while 8.1% of the sample had used all five with their child.

The top portion of Table 2 displays the percentage of individuals whose child with ASD underwent specific ASD-related therapies. The average age that therapy was commenced varied across the five therapies. A one-way analysis of variance [$F(4,1309) = 2.378$, $p < .001$] indicated that, after adjusting for omnibus testing, SLT was engaged significantly earlier than BT ($p < .001$), OT ($p < .001$), and DI ($p < .001$), while BT was engaged significantly later than OT ($p < .001$) and DI ($p = .044$). With respect to intervention costs, scrutiny of the data reveals that SLT, BT and OT were more likely to be funded by the Government, while iABA and DI were more likely to be funded by the parents themselves. Pearson's Chi square tests revealed that there were significant differences between self-funded and government funded groups across all interventions. There was a link between utilising SLT [$\chi^2(1) = 81.012$, $p \leq .001$], BT [$\chi^2(1) = 64$, $p \leq .001$], and OT [$\chi^2(1) = 147.572$, $p \leq .001$] and a bias towards government funding. In contrast, there was a link between utilising iABA [$\chi^2(1) = 43.841$, $p \leq .001$] and DI [$\chi^2(1) = 37.592$, $p \leq .001$] and a bias towards self-funding.

Parents were also asked to declare the autistic trait that the intervention primarily attempted to address. For both SLT and iABA interventions, language traits were the most frequently cited target, while for BT the emphasis was largely on social deficits. In relation to OT, sensory and motor deficits were the most frequently cited target traits. Eating issues were the most common trait listed for DI after the 'Other' category.

Further scrutiny of Table 2 reveals that the sources of influence for selection of the various interventions also differed across intervention type. For SLT and OT, the main

influence came from clinical representatives from the Ministry of Education, paediatricians, or school teachers. This was also true in relation to BT, though Clinical Psychologists were also a commonly cited influence. Interestingly, the choice to engage either iABA or DI was strongly influenced by information obtained from the internet. However, unlike iABA, the decision to try DI appears to be influenced by Paediatricians. Figure 1 shows the total number of recommendations without respect to intervention type. Here, paediatricians and workers for the Ministry of Education emerge as the main influence on parents' intervention choices for their child.

Non-Engagement of Interventions

Table 3 presents responses from parents who were asked why they had rejected specific interventions with their child. Of the five interventions, the most rejected was iABA followed by DI. Immediately apparent is the variation in reasons for rejection across the five interventions. For SLT most rejecters deemed the intervention of no relevance to their child's ASD symptoms, while for BT the issues were around access to the intervention or a lack of awareness as to their existence. For iABA a lack of awareness was prominent, while expense also figured. Interestingly, for DI, the most frequently cited reason was a lack of confidence in the efficacy of this approach. The final row in Table 3 shows those parents expressing a desire to engage the interventions. A battery of Chi square tests revealed that, across the five interventions, perceived expense was consistently linked to a desire to engage the intervention. Additionally, the desire to engage iABA or DI was related to both a lack of awareness or availability of these interventions, while a desire to engage BT was linked to parents' unawareness of this

intervention (all $p < .05$). Finally, a lack of desire to engage in iABA and DI was associated with scepticism towards the interventions' effectiveness.

Disengagement of Interventions

Table 4 displays the subset of parents who had engaged interventions and then ceased. Inspection reveals that, consistent with different starting ages, the age of the child in which an intervention is terminated differs across intervention modality. Given that differences in mean age when starting the intervention differs across interventions, a more useful measure is the total time engaged. Here, a one-way ANOVA [$F(4,1158) = 4.209$, $p = .002$] revealed that SLT ($p < .001$), OT ($p < .01$), and BT ($p < .05$) were all engaged for a longer periods than DI. For SLT the most common reason parents gave regarding cessation of intervention was the realisation of objectives, while for DI the opposite was true: the therapy was not perceived to be effective. Across the three government-funded interventions, SLT, BT and OT, intervention cessation appears related to the loss of funding. Likewise, the most common reason given for ending iABA therapy was expense.

Predictors of Intervention Engagement

For each of the five interventions a logistic regression model was created, with intervention engagement being the predicted variable and parent age, gender and education, child age and gender, number of siblings, the four AIM subscales, and four sources of support acting as predictor variables. Four of the five logistic regression models were statistically significant: SLT [$\chi^2(17) = 106.88$, $p < .001$]; BT [$\chi^2(17) = 69.32$, $p < .001$]; iABA [$\chi^2(17) = 54.628$, $p < .001$],

Fig. 1 Frequency of individuals citing various sources of information as the dominant influence on their intervention decisions without respect to intervention type
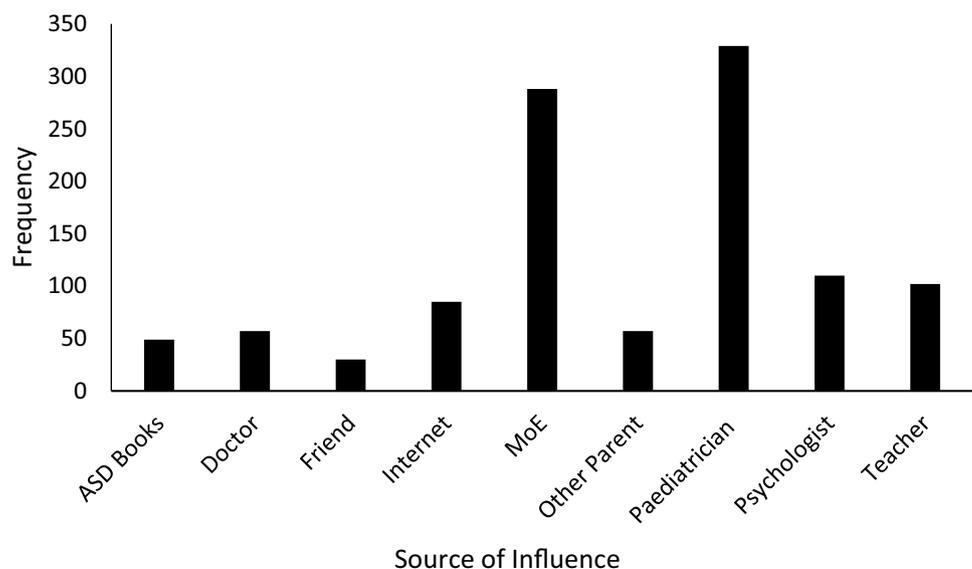
Table 4 The subset of engagers who had ceased exposing their child to one-or-more interventions but had subsequently discontinued

N (%)	SLT $n=256$ (65.5%)	BT $n=206$ (72.2%)	iABA $n=56$ (71.8%)	OT $n=253$ (68.4%)	DI $n=130$ (55.5%)
Mean age ceased[a]	6.29 (4.20)	8.52 (5.49)	7.52 (4.34)	7.32 (4.73)	6.47 (4.75)
Mean time engaged[a]	2.53 (3.97)	1.84 (1.84)	2.89 (4.77)	2.18 (4.34)	1.10 (4.16)
Expense	34 (13.3)	32 (15.5)	28 (50)	31 (12.3)	24 (18.5)
Not working	32 (12.5)	28 (13.6)	10 (4.9)	23 (9.1)	63 (48.5)
Availability	73 (28.5)	49 (23.8)	8 (14.3)	95 (37.5)	7 (5.4)
Time pressure	12 (4.7)	8 (3.9)	6 (10.7)	9 (3.6)	11 (8.5)
Too risky	1 (<1.0)	0 (0.0)	2 (3.6)	0 (0.0)	4 (<1.0)
Goal realised	74 (28.9)	41 (19.9)	7 (12.5)	55 (21.7)	24 (18.5)

The table presents the mean age of discontinuation, how long on average the intervention was engaged, and reasons for discontinuation

[a]Parentheses contain standard deviations

and; OT [$\chi^2(17)=39.78$, $p<.001$]. However, for DI significance was not noted [$\chi^2(17)=106.88$, $p=.446$], indicating that the predictors could not be used to distinguish between those that engaged DI and those who did not beyond a constant-only model. Consequently, this model will not undergo further interpretation. For SLT, the model explained 24.5% (Nagelkerke R^2) of the variance in engagement, with the combination of predictor variables correctly classifying 69.7% of cases in terms of intervention use (or not). Considering the two behavioural interventions, the predictor variables successfully predicted 63.9% of intervention choices for BT ($R^2=15.8$), and 87.8% of the intervention choices for iABA ($R^2=17.6$). Finally, for OT ($R^2=10.1$), the predictors correctly classified 66.7% of cases.

Table 5 presents a selection of predictor variables for the four significant regression models. The predictors displayed are the four AIM subscales representing parents assessments of their child's core ASD symptoms, and four sources of support that they receive when caring for their child: friends, professional, partner, and family support. For the remainder of the predictor variables in the models, only gender of child, age of child, and number of siblings reached significance, and then only for the BT model. Of note across the four models is the failure of the four support variables to predict which of the four interventions would be engaged.

Considering SLT first, the Wald (Z) statistic indicates that only severity of language/communication impairment is a predictor of SLT engagement. Here, a two point increase in severity score leads to a doubling of the odds that the child will undergo SLT. For BT, both the gender ($B=-0.546$, $Z=4.76$, $p=.029$) and age ($B=-0.053$, $Z=5.65$, $p=.017$) of the child with ASD were significant predictors, as was how many siblings they have ($B=0.278$, $Z=7.706$, $p=.006$). For gender, the odds of a parent deciding whether to send their child with ASD to BT is 3.38 times higher if the child is a female. Additionally, with each passing year, the odds of a parent engaging their child in BT is cut in half, while each additional sibling increases the odds of engagement by a multiplicative factor of 1.32. Of the four AIM subscales, three were statistically significant, with the Social-Emotional Reciprocity scale being the exception. For both the Restricted/Ritualized and Odd/Atypical behaviour subscales, a two point increase in symptom severity doubles the odds that BT will be engaged, while an equivalent increase in Communication/Language impairment halves the odds of engaging BT. For the other behavioural intervention, iABA Therapy, both Restricted/Ritualized Behaviours and the Communication/Language subscales were significant predictors, though unlike BT the Odd/Atypical Behaviour subscale did not predict uptake of iABA Therapy. For both the Restricted/Ritualized Behaviours and the Communication/Language subscales, a two point increase in symptom severity doubled the odds that iABA would be engaged. Finally, considering OT, the Communication/Language and Social-Emotional Reciprocity subscales predicted engagement of OT. For the Communication/Language subscale, a two point increase in symptom severity doubled the odds that OT will be engaged, while an equivalent increase in Social-Emotional Reciprocity impairment halved the odds of engaging BT.

Discussion

Our findings offer additional insights into the interventions parents choose for their child with ASD and why they choose them. To begin, the finding of Bowker et al. (2011) that only 57.1% of their Australia/NZ sample utilised interventions is not replicated in our study. In fact our sample contained a higher rate of engagement (96.2%) than their North American sample (76.7%). While Bowker et al. (2011) urged that their result be interpreted with

Table 5 Summary of logistic regression analysis for factors predicting decisions to engage in ASD-related interventions

	B	$SE\ B$	Wald	e^{B}	CI (lower)	CI (upper)
Speech therapy						
Restricted/ritualized	0.04	0.02	3.18	1.04	1.00	1.08
Communication/language	−0.20	0.03	55.23***	0.82	0.78	0.87
Social-emotional	0.02	0.02	0.61	1.02	0.98	1.06
Odd/atypical behaviour	0.00	0.03	0.01	1.00	0.94	1.06
Support friends	0.18	0.10	2.94	1.19	0.98	1.46
Support professional	−0.05	0.10	0.30	0.95	0.78	1.15
Support partner	−0.07	0.06	1.52	0.93	0.83	1.04
Support family	−0.13	0.09	2.33	0.88	0.74	1.04
Constant	2.24	0.85	6.94**	9.35		
Behavioural therapy						
Restricted/ritualized	−0.05	0.02	7.19**	0.95	0.92	0.99
Communication/language	0.06	0.02	7.70**	1.06	1.02	1.11
Social-emotional	0.02	0.02	0.61	1.02	0.98	1.05
Odd/atypical behaviour	−0.08	0.03	8.59**	0.92	0.87	0.97
Support friends	0.08	0.06	1.83	1.08	0.97	1.20
Support professional	0.07	0.08	0.83	1.07	0.92	1.25
Support partner	0.01	0.09	0.00	1.01	0.84	1.21
Support family	−0.15	0.09	2.80	0.86	0.72	1.03
Constant	1.97	0.76	6.77	7.17		
ABA therapy						
Restricted/ritualized	−0.08	0.03	9.77**	0.93	0.91	0.98
Communication/language	−0.13	0.03	16.69***	0.88	0.83	0.94
Social-emotional	0.01	0.03	0.03	1.01	0.96	1.06
Odd/atypical behaviour	−0.06	0.04	2.06	0.94	0.87	1.02
Support friends	−0.05	0.08	0.36	0.95	0.81	1.12
Support professional	−0.06	0.12	0.29	0.94	0.75	1.18
Support partner	0.20	0.14	1.88	1.22	0.92	1.62
Support family	0.08	0.14	0.37	1.09	0.83	1.42
Constant	3.37	1.16	8.40	29.02		
Occupational therapy						
Restricted/ritualized	−0.03	0.02	2.81	0.97	0.94	1.01
Communication/language	−0.06	0.02	7.32**	0.94	0.90	0.98
Social-emotional	0.07	0.02	11.44***	1.07	1.03	1.11
Odd/atypical behaviour	−0.03	0.03	1.28	0.97	0.91	1.02
Support friends	−0.10	0.06	2.98	0.91	0.82	1.01
Support professional	0.02	0.08	0.04	1.02	0.87	1.19
Support partner	0.17	0.10	3.17	1.19	0.98	1.43
Support family	−0.12	0.09	1.67	0.89	0.74	1.06
Constant	0.22	0.76	0.08	1.25		

For brevity, parent and child ages and gender, and parent education have been omitted from table. Intervention engagement coded as 0 for yes and 1 for no

*$p < .05$; **$p < .01$; ***$p < .001$

caution due to difference in group sizes, their point that more international data is required is evidently well made. For example, while they report that 37% of their sample indicated use of interventions that would fall into Green et al.'s (2006) ABA category, our New Zealand data indicated that 53% of parents could be placed in the same category. What is clear from our data is that interventions that are government-funded are much more likely to be chosen than those interventions that are self-funded. Thus it can be concluded that a major factor influencing parents' decision-making is the availability of funding. That said, parents may assume that those interventions that are

government-funded are also those that have been proven to be the most effective.

Both OT and SLT are reputable interventions, and were reportedly utilised by over 50% of parents in an American survey (Goin-Kochel et al. 2009). These participation rates are comparable to those reported in the present study, which were 66 and 63% for SLT and OT respectively. However, while iABA is the gold standard evidence-based intervention for autism in America (Keenan et al. 2015), this approach was chosen by a minority of the participants in the present study. Given that iABA is the most validated of the interventions, our data supports the assertion made by Bowker et al. (2011) that empirical evidence is not necessarily the dominant factor in parental decision-making. Instead, considering the New Zealand context, funding and a parent's financial reach are more likely to be the dominating factors. In New Zealand both SLT and OT are largely Government-funded, while iABA interventions are not usually funded, and the engagement rate of 13.3% that we report is much lower than the rates reported in America, where iABA attracts state funding (Keenan et al. 2015).

Of interest was that two-out-of-five parents implemented a dietary intervention with their child, even though this approach has consistently been found to lack the efficacy (e.g., Levy and Hyman 2002). This finding suggests that a substantial proportion of parents may be vulnerable to claims made by advocates of unsupported interventions. Parents may feel pressured to engage unsupported interventions, though are likely to discontinue the interventions when they are perceived to be ineffective (Levy and Hyman 2002). Regrettably, not only do these often unsubstantiated interventions give parents false hope for their child, they also waste time and financial resources that would have been better spent on validated interventions. This is supported by the high rate of discontinuation for this intervention approach when "lack of progress" was cited as the reason for disengagement (48%), which is substantially higher than those reported for the other four interventions.

Our data support the position that child age is also an important factor when parents are considering interventions. Considering the iABA approach, Hebert (2014) asserts that age is an important consideration as the child needs to be old enough for a structured approach. This notion that young children are not developmentally ready for behavioural interventions appears to be one adopted by the major funder of ASD interventions in New Zealand, the Government. While the mean age at intervention onset for SLT was 3.7 years, the mean age for OT (5.1 years) and BT (6.7 years) was much higher. This pattern may reflect the New Zealand context and further highlight international differences in intervention use, where, for example, drug-based interventions are all but not practiced in New Zealand. In contrast, studies undertaken in the USA (Goin-Kochel et al. 2007; Hebert 2014) found that younger children are introduced to more behaviourally-orientated interventions while older children are more likely to be placed on dietary and medicine-based interventions. However, the effect of age on intervention take-up may be overstated, as with reference to the regression models reported in Table 5, only the uptake of BT was predicted by age of child. Instead, perceived symptom severity may better predict intervention uptake, a finding we turn to next.

There is evidence in the literature indicating that intervention choice may be driven by symptom severity (e.g., Bowker et al. 2011; Carlon et al. 2013), and that parents adopt interventions purporting to target specific dysfunction, for example, OT and fine motor skills. Employing binary logistic regression analyses, we found predictably that the more parents perceived their child's language function as a problem, the more likely they were to engage (or had previously engaged) SLT. Likewise, the two behavioural categories (BT, iABA) targeted ASD-related behavioural traits and language deficits, while OT engagement was predicted by the severity of perceived social and language dysfunction. These findings indicate either that parents are considering the functional abilities of their child and prioritising accordingly, or else the services on offer are doing an effective job of matching interventions to their child's symptoms and severity there-of. Either way, the descriptive data we present in Table 2 shows strong matches between target symptom and the most appropriate intervention. These results support the findings of Carlon et al. (2015), who reported that the individual needs of the child was the factor judged the most important by parents. Of further interest is that the use of the intervention mode associated with the least evidence, DI, was not predicted by any of the four core symptoms comprising the AIM scale. This finding suggests that for the DI approach, factors other than symptom severity are informing decisions. For example, Bowker et al. (2011) suggest that, in relation to those interventions lacking an evidence base, a "try and see" approach is adopted. However, Hall and Riccio (2012) reported that symptom severity was related to the use of alternative interventions, and so more data is required to confirm the direction of this relationship.

A further interesting, and somewhat surprising, finding emerging from the regression analyses is the failure of support sources to predict intervention use. Research has explored the effect of perceived support from professionals (Mak and Kwok 2010) and family and friends (Zaidman-Zait et al. 2016) on parental stress levels, which suggests that high levels of support are associated with an enhancement of parental wellbeing and a decrease in their stress levels. Such an outcome might be expected to enhance a parent's energy levels and hence resolve to engage their child in interventions. This is especially true in the ASD context which is characterised by home-based interventions in which

parents are required to play a central role. The findings of the present study suggest that support is not a factor in intervention choice, though it should be noted that we measured support using a single scale and future studies employing multi-dimensional support scales such as the interpersonal support evaluation list (Cohen et al. 1984) are required to bring greater clarity to the relationship.

The data we collected afford an examination of the weighting of influence on intervention decisions by asking parents which agency of information most influenced their decision. In terms of internet use, our findings indicate that contrary to the findings of Green (2007), and consistent with those of Carlon et al. (2015), the internet is not the major source of influence for 4/5 of the interventions we presented. The exception is the iABA intervention, where approximately a quarter of engagers indicated this source of information as the dominant influence. Our results largely agree with an Australian study (Carlon et al. 2015) reporting that advice from medical professionals and therapists was weighted higher than advice from other parents and friends. Note that while we report that employees of the Ministry of Education were ranked either the first-or-second most dominant source of influence for SLT, BT, and OT interventions, these employees themselves are practitioners, supporting the notion that professional recommendations maybe exert high levels of influence on parents (Deyro et al. 2016). The influence of professionals does not appear equivalent, however, with our finding that general medical doctors (i.e., G.Ps or M.Ds) exert very little influence over the care parents choose for their child with ASD, possibly due to their lack of training in ASD-related intervention options (Unigwe et al. 2017).

Paediatricians had the greatest influence in three of the five categories (BT, OT, and DI), which is consistent with Romanczyk and Gillis' (2005) finding that often those professionals involved at the time of diagnosis have a major influence on a child's intervention trajectory. It is noteworthy that in the current study, 68% of the parents reported that a formal diagnosis had been received from a Paediatrician. As medical specialists, it is interesting that Paediatricians appear to champion the less validated DI, while failing to endorse the most evidenced intervention: iABA. This finding is interesting, as previous research has indicated that parents are reluctant to disclose the use of alternative interventions to their child's paediatrician (O'Keefe and Coat 2010), but the reverse may not be true. Finally, Miller, Schreck, Mulick and Butter (2012) and Deyro et al. (2016) identified that autism-related books were one of the most influential sources of information for parents making intervention-related decisions, a finding not replicated in our study.

The extant literature focusing on parental decisions regarding intervention for their child with ASD is sparse, however, it is even more impoverished when considering why parents shun specific interventions (Carlon et al. 2015). Our data showed marked differences across the five interventions in respect to intervention rejection. Specifically, iABA approaches were most likely to be rejected outright, although the main reason appears to be a lack of awareness of this intervention, followed by expense. For DI, the main reason driving avoidance is scepticism, suggesting that at least a third of parents are in fact referencing scientific evidence when making their decisions. For SLT the major reason was that the approach did not fit the symptoms of the child, supporting previous findings indicating that the individual needs of the child most likely determine if an intervention is rejected (Carlon et al. 2015). Of the remaining two government-funded interventions, BT and OT, a lack of awareness or availability largely accounted for the decision not to engage.

A hitherto unreported finding is that intervention rejection may not in itself imply an outright opposition to that intervention. Parents who indicated that their child had not engaged a specific intervention were asked to indicate that, if given the chance, they would engage their child in that intervention. Here, responses ranged from 44% (DI) to 66% (BT). A Chi square analysis revealed that across the five interventions, expense was a primary reason why a parent might want to engage their child in a particular intervention but did not. Additionally, for the two behavioural interventions (i.e., BT and iABA) and DI, a lack of awareness was associated with a desire to engage. Thus practitioners maybe failing to fully inform parents about the broad spectrum of available interventions, and in the case of the evidence-based iABA approach, most of the actual engagers indicated that the internet was the prime source of information. Finally, the finding that parental scepticism towards iABA and DI is significantly linked with a desire to avoid them offers evidence that some parents are not taking the "try and see" approach described by Bowker et al. (2011). This finding is interesting as these two interventions sit on opposite poles in terms of reported efficacy.

There was a noted consistency across the five interventions in the small numbers of parents indicating that time constraints were a barrier to engaging an intervention with their child, nor were time-related barriers commonly a reason to discontinue an already-engaged intervention. A similar finding was noted for the perceived risk of an intervention. In relation to risk and safety, this result may be explained in part by the fact that four-of-the-five interventions presented in this study have a strong evidence base. Interestingly, the intervention most recognised as being effective, iABA, was either rejected or discontinued more due to perceived risk than the intervention with the least evidence of effectiveness (i.e., DI). This finding supports Call et al. (2015), who reported that parents find it difficult to judge the safety of interventions, and may be in part because

New Zealand based ASD websites are generally negative towards iABA (Stephenson et al. 2012).

The rates of using, and then discontinuing an intervention, are much higher in the current study than the 29% reported by Bowker et al. (2011). Bowker et al. did not indicate the average length of intervention engagement in their predominantly North American sample, and so the difference between the two studies could reflect difference in intervention availability. In the predominantly government-funded intervention environment that characterises the New Zealand situation, the average engagement time across the five modalities was 2.11 years. Thus, the greater discontinuation rates in the present study may reflect a general tendency for interventions to be engaged in shorter time frames than other countries. This is borne out in our data, where 'availability' was consistently indicated to be a dominant reason for discontinuing the three government-funded interventions. It is not inconceivable that the least discontinued intervention, DI, may reflect the fact that this intervention modality is in a constant state of flux, and that parents may be moving from one fad-intervention-to-another. Hebert (2014) reported that parents view the exploration of alternative interventions such as DI as a duty, lest they be seen as negligent, and thus maybe caught in cycles of adopting and then discontinuing less credible interventions.

The reasons for the discontinuation of an intervention differed across intervention modality. For SLT and OT the most cited reasons were availability and the realisation of intervention goals. This latter explanation is consistent with overseas data, indicating that parents tend to rate the effectiveness of SLT and OT very favourably (Goin-Kochel et al. 2009). The same pattern of discontinuation was true of the third government-funded intervention, BT, which differed, however, from the more intensive iABA approach. The iABA approach is not funded in New Zealand, and of those discontinuing iABA, half stated that cost was the main reason. Finally, Bowker et al. (2011) reported that 38% of the parents in their sample stated that interventions were discontinued as they were perceived to be ineffective. For our data, however, this tended only to be true for dietary interventions, the approach most lacking supporting evidence.

The limitations of the current cross-sectional study need to be considered when interpreting its findings. Firstly, parental perceptions of their child's core symptoms were obtained as part of the survey and so the reported relationship between perceived symptoms and intervention use may not be as clear as it might otherwise be. Pertinently, these perceptions may have differed when an intervention had been considered or engaged in the past, and since this time a number of factors may have improved or worsened parental perceptions. Secondly, ASD symptom severity was measured from the parents' perspective, which can be argued to be either a limitation or, given the current research context,

a strength in-as-much as the parent may have better insight into the functional limitations of their child outside of clinical settings. Thirdly, the use of only five specific intervention approaches may be seen as a limitation. However, Bowker et al. (2011), who adopted Green et al.'s (2006) more broad and generalised approach to intervention classification, appealed for future studies to utilise more considered and interpretable categories. We would argue that, considering the New Zealand context, our five interventions have answered this call. Fourthly, it should be acknowledged that much of the data was reliant on parent's memories of the reasons their child engaged (or not) a particular intervention, and therefore the validity of the data could possibly be compromised by processes such as memory decay. Finally, by recruiting from national autism associations the results should not be generalised to the greater ASD parent population without a degree of caution.

Conclusion

The findings reporting in the current study have implications for the agencies directly charged with providing evidence-based interventions for ASD children. While intervention choices typically lie with parents, it is arguably the responsibility of professionals to guide the selection process and ensure that parents choose validated and cost-effective interventions for their child. Data such as that collected in the current study can assist professionals in understanding the factors influencing parental decision-making, and guide them in influencing intervention choices. Pertinently, parents need to be guided away from interventions that could potentially harm their child, or place sufficient stress on the parents to reverse any previous intervention gains.

Our study shows that professionals most likely impart the most influential recommendations to parents, and so parent-professional conversations may be crucial to guide parents towards optimal intervention selection. Furthermore, engaging in a collaborative relationship will also allow professionals to understand why some parents are still choosing interventions that are untested and potentially harmful, and to better support them accordingly in their decision-making process. We also found that, consistent with the literature, the individual needs of the child (i.e., symptom severity) is likely to be the dominant factor in intervention selection. Thus it is incumbent on professionals to not only listen to parents when they express the behavioural and functional issues occurring in the home, but also possess accurate and updated information on best-practice interventions that can address those issues. Failure to listen may result in parents expending substantial resources on ineffective interventions that are kept from professional view.

The current findings also adds to the limited base of studies reporting on the factors that lead parents to reject interventions. Particularly, we found that even though many parents reject specific interventions, the factors explaining their avoidance may reflect barriers rather than genuine opposition. While this finding would need to be replicated in health-delivery contexts outside of New Zealand, it might be expected that such a finding is universal. On this matter, future research is required to better elucidate barriers to interventions and how service-providers can improve both awareness and availability. Ultimately, having conferred parents with the burden of intervention choice, the professional community should acknowledge its influence on that choice and act to assist parents make informed decisions leading to the selection of evidence-based interventions.

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