Supporting Parents of Children with Autism Spectrum Disorders to Become Informed
Consumers of Evidence Based Speech Pathology Practice

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Abstract

The aim of this pilot study was to evaluate the effectiveness of an intervention program designed to help parents of children with Autism Spectrum Disorders (ASD) to become informed consumers of evidence-based speech pathology services. The program comprised an interactive workshop and the provision of written materials aimed at increasing the participants' knowledge of evidence-based practice (EBP) principles and confidence discussing EBP with their children's speech pathologists. Using a repeated measures within group design (pre/post) and mixed methods of analysis, the results indicate that the participants' knowledge and confidence increased following their participation in the program. Qualitative analysis revealed that parents differed with regard to which component (workshop or written information) was most helpful. The results provide preliminary evidence to support the further development and testing of intervention programs aimed at supporting parents of children with ASD to become informed consumers of evidence-based speech pathology services.

Key words: Evidence based practice, parent training, Autism Spectrum Disorders, speech pathology

Introduction

Autism Spectrum Disorders

Autism spectrum disorders (ASD) affect approximately 1 in 110 children (Barbaro & Dissanayake, 2010; Rice, 2009) and are characterised by a pervasive impairments in communication and socialisation, as well as repetitive and restricted interests and behaviours (American Psychological Association, 2000). Communication impairment is central to ASD, impacting negatively on learning, social interaction, and participation across the lifespan. Given that early communication development is a key prognostic indicator for long term outcomes in individuals with ASD, it is crucial that these children receive effective, evidence-based interventions at an early age (Howlin, Magiati, & Charman, 2009; National Research Council, 2001).

Evidence-Based Practice

Evidence-based practice (EBP) requires the integration of the best available research evidence, the best available evidence from clinical practice, and the individual client preferences and values in the provision of treatment. There is strong support for EBP amongst professional bodies including Speech Pathology Australia and the American Speech and Hearing Association, as evidenced by the strong emphasis of EBP in recently published position statements on the roles and responsibilities of speech pathologists working with children with ASD (American Speech Language and Hearing Association, 2005; Speech Pathology Australia, 2010). Similarly, research examining the views of speech pathologists towards EBP, and its application in clinical practice, has also revealed strong support amongst individual speech pathologists.

In one of the first studies to examine EBP in the field of speech pathology, Vallino-Napoli and Reilly (2004) surveyed 378 speech pathologists from across one state in Australia regarding their views toward EBP, their access to EBP resources, the amount of time they spent researching evidence for treatments, and their interpretation of the research evidence. The

authors reported that 79% of respondents considered research to be ‘exciting’ in the context of informing clinical practice. However, despite strong support for EBP amongst the speech pathologists surveyed, the participants also identified a range of barriers which impacted their use of EBP. These barriers included a lack of time to research treatments they provided to clients and poor access to EBP resources including research literature.

Zipoli and Kennedy (2005) identified similar barriers to EBP through their survey of 240 speech pathologists. The participants reported positive attitudes towards research, however identified lack of professional time to review and critique the research as the primary barrier to their use of EBP. Consequently, the participants reported that they based most treatment decisions on clinical experiences and the opinions of colleagues, rather than the research evidence. These findings are consistent with those of Reilly (2004), indicating that speech pathologists face multiple barriers to their use of EBP to guide their decision making. In addition, the consistent results also provide clear avenues for the development and evaluation of strategies to facilitate speech pathologists to engage in EBP. However, to date little attention has been paid to supporting parents to access evidence-based speech pathology services. This is despite the fact that the involvement of a fully informed client (or carer) is fundamental to EBP (Dollaghan, 2007).

Parents and Evidence-Based Practice

There is evidence to suggest that parents of children with ASD face difficulties evaluating the evidence for treatments. Green, Pituch, Itchon, Choi, O'Reilly, and Sigafoos (2006), for example, surveyed 552 parents of children with ASD regarding their treatment choices, and reported that a presence or lack of research evidence had little bearing on their decisions. Although the most common treatment used by parents (speech therapy) had supportive scientific evidence, the third most common treatment (sensory integration) lacked scientific validation. The authors suggested that while professionals emphasise the importance of basing

treatment decisions on scientific evidence, parents often remain unaware of or are unable to access the information they require to make informed decisions when choosing between treatments.

Based on their findings, Green et al. (2006) highlighted the importance of parents having access to evidence-based information so that they can make informed decisions regarding treatments provided to their children. However, parents may face difficulties finding this information and thus turn to non-empirical sources. Mackintosh, Myers, and Goin-Kochel (2006) surveyed parents of children with ASD to examine the sources of information they used to make decisions about treatments. The most common source was the opinions of other parents of children with ASD, followed by books and websites, rather than health professionals. Mackintosh et al. argued based on this finding that parents may be receiving unreliable information. Given that guidelines for selecting treatments are available (e.g., Roberts & Prior, 2006), health professionals, including speech pathologists, have a responsibility to ensure that this information is communicated to parents to empower them to make informed decisions.

Communication between Speech Pathologists and Parents

Osborne and Reed (2008) examined communication between health professionals and parents of children with ASD using focus groups. The parents reported difficulty obtaining information from professionals during this time, and found that locating information on their own increased their feelings of worry and hopelessness. Based on their experiences, the parents reportedly suggested that health professionals required increased training on how and what information to provide parents with regarding ASD. Hand (2006) also identified professionals as a possible barrier to information giving through a study which analysed parent-professional interactions in initial speech pathology sessions. Although speech pathologists aimed to empower parents, Hand noted that they asked questions and explained information in a manner which did not invite parents to ask questions in order to receive new information. This may, in

part, explain the findings of Mackintosh et al. (2006), that parents often turn to less reliable sources for information and advice, rather than professionals or more scientific sources.

Ways to Educate Parents About EBP

In an effort to support parents to become informed consumers of evidence-based interventions for their children with ASD, government and non-government organisations including Positive Partnerships (2009) and the Organization for Autism Research (2003) have published freely available readings, guidelines, and other sources of information. However, there has been no research into the accessibility of these resources to parents. Kuhaneck, Burroughs, Wright, Lemanczyk, and Darragh (2010) and Altieri and Von Kluge (2009) both presented evidence that the act of seeking and finding information of this type helps parents of children with ASD to feel more knowledgeable, confident, and in control. Nevertheless, no studies have examined the best way to support parents to find relevant information, and it is not known if simply making information publicly available, without providing support for parents to find and interpret this information is enough to empower them to gain this sense of knowledge, confidence, and control.

An alternative to simply making information publicly available online may be to direct parents towards specific relevant information, or provide this information through professionals, via an interactive workshop. Parent training workshops are commonly used in the area of lifelong disability as a way to educate parents on the techniques of intervention programs (e.g., National Autistic Society, 2006; Sussman, 1999). According to Mackintosh et al. (2006), workshops provide an ideal opportunity for parents to receive the latest information on treatments and research. However, the value of providing EBP information through workshops has not been evaluated.

Given the need for EBP when working with children with ASD, and the lack of research into ways of supporting parents to become informed consumers of evidence-based interventions,

the aim of this study was to evaluate the effectiveness of an intervention program designed to help parents of children with ASD to become informed consumers of evidence-based speech pathology services. The specific aims were to examine (a) parents' current knowledge of EBP, (b) their confidence discussing EBP with their child's speech pathologist, (c) the effect of the intervention program on their self-reported knowledge of EBP and confidence discussing EBP with their child's speech pathologist, and (d) their recommendations for what should be done to ensure parents are informed consumers of EBP.

Method

Design

A repeated measures within-group design (pre/post) using mixed methods was used to address the research aims. An attempt to recruit a non-randomised control group of parents attending the same early intervention service as participants (but who would not receive the treatment program) yielded only one participant, thus making it a non-viable comparison group.

Participants

The participants were 28 parents (2 fathers and 26 mothers) of children with ASD who accessed an early intervention and support group program for children with autism and their parents across eight sites in one state of Australia. No additional inclusion or exclusion criteria were applied, and information was not collected on the parents' age, level of education, or socioeconomic status. The participants' children ranged in age from 29 to 60 months ($M = 43$ months) and had been diagnosed with an ASD between 1 and 24 months ($M = 13$ months) prior to the study. All children were receiving speech pathology services as part of the group program and 30 children (97%) had accessed, or were currently accessing, speech pathology services outside of the program. Pseudonyms have been used throughout this article in an effort to protect the participants' privacy.

Intervention Program

The intervention program comprised two components: a set of printed information sheets distributed to participants and an interactive workshop. Due to time constraints and in an effort to account for order effects, 9 parents received the information sheets followed by the workshop while the remaining 19 parents received the workshop followed by the information sheets.

Information sheets. The EBP information sheets were available through the Positive Partnerships website (www.autismtraining.com.au) at the time of the study. These information sheets covered the three broad areas of (a) '*Using evidence to guide decision making*' – providing parents with knowledge of EBP and the levels of evidence, (b) '*What do we know about the effectiveness of different interventions for children with autism and their families?*' – providing parents with an evaluation of the levels of evidence for different treatments available for children with ASD, and (c) '*Questions to ask when choosing interventions*' – providing parents with a range of questions to ask professionals regarding the efficacy of interventions.

Workshop. A 90 minute workshop titled '*Interventions for young children with autism and their families*' was presented to parents by the second and fourth authors who are both experienced clinicians and researchers in the field of autism. The workshop was designed to present exactly the same information as the information sheets in an interactive format. Parents were invited by the presenter to comment, ask questions, and discuss personal experiences throughout the workshop. As such, the same three broad topics covered in the information sheets were covered in the workshop. Parents were provided with a hardcopy of the slides at the beginning of the workshop to facilitate note taking.

Outcome Measures

A customised questionnaire comprised yes/no, likert-scale, and open-ended items was used to assess changes in the participants' self-reported knowledge of EBP and confidence in discussing EBP with their children's speech pathologists (see Appendix), as well as to gain

qualitative information regarding the parents views towards, and experience accessing, EBP speech pathology services. Participants completed the pre-intervention questionnaire in the week prior to commencing the intervention program. A four-week delay in asking parents to complete the post-intervention survey, following the completion of the intervention program, was implemented in an attempt to measure sustained, rather than transient, treatment effects.

Analysis

Of the 28 parents who completed the pre-test questionnaire, only 12 completed the post-test questionnaire representing a completion rate of approximately 43%. Group coordinators of the intervention and support program suggested that high drop-out was most likely due to parents struggling to meet multiple child and family commitments. Consequently, due to the small sample size and ordinal nature of the data, Wilcoxon signed-rank tests were used to compare the responses of the 12 parents who completed both the pre- and post-questionnaire to Likert scale items examining changes in their self-reported (1) knowledge of EBP and (2) confidence discussing EBP with their children's speech pathologists before and after the intervention program. For each question, participants indicated their level of agreement on a 5-point scale where 1 = Strongly Disagree and 5 = Strongly Agree. Alpha was set at 0.05 and Bonferroni correction was not applied as the measures tested dependent, rather than independent, null-hypotheses (Motulsky, 1995).

The qualitative data collected through open-response items in the questionnaires were analysed using key elements of the process of thematic analysis outlined by Braun and Clarke (2006). Specifically, this involved (a) transcribing and becoming familiar with the data through repeated readings, (b) line by line analysis in order to generate codes representing discrete ideas, events, and phenomenon in the data, (c) searching for and collating codes into potential themes, and (d) constantly reviewing the codes and themes to ensure they fit with relation to the entire data set. The results of the qualitative analysis are presented alongside the quantitative results to

expand on these findings and allow for comparison, as is consistent with the mixed methods approach to evaluating outcomes (Vitale, Armenakis, & GFeild, 2008).

Results

Parents’ Knowledge of EBP

Parents reported on their knowledge of evidence for treatments provided to their children (see Appendix Q3, Q4, Q5). Only eight parents (27%) reported their child’s speech pathologist had explained to them the evidence behind treatments provided, and in further comments stated this was about the general benefits of the treatment and not specific to the research evidence. In order to explore the sources of the parents knowledge of EBP, they were asked to rank a list of ten common sources of information about interventions from most to least useful and to explain their rankings. As presented in Table 1, ‘talking with professionals’ was rated by parents as the most useful information source.

[Insert Table 1 about here]

In their explanatory remarks, parents described professionals as good sources of information due to their experience and expertise. They stated professionals were able to provide accurate information and advice specific to their child.

“These people can give you their thoughts based on their experiences with my child... They, as professionals, should know what they are talking about so I trust that.” (Kim)

In comparison, only a small number of parents indicated that they chose sources of information based on their scientific merit. Bob was one such parent who explained why he looked to journals for information.

“Journal articles provide evidence-based trials... [they] provide evidence of therapies that actually work.”

Parents' Confidence Discussing EBP

Prior to the intervention program, only two parents (7%) reported they had asked their child's speech pathologist about the research evidence behind interventions provided. The participants identified several barriers preventing them from asking the professionals who work with their child about the research evidence behind interventions. Lack of knowledge, powerlessness, and limited opportunity were the key themes identified to account for these experiences. More specifically, parents reported they did not know enough about the evidence and types of questions to ask in order to confidently discuss EBP with professionals.

"[Parents need] more basic knowledge and information, so we have some idea of questions to ask and don't feel so stupid." (Sam)

This lack of information was viewed in the analysis as indicating a sense of powerlessness in the therapy process. Some parents recognised this knowledge and power imbalance:

"Speech pathologists have the knowledge and experience; parents only read reports." (Laura)

Meanwhile, other parents suggested strategies to overcome this:

"I don't think it's the therapist's responsibility to be the solo educator.... parents should be empowered to ask questions and make decisions." (Donna)

Parents also suggested changes within professional bodies such as Speech Pathology Australia to encourage disclosure of information and increase time and opportunities to discuss in sessions.

Parents agreed that they need support to increase their knowledge and confidence regarding EBP.

Increasing their knowledge and confidence was the second aim of the study.

Intervention Outcomes

Changes in participants' self-reported knowledge of EBP were assessed quantitatively using four Likert scale items from the pre-post questionnaire. As presented in Table 2, significant pre-post differences were identified for three of the four questionnaire items: "I have a good

understanding of the range of treatments available to my child” (Q14), “I am aware of the research evidence to support the particular treatments that are being used with my child” (Q15), and “I know what questions I need to ask my child’s speech pathologist about the treatment s/he provides” (Q17). However, no significant pre-post difference was found in response to the item: “I know what ‘evidence-based practice means” (Q18). There was also no significant pre-post difference revealed for the item: “I feel comfortable asking my child’s speech pathologist for information about the treatment being provided” (Q16).

[Insert Table 2 about here]

Qualitative analysis of parents’ open-ended responses revealed three key themes of increased confidence, empowerment, and awareness regarding EBP post-intervention. Parents reported feeling more knowledgeable and confident asking questions of professionals. They described an increased awareness of their right to information, as well as an awareness of the importance of evidence-based interventions. Parents indicated a sense of responsibility to ask questions and reported feeling empowered to do so, while at the same time having raised expectations of the speech pathologists working with their children.

“[The interventions] made me more confident to ask questions as I have more knowledge myself.” (Greta)

“In the past I would let them do all the talking, now I go in with an expectation of the level of information I want.” (Kim)

Although most parents reported that the workshop and information sheets were beneficial, some parents did not report either as having an impact on how they work with their child’s speech pathologist. These parents said they already had a trusting relationship with their child’s speech pathologist and that they were confident in their decisions.

“I haven’t seen the need to ask about research behind her methods, we have a very trusting relationship.” (Sarah)

In order to explore the contribution of the two components of the intervention program, parents were asked to respond to the following question: “*Do you think the information sheet or the workshop was more helpful to you in learning about the research evidence behind treatments provided to children with autism?*” Of the parents who responded to this question, five (62.5%) preferred for the workshop and three (37.5%) preferred the information sheets. Using qualitative analysis, seven themes were identified to account for the parents’ differing views towards the workshops and information sheets. As summarised in Table 3, the key benefits of the workshop were that it was *interactive*, which meant they could have information explained in alternative ways, and was a more *powerful* way to present the information, which encouraged them to use it elsewhere. The key benefits of the information sheets were that they provided information in a *clear* and concise manner, and was the same information as the workshop with the benefit of having *tangible* material to refer back to. Overall, parents said that both conditions provided *evidence-based* information that they could easily understand.

Parents’ Recommendations for Interventions Aimed at Support Parents

Parents were asked to rank a list of eight proposed methods for helping parents to become informed consumers, and to suggest additional methods that would be beneficial (See Appendix, Q11). As indicated in Table 4, parents ranked a ‘single website/booklet outlining treatments and their evidence’ as the most useful method to help them make informed decisions. However, parents also suggested that (a) a change within the culture of professionals so that parents feel more valued and accepted in the treatment process, (b) more simplified language and information within and across professions, and (c) more simplified information about what to do after diagnosis would also help them to make informed decisions.

[Insert Table 4 about here]

Discussion

The aims of this pilot study were to examine (a) parents' current knowledge of EBP, (b) their confidence discussing EBP with their child's speech pathologist, (c) the effect of the intervention program on their self-reported knowledge of EBP and confidence discussing EBP with their child's speech pathologist, and (d) their recommendations for what should be done to ensure parents are informed consumers of EBP. The results provide preliminary evidence that parents of children with ASD desire information about the research evidence behind interventions, and that both information sheets and workshops are effective ways of providing this information.

Parents' Knowledge and Confidence

Consistent with the findings of previous studies (Green, et al., 2006; Mackintosh, et al., 2006), parents in this study reported they want to learn about their children's intervention programs, and sought information from a range of sources including professionals, other parents, and the internet. However, a finding unique to this study was that the parents identified professionals as their most valued source of information. Parents valued information from professionals as they are a 'trusted' source, suggesting that the messenger in information giving is significant. This is in contrast to the results of Mackintosh et al (2006), who reported that parents relied on books, websites, and other parents for information more than professionals, and Green (2006) who found that parents relied most frequently on other parents and the internet for information. Whilst fellow parents and websites were reported to be useful sources of information in this study, professionals were still seen as the most valuable. One possible explanation for this difference is that the parents in this study were all attending a parent support program run by professionals and designed specifically to provide parents with education, as opposed to a child-focused intervention program.

Although parents reported professionals to be the most valuable source of information, the results indicate that many parents were still not well-informed about their children's treatments and had difficulty knowing what questions to ask and feeling confident doing so. Hand (2006), in a study of speech pathologists interactions during initial sessions, and Osborne and Reed (2008), in their study of parents' experiences with professionals during diagnosis of ASD, reported similar findings highlighting what appears to be a systemic barrier to parents' involvement as informed and valued partners in their children's therapy programs. Participants expressed a need for speech pathologists to create opportunities to discuss treatment decisions and for professional bodies, such as Speech Pathology Australia and the American Speech and Hearing Association, to ensure mandatory disclosure of information to parents.

Increasing Knowledge and Confidence

This study attempted to address parents' need for information and comfort asking questions of their speech pathologists directly, through the provision of written information sheets and an interactive workshop. To this end, parents showed an increase in their knowledge of EBP after receiving the interventions, with significant changes in three of the four measures of knowledge, including their knowledge of treatments and their evidence and knowledge of questions to ask regarding EBP. However, no significant increase was found post-intervention in parents' feelings of comfort asking questions of professionals. This is in contrast to the strong themes of increased confidence that came through during qualitative analysis of parents' open-ended responses. One possible reason to account for this is that parents reported in the pre-questionnaire that they were confident interacting with their child's speech pathologist. The information provided to parents in the study therefore appears to have given them knowledge of what questions to ask in a situation where they already felt comfortable.

Parents expressed that both the information sheets and workshop were effective in helping them to increase their knowledge and confidence regarding EBP. They differed as to

which method they preferred, and also suggested additional methods of information delivery that may be more beneficial to them, such as a single website or booklet outlining treatments and their evidence, or information sheets on new treatments provided by speech pathologists. Neither workshops nor information sheets were considered by all parents to be the most valuable way to deliver information, suggesting that there is no single method of information delivery likely to work effectively for all parents and a need for a more tailored approach to information delivery.

Clinical Implications

The results of this pilot study must be viewed with caution given the small sample size and lack of control group. Nevertheless, the results, and particularly those arising from the qualitative data, have two main clinical implications for speech pathologists working with parents of children with ASD. The first relates to the way speech pathologists work with parents to help them learn about the evidence behind treatments. In this study, parents reported that speech pathologists needed to provide more opportunities to ask questions and discuss information. This finding suggests that speech pathologists should aim to create time for discussion on a regular basis to ensure parents feel informed and included in the therapy process. However, parents also expressed that they need an idea of questions to ask in order to be able to confidently discuss with professionals. Speech pathologists may need to pre-empt these questions and either provide parents with a list of questions or offer this information upfront in order to ensure parents are able to make informed decisions.

The second clinical implication relates to the fact that parents in this study each had unique needs and preferences regarding information delivery, and that a ‘one size fits all’ approach to information giving is likely to be ineffective. This finding fits with Osborne and Reed’s (2008) observation that parents’ informational needs change over time, and information to parents needs to be tailored over the course of living with ASD. Therefore, speech pathologists, and other professionals who provide support to children with ASD and their

families, need to cater for individual differences through flexible delivery and support in multiple forms (e.g. workshops for recent diagnosis, information sheets for new treatments).

Limitations

In addition to the small sample size and lack of control group, a limitation of the current study is the poor response rate of parents to the questionnaires. Parents who participated were most likely those motivated by the study, and may not be representative of all parents. Several factors may have impacted on response rate including staff and group member changes which occurred during the study and the pressure that parents of children with ASD are under. Given that the EBP information sheets were publicly available online, it is possible that parents may have read these prior to participating in the study. However, no parents reported having seen the EBP information sheets previously, and even if they had, the likely effect would be to dampen, rather than inflate, the intervention outcomes reported.

Future Research Directions

Parents in this study had different preferences regarding the most effective method of information delivery. Future research could help to identify and understand possible factors underlying differences in preferences, such as time since diagnosis, and previous knowledge of treatments for ASD, as well as the benefits in tailoring the delivery of information to meet each parent's preferences. Parents also reported valuing information from 'trusted' sources, such as professionals and fellow parents, over other sources. Future research could therefore examine the significance of 'the messenger' in information delivery. Future studies could also examine the extent to which increasing parents' knowledge and confidence, as attempted in this study, lead to meaningful changes in parent self-efficacy and treatment outcomes for their children with ASD.

In response to the final research question, parents indicated that a single website/booklet outlining treatments and their evidence base would be the most effective way to help them

become informed consumers of interventions. However, it is arguable that sources of information such as these currently exist (e.g., Organization for Autism Research, 2003; Positive Partnerships, 2009). Future research may therefore focus on developing methods to help parents learn what information is already available, and helping speech pathologists to integrate these resources into their therapy programs.

Conclusion

The results of this pilot study provide preliminary evidence for the effectiveness of two approaches for supporting parents to become informed consumers of evidence-based speech pathology for their children with ASD. The combination of information sheets and an interactive workshop led to significant increases in parents' self-reported knowledge and confidence regarding EBP. Parents saw benefits to both methods of information delivery, though differed as to which method they preferred based on various factors, such as learning style. Speech pathologists have a responsibility to address these needs through flexible information delivery and support to ensure that parents are valued and informed partners in the therapy process, consistent with the principles of EBP.

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Tables

Table 1

Parents’ Rankings of the Helpfulness of Sources of Information

Source of Information	Total ranked score ^a	n of parents ranking as most preferred
Talking with professionals	71	16
Talking with other parents of children with ASD	87	7
Attending workshops/conferences	105	2
Reading online	109	2
Service providers’ advertisements	126	1
Attending a support group	131	1
Reading books	148	0
Reading information provided by organisations	148	1
Reading government information	163	0
Reading journal articles	182	2

^a calculated by totalling the number of respondents selecting an information source as a rank (1-10), multiplied by that numerical rank. Lower total ranked scores equal more preferred source of information.

Tables

Table 2

Pre and Post Intervention Likert-Scale Response Measures

Items ^a					Wilcoxon Signed Ranks Test
	Pre		Post		
	M	SD	M	SD	p
Q14	3.89	.78	4.44	.53	.025
Q15	2.89	.93	4.11	.33	.018
Q16	4.00	1.00	4.11	.78	.655
Q17	3.00	.87	4.00	.71	.014
Q18	3.89	1.05	4.11	.60	.527

^a See Appendix, or below, for full questions.

Tables

Table 3

Key Themes Identified Regarding the Benefits of the Workshop and Information Sheets

Benefits of information sheets		Benefits of workshop	
Theme	Examples from parents	Theme	Examples from parents
Tangible	<i>Sometimes situations are overwhelming so having the sheet to refer back to is really helpful. (Kim)</i>	Interactive	<i>You can ask questions there and then. Anything can be discussed with others in the same situation while you are there. (Sarah)</i>
Learning style	<i>I am a visual learner. I can refer to info sheet at any time. (Maree)</i>	Learning style	<i>I always find it more effective to hear about things rather than reading. (Greta)</i>
Evidence-based	<i>I learnt about evidence based findings of treatment. I can ask now what information is out there about treatments. (Iris)</i>	Evidence-based	<i>Very informative with regards to treatment options and scientific evidence. (Sophie)</i>
Clear	<i>Relatively easy to read. Gives info clearly. (Mel)</i>	Powerful	<i>When a person suggests you do something it's stronger than an info sheet. (Greta)</i>
		Personal	<i>The ability to connect with other parents “in the same boat” and a professional who could answer questions face to face was most crucial and supportive, especially for a parent with a recent diagnosis. (Katie)</i>

Tables

Table 4

Helpfulness of Methods for Informing Parents’ Decisions

Method of Providing Information	Total ranked score ^a	n of parents ranking as most preferred
Single website/booklet outlining treatments and their evidence	26	3
Speech Pathologists providing an information sheet about treatments	28	5
Organisations ensuring EBP is covered in early intervention programs	34	1
Workshops like the one in this study	38	2
Information sheets like the one in this study	40	2
Speech Pathologists should encourage parents to ask Questions about EBP	45	2
A conference each year where service providers give information on treatments they provide	60	0
Parents forming advocacy groups to advocate for EBP use with their children	77	2

^a calculated by totalling the number of respondents selecting an information source as a rank (1-8), multiplied by that numerical rank. Lower total ranked scores equal more preferred idea for informing decisions.

Appendix

Questionnaire Items

Pre-intervention Questionnaire Only

Q1. Please write the numbers 1 to 10 in the right hand column, to indicate which information sources were least and most helpful to you in learning about the different treatment options available to your child. *(10 options provided)*

Q2. Why did you find the information source you listed as number 1 to be the most helpful?

Q3. Have you looked into the research evidence behind different interventions (e.g., reading articles, asking professionals, etc)? Yes /No (Please describe)

Q4. Has your child’s speech pathologist provided or explained the research evidence behind the treatment s/he provides to your child? Yes/No (Please describe)

Q5. Have you asked your child’s speech pathologist to provide or explain the research evidence behind the treatment s/he provides? Yes/No (Please describe)

Q6. Some parents may not feel comfortable discussing treatment options with professionals. What do you think could be done to help parents to feel confident and comfortable to ask their child’s speech pathologist questions about the treatments s/he provides?

Q7. Do you think parents can encourage speech pathologists to use more evidence based approaches to working with children with autism? Yes/No (Please explain)

Post-intervention Questionnaire Only

Q8. How helpful was the information sheet/workshop in helping you know what questions to ask your child’s speech pathologist? Why?

Very unhelpful Unhelpful Neutral Helpful Very helpful

Q9.How helpful was the information sheet/workshop in helping you to feel comfortable to ask your child’s speech pathologist questions about the evidence behind the treatments he or she provides? Why? (Please explain)

Very unhelpful Unhelpful Neutral Helpful Very helpful

Q10. Do you think the information sheet or workshop was more helpful in learning the research evidence behind treatments provided to children with autism?

Q11. The following ideas have been suggested to help parents make informed decisions about the treatments provided to their children with autism. Please write the numbers 1 to 8 in the right hand column, to indicate which approaches you think would be least and most helpful to parents. (8 options provided)

Q12. Do you have any other suggestions for how to support parents to make informed decisions about the treatments provided to their children? If so please list them below.

Q13. Now that you have participated in this study, do you think more could be done to help parents to feel confident and comfortable to ask their child’s speech pathologist questions about the treatments s/he provides? Why? Yes / No

Pre-Post Questionnaire Likert-scale Items

Q14. I have a good understanding of the range of treatments available to my child.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

Q15. I am aware of the research evidence to support the particular treatments that are being used with my child.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

Q16. I feel comfortable asking my child’s speech pathologist for information about the treatment being provided.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

Q17. I know what questions I need to ask my child’s speech pathologist about the treatment s/he provides.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

Q18. I know what the term ‘evidence based practice means.’

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly Agree