

Research Summary: Pilot Study of a Parent Education Package for ASD Intervention Decision-Making

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Websites have been developed by government bodies and other organisations in order to share information about the efficacy of different interventions for autism spectrum disorder (ASD) with parents (e.g., Raising Children Network, 2006-2014; Research Autism, 2006-2014). However, parents often employ interventions without empirical support, and also place less importance on research evidence in their decision-making than on other factors, such as their own intuition or staff attributes (Carlon, Carter, & Stephenson, 2014; Carlon, Stephenson, & Carter, 2014; Green et al., 2006). It is not clear whether this is because parents are unaware of the concept of evidence-based practice, unaware of the level of research support for different interventions, or dismissive of the evidence. This small scale pilot study aimed to investigate whether a DVD resource package providing guidelines for choosing interventions and guided access to two reliable websites would change parental views and/or behaviours related to intervention decision-making.

Method

Participants

Participants were parents of preschool age children with ASD. Those who completed the trial were eight mothers and four fathers from five states or territories. The highest level of education obtained was Technical and Further Education (TAFE), college or further training for three of the participants; an undergraduate university degree for two of the participants and a postgraduate university degree for seven of the participants. All parents reported that their child had been formally diagnosed with an ASD (8 autism spectrum disorder, 3 autistic disorder, and 1 pervasive developmental disorder – not otherwise specified [PDD – NOS]). The children were nine boys and three girls. At the time of recruitment their ages ranged from 21 to 36 months ($M = 51.8$) and the time since diagnosis ranged from 2 to 32 months ($M = 15.2$).

DVD-based Package

A DVD was developed by the three authors. The first section provided guidelines for choosing interventions adapted from the Raising Children Network (2009). It included information about evidence-based interventions, the importance of questioning claims and evidence, choosing a good fit for the child and family, and warning signs that an intervention may be ineffective. The second section contained guidelines for accessing two websites that had been examined by the authors and two external experts in the area of autism (Raising Children Network, 2006-2014; Research Autism, 2006-2014). All parties agreed that the sites provided a reasonably balanced and accurate view of the available research.

Instruments and Procedure

The authors developed pre-test and post-test questionnaires (available on request). Ethics approvals were obtained from all of the relevant ethics committees. Sixteen parents consented to participate but two withdrew prior to the commencement of the study (one because her child had started school and was therefore no longer eligible to participate). The pre-test questionnaire was administered over the phone before the parents were sent the

DVD-based package, followed by the post-test questionnaire approximately 3 months after the participants were sent the package. Two participants chose not to complete the post-test questionnaire.

Results

Parent Views on the Usefulness of the Package

All of the parents indicated that they would recommend the DVD package to other parents of children with ASD, and six parents added that they believed it would be helpful for parents whose children had recently been diagnosed with ASD. Eight parents indicated that it was very likely that they would consult the guidelines for choosing interventions before commencing an intervention in the future, two somewhat likely, one very unlikely, and one unsure. Eleven parents stated that it was very likely that they would visit the Raising Children Network website before commencing an intervention in the future, and that they would recommend the website to other parents of preschool-age children with ASD.

Two parents did not look at the Research Autism website. Seven stated that it was very likely that they would visit the website before commencing an intervention and three that it was somewhat likely. All 10 parents indicated that they would recommend the website to other parents of preschool-age children with ASD, although three added that they would be more likely to recommend the Raising Children Network website because they thought it was more accessible to parents.

Parent Confidence

Participants indicated how confident they felt in making decisions about interventions (on a 5-point Likert-type scale from [1] not at all confident to [5] very confident), at pre-test and post-test. The mean score increased from 3.8 in the pre-test to 4.7 in the post-test. Wilcoxon Signed Ranks test revealed that the difference between pre-test and post-test scores was not statistically significant ($z = -1.802, p = .072$).

Importance of Factors in Decision-Making

Parents indicated how important they considered different factors to be in decision-making (on a 5-point Likert-type scale from [1] very unimportant to [5] very important). There was very little change in the importance placed on different factors. The mean (4.75), range (4-5) and standard deviation (0.45) for research evidence remained constant.

Parent Desire to Use, and Ratings of the Level of Research Support for Interventions

For 36 interventions commonly available in Australia, parents were asked to indicate on Likert-type scales: (a) their desire to use the intervention (1. No desire to use. 2. Some desire to use. 3. Strong desire to use. 4. Currently using; with the additional option “have not heard of this”); and (b) their understanding of the level of research support (1. No evidence, or negative evidence. 2. Weak research evidence. 3. Moderate research evidence. 4. Strong research evidence; with the additional option “unsure”).

A general trend was that the number of parents that had not heard of interventions, and the number of parents that were unsure about the level of research support for interventions decreased from pre-test to post-test. This was true both for interventions where information about the research support for the interventions was available on the websites, and for those that were not rated on the websites or that were unable to be rated.

Statistical testing showed that the research ratings provided by participants were related to their desire to use the interventions. There was a moderate positive mean

correlation between the level of desire to use interventions and research ratings provided by participants at pre-test, and a small-to-moderate positive mean correlation at post-test.

Limitations

Limitations of the present study should be acknowledged. Despite efforts to recruit participants for the study from all states and territories in Australia, only fourteen parents participated and two of these withdrew prior to the post-test interviews. Further, the sample was well educated and probably highly motivated. Caution should therefore be used in interpreting the results.

In the recruitment process two different service providers suggested to the researchers that parents may not wish to be involved in the present study because they had already made decisions regarding interventions to employ. All participants in the present study were already using interventions and it is possible that the DVD-based package may have different impacts on parents who had not yet committed to a specific intervention. The effect of the DVD-based package on parents whose children had been recently diagnosed could be explored in future research.

Discussion and Conclusions

Parents in the present study provided positive feedback regarding the DVD-based package and reported an increased confidence in making decisions after using it. However, the DVD-based package, which provided guided access to reliable websites, did not appear to influence the factors that they considered important in decision-making, their understanding of the level of research support for interventions, nor their desire to use different interventions. It should be noted that parents in the present study were provided with guidance on how to access two reliable websites, along with additional guidelines for choosing interventions (adapted from Raising Children Network, 2009). Thus, these parents were provided with considerably more guidance than parents who would normally access the websites independently. Given that even with the extra guidance the websites in the present study did not appear to influence the views or decision-making of the participants, this raises questions about the role of websites such as Raising Children Network (2006-2014) in providing information about the efficacy of interventions to parents. This research also raises questions regarding the difference between the decision-making processes for those that have already made decisions to employ interventions and those with children who are newly diagnosed and who have not yet formed opinions on interventions. These issues could be explored in future research.

References

- Carlson, S., Carter, M., & Stephenson, J. (2014). *Decision-making regarding early intervention by parents of children with autism spectrum disorder*. Manuscript submitted for publication.
- Carlson, S., Stephenson, J., & Carter, M. (2014). Parent reports of treatments and interventions used with children with autism spectrum disorders (ASD): A review of the literature *Australasian Journal of Special Education*, 38, 63-90. doi: 10.1017/jse.2014.4
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27, 70-84. doi: 10.1016/j.ridd.2004.12.002

Raising Children Network. (2006-2014). *Parent guide to therapies*. Retrieved 30 May, 2012, from http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html

Raising Children Network. (2009, 8 October 2010). *Choosing interventions for autism spectrum disorder*. Retrieved 29 March, 2012, from http://raisingchildren.net.au/articles/autism_spectrum_disorder_choosing_interventions.html

*Research Autism. (2006-2014). *Treatments and therapies for autism currently under scientific evaluation by Research Autism*. Retrieved 1 June, 2012, from http://researchautism.net/autism_treatments_therapies_interventions.ikml

*Note: *The Research Autism website has since been updated, and the Treatments and therapies for autism currently under scientific evaluation by Research Autism page has been removed. The same information is now available from:* <http://www.researchautism.net/autism-interventions/our-evaluations-interventions>