

**Intervention Decision-Making of Parents of Young Children with Autism Spectrum
Disorders.**

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REQUIREMENTS AND FORMAT OF A THESIS BY PUBLICATION

This statement provides an overview of the requirements and format of a thesis by publication, in relation to University and Departmental requisites.

A thesis must form a distinct contribution to knowledge either by the discovery of new facts or by the exercise of independent critical power. The thesis as a whole should be focussed on a single project or set of related questions and should present an integrated body of work, reflecting a coherent program of research.

The basic structure of a thesis by publication is as follows:

- An introduction providing a coherent overview of the background of the thesis, the research questions and the structure and organisation of the remaining chapters. The distinct contribution of the thesis should be clearly identified.
- A number of chapters, each written in the format of self-contained journal articles.

These chapters should be published, in press or submitted. Where articles are published, they do not need to be reformatted for inclusion in the thesis. Each chapter should be prefaced by a brief introduction outlining how the chapter fits into the program of research and, in the case of jointly authored chapters, the student's contribution should be clearly specified.

- The final chapter should provide an integrative conclusion, drawing together all the work described in the other parts of the thesis and relating this back to the issues raised in the Introduction.
- The length for a thesis completed at the Macquarie University Special Education Centre should generally be 50,000-70,000 words for a Doctorate and 20,000-40,000 words for a Master of Philosophy.

SYNOPSIS

This thesis by publication presents a series of related papers examining the decision-making of parents of children with autism spectrum disorders (ASD) regarding the interventions that they use with their children. The primary aims of the program of research were to investigate the range of interventions being used, how parents made decisions about intervention use, and whether being provided with information about the efficacy of interventions would influence their decision-making. In recent years there have been an increasing number of interventions available for children with ASD. Although studies reporting parent use of different interventions exist there had been no attempts to synthesise the findings. Therefore, a systematic review of parent reports of interventions used with their children with ASD was conducted. It revealed a global trend of parents using multiple interventions, with varying levels of efficacy, concurrently. Although Australian data about intervention use were sparse, a small survey study revealed a similar trend in Australia as that reported in the international studies.

To address the question of why parents choose, reject, continue, or discontinue interventions, a review of studies reporting factors declared by parents as influencing their decision-making was undertaken. This was the first review of this type and provided insight into factors reported to be considered by parents. Limited data were available from populations in Australia. Additionally, few studies examined the weight placed by parents on different factors in decision-making. With the intent to provide information to inform later survey research, interviews were conducted with Australian parents of preschool-age children with ASD. Qualitative analysis of these interviews gave preliminary insights into why these parents valued recommendations from some sources over others and indicated that parents do regard some factors as more important than others in their decision-making.

The review of declared factors in parent decision-making and results of the exploratory qualitative study were used to develop a survey examining the importance of different factors in decisions to use and reject interventions. The results of this survey

supported the hypothesis that parents placed greater importance on some factors than others in decision-making. However, the factors that were most frequently reported in previous studies (advice from others) were ranked significantly lower than the other factors, indicating that the frequency with which decision-making factors are reported in the literature may not be an accurate reflection of the importance of the factors in parental decision-making. In addition, research evidence was ranked lower in importance than a number of other factors. Further analysis of the survey data examining the possible underlying parent and child factors that may have been influencing the decisions of the parents revealed few significant relationships between underlying factors and the number or type of interventions used, suggesting that a complex and individualised interplay of factors is likely to be involved.

Based on the preceding reviews and studies, it appeared that research evidence was less important than several other factors in parental decision-making. Thus, a small scale intervention study was conducted to investigate whether providing parents with a DVD training package affected their understanding of the research evidence and desire to use interventions. The package provided guidelines for choosing interventions and instructions for accessing two websites, which were assessed by external experts as providing generally accurate information about the efficacy of different interventions for ASD. The results of a pilot intervention study indicated that the intervention appeared to increase the parents' confidence in choosing interventions but did not appear to improve their understanding of the level of research support for interventions or change their desire to use strategies with a stronger evidence base.

STATEMENT OF CANDIDATURE

I certify this thesis entitled “Intervention Decision-Making of Parents of Young Children with Autism Spectrum Disorders” is an original piece of research and my own work. All assistance from others in conducting the research and preparing this thesis has been appropriately acknowledged.

I also certify that the work in this thesis has not been submitted for a higher degree to any university or institution other than Macquarie University.

In addition, I certify that all sources of information and literature used are indicated in the thesis.

The research presented in this thesis was approved by the Macquarie University Faculty of Human Sciences Human Research Ethics Sub-Committee, on 15th April 2010 (referenced no. 5201000231PG); 27th June 2011 (referenced no. 5201100291D); 29th March 2012 (referenced no. 5201200088D); and 21st August 2012 (referenced no. 5201200602). The research presented in this thesis was also approved by the Aspect Research Approvals Committee, on 8th April 2010; 13th May 2011 (referenced no. 1109); 28th May 2012 (referenced no. 1211); and 28th September 2012 (referenced no. 1220). Additionally, the research presented in this thesis was approved by the STaR Research Committee on 27th June 2013; and the Professional Practice Committee of Autism SA on 20th September 2013.

STATEMENT OF CONTRIBUTION

This is a statement of my contribution to this thesis and the jointly written papers included in it. The following is a list of papers written in conjunction with my Co-Supervisors Associate Professor Mark Carter and Associate Professor Jennifer Stephenson, and with Dr Naomi Sweller.

1. Carlon, S., Stephenson, J., & Carter, M. (2014b). 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

I wrote this review with advice and input from Associate Professor Jennifer Stephenson and Associate Professor Mark Carter.

2. Carlon, S., Carter, M., & Stephenson, J. (2011). An internet survey of treatments used by Australian parents of children with autism spectrum disorders. *Special Education Perspectives*, 20, 40-57.

I conducted this study and wrote this paper with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

3. Carlon, S., Carter, M., & Stephenson, J. (2013). A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions. *Research in Autism Spectrum Disorders*, 7, 369-381. doi: 10.1016/j.rasd.2012.10.009

I wrote this review with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

4. Carlon, S., Stephenson, J., & Carter, M. (in press). Parent perspectives on sources of information about autism interventions in Australia. *Australasian Journal of Special Education*.

I conducted this study and wrote this paper with advice and with input from Associate Professor Jennifer Stephenson and Associate Professor Mark Carter.

5. Carlon, S., Stephenson, J., & Carter, M. (2014a). “*Can you tell me how you came to your decision...?*”: A qualitative consideration of intervention decision-making of parents of preschoolers with autism spectrum disorder. Manuscript submitted for publication.

I conducted this study and wrote this paper with advice and input from Associate Professor Jennifer Stephenson and Associate Professor Mark Carter.

6. Carlon, S., Carter, M., & Stephenson, J. (in press). Decision-making regarding early intervention by parents of children with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*.

I conducted this study and wrote this paper with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

7. Carlon, S., Carter, M., Stephenson, J., & Sweller, N. (2014). *Parent and child factors predicting early intervention choices of Australian parents of children with ASD*. Manuscript submitted for publication.

I conducted this study with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson, and wrote this paper with input advice and input from Associate Professor Mark Carter, Associate Professor Jennifer Stephenson, and Dr Naomi Sweller.

8. Carlon, S., Carter, M., & Stephenson, J. (2014). *Pilot study of a parent education package for ASD intervention decision-making*. Manuscript submitted for publication.

I conducted this study and wrote this paper with advice and input from Associate Professor Mark Carter and Associate Professor Jennifer Stephenson.

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CHAPTER 1: INTRODUCTION

Chapter Overview

This chapter introduces the purpose of the research contained in this thesis. The background to the research, including the definition and prevalence of autism spectrum disorders (ASD), interventions available, the role of parents in decision-making, and the rationale for the research are presented. This is followed by an outline of the research plan and an overview of each chapter of the thesis.

Purpose of the Research

The purpose of the research presented in this thesis was to explore the decision-making of parents of children with ASD regarding intervention use. Initially, a broad approach would be taken to encompass a review of decision-making of parents of children of all ages in a variety of geographic locations, before undertaking research related to the decision-making of Australian parents of preschool-age children.

Background to the Research

Definition and Prevalence of ASD

Autism spectrum disorder is characterised by deficits in social communication and social interaction, along with restricted or repetitive interests and behaviours. These deficits are present from the early childhood period and cause significant impairment to the individual's social and/or occupational functioning, and are not better explained by intellectual disability. This definition and these criteria for Autism Spectrum Disorder were presented in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013a), which was released during the course of the research being undertaken for this thesis. Earlier, the terminology "autism spectrum disorders" was often used to describe any of four different pervasive developmental disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive

developmental disorder- not otherwise specified (American Psychiatric Association, 2013b). These disorders were also characterised by impaired social and communication skills, and restricted interests and/or repetitive behaviours. The acronym ASD is used for both autism spectrum disorder and autism spectrum disorders. In this thesis the terms “autism spectrum disorders” and “autism spectrum disorder” are used interchangeably.

In the period leading up to the commencement of this program of doctoral research, review studies indicated that there had been a global increase in the prevalence of ASD (Fombonne, 2009; Matson & Kozlowski, 2011; Waterhouse, 2008). The prevalence of ASD in Australia was also increasing, and was estimated at 9.6 to 40.8/10,000 for those aged 6-12 years old in 2003-2004 (Williams, MacDermott, Ridley, Glasson, & Wray, 2008). Researchers have agreed that the increasing prevalence did not necessarily reflect an increasing incidence of ASD (Fombonne, 2009; Matson & Kozlowski, 2011; Waterhouse, 2008; Williams et al., 2008). The increasing prevalence of ASD, however, did coincide with an increasing awareness of ASD and an increasing number of intervention options.

Interventions for ASD

There are a range of interventions available for ASD, which are commonly referred to in the literature as interventions, treatments, and/or therapies (Carter et al., 2011; Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Prior, Roberts, Rodger, Williams, & Sutherland, 2011). The terms are used interchangeably throughout this thesis, and the term “intervention” is used most frequently. At the time of the commencement of this doctoral research program, researchers had collected data about the number and types of interventions used with children with ASD (e.g., Bowker, D'Angelo, Hicks, & Wells, 2011; Goin-Kochel et al., 2007; Green et al., 2006), but data regarding intervention use in Australia were very limited (Carter et al., 2011), and there had not been any attempts to synthesise these data.

The interventions available for children with ASD included some with sound empirical support, such as those based on the principles of applied behaviour analysis (ABA), but many which lacked such support, including many medications, complementary and

alternative medical (CAM) treatments, and sensory integration (Matson, Adams, Williams, & Rieske, 2013; National Autism Center, 2009; Odom, Boyd, Hall, & Hume, 2010; Prior et al., 2011). Some interventions available for ASD were not only unsubstantiated but also potentially dangerous (e.g., facilitated communication and chelation; Metz, Mulick, & Butter, 2005; Schechtman, 2007).

The Role of Parents in Decision-Making Regarding Interventions for ASD

It is the parent's role to make health decisions on behalf of their child. For many medical and health related conditions parents of children have few intervention options available to them and are generally guided by medical professionals regarding their decision-making. For parents of children with ASD, however, the situation is very different. As noted above, there are many interventions to choose from. Additionally, the parent takes the role of the primary decision-making agent. Some parents have described this role as an obligation and have reported that they felt unprepared to be making such decisions (Valentine, 2010).

Information regarding interventions is available from a number of sources, including non-professional sources such as other parents, the internet, and commercial providers of interventions (Hanson et al., 2007; Miller, Schreck, Mulick, & Butter, 2012; Valentine, 2010). In addition, professionals and peak bodies appear to be reluctant to provide specific recommendations or advice to parents regarding intervention decisions (Stephenson, Carter, & Kemp, 2012; Valentine, 2010), which may have implications for parental decision-making. Information regarding the efficacy of interventions has been disseminated by government bodies and other organisations using the internet (e.g. Raising Children Network, 2006-2014; Research Autism, 2006-2014), but there is some evidence to suggest that many Australian parents were not accessing that information (ARTD Consultants, 2012).

Parent decision-making may be influenced by financial support available. The funding available to parents varies from country to country and can also be dependent on the age of the child. For example, funding is available in Australia from the Federal government for parents of children with ASD younger than 7 years of age to access early intervention services

from approved providers (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012). Private health insurance in Australia may cover some of the costs of services provided by allied health professionals, such as occupational therapists, but behavioural interventions are not covered. There has been limited Australian research to date regarding the range of factors, such as sources of information about interventions and funding available, that may influence intervention decision-making of parents (Lynch, 2004; Rajkovic, Thompson, & Valentine, 2010; Valentine, 2010; Valentine, Rajkovic, Dinning, & Thompson, 2010).

Rationale for the Research

Parents of children with ASD have a range of interventions to choose from, including some that are supported by research evidence and many without empirical support. Although data existed regarding intervention use and factors in decision-making there had been no attempts to synthesise these data, and Australian data appeared to be very limited. Parents were required to make decisions on behalf of their children, often without the professional support that would usually be provided for other decisions, such as medical treatments for health conditions. Some supports, such as financial assistance, varied from country to country, and therefore, the context for decision-making in Australia was unique. Investigating the decision-making of Australian parents of children with ASD regarding intervention use offered the potential to better understand how parents made decisions and to develop resources to support them to make informed choices in the future.

Although information regarding the efficacy of interventions was available online, many Australian parents may not have been aware of this information. Furthermore, there had not been any research to determine whether access to information about the efficacy of interventions for ASD would have any effect on either parental opinions about interventions or parental desire to use interventions with empirical support.

Aims of the Research

Broadly, the aims of the research were to explore the following questions:

1. What are the number and types of different interventions used by parents of children with ASD? (See Chapter 2)
2. How do parents find out about possible interventions? (See Chapters 3 & 4)
3. What are the main factors that play a role in parental decision making? (See Chapters 3, 4, & 5)
4. Are there any relationships between parent and/or child characteristics and intervention choices? (See Chapter 5)
5. Would the provision of information about empirically supported treatments influence parent's opinions about interventions and/or their intervention choices? (See Chapter 6)

Structure of the Thesis

This thesis is presented in the format of a series of self-contained manuscripts, each formatted in a journal article style. The manuscripts are presented along with an introductory chapter, concluding chapter, and linking paragraphs. As a result of the manuscripts being self-contained this thesis includes some repetition of information. Furthermore, there is some inconsistency in formatting (e.g., the style of headings, the use of American English/British English spelling) due to the varying requirements of different journals. Information regarding the publication status of each of the papers is presented in each chapter introduction. Some chapters include a single manuscript while others include two related manuscripts. Further details are included in the chapter outline.

Methodological Approach

A range of methodologies were employed in the studies contained in this thesis. In Chapters 2 and 3 systematic reviews were employed to facilitate the synthesis of the literature

related to the number and types of interventions used and to the factors explicitly stated by parents as influencing their decision-making. Furthermore, in Chapter 2 a survey study (in replication of Green et al., 2006) was employed to obtain data related to the use of interventions specific to the Australian population. Due to a scarcity of literature specific to parent decision-making regarding ASD interventions in the Australian context, an exploratory qualitative approach was utilised in the study contained in Chapter 4. Informed by the findings of the review presented in Chapter 3 and the qualitative study presented in the papers in Chapter 4, a survey methodology was employed in the study contained in Chapter 5. This methodology was used to quantify the weight that Australian parents placed on different explicit declared factors in their decision-making, and to facilitate the exploration of the relationship between intervention use and underlying, implicit factors through regression analyses. The final study, presented in Chapter 6, was originally conceptualised as a randomised control trial of a parent education resource. However, despite the wide distribution of recruitment notices via autism associations and service providers in all seven Australian states and territories, only 14 parents consented to participate. Therefore the study was conducted as a pilot, employing a pre-test post-test design.

Chapter Outline

Chapter 2

Chapter 2 includes a review paper published in the *Australasian Journal of Special Education* (Carlon, Stephenson, & Carter, 2014b) and a small pilot survey study published in *Special Education Perspectives* (Carlon, Carter, & Stephenson, 2011). In recent years, as the variety of interventions available to parents of children with ASD increased, a number of researchers collected data from parents about the different interventions they were using with their children (e.g., Bowker et al., 2011; Goin-Kochel et al., 2007; Green et al., 2006; Hanson et al., 2007). However, by 2011 there had not been any attempts to review the growing number of studies nor to synthesise these data. Carlon, Stephenson, and Carter (2014b) provided the first review of parent reports of interventions used with their children with ASD.

Forty-two studies which included quantitative data about interventions used were included in the review. Parents were found to be using a variety of interventions, with varying levels of research support. Methodological issues regarding the collection of such data were identified, and recommendations for future research were made. Data specific to parents of children in Australia were sparse.

An online survey, in replication of Green et al. (2006), was conducted with a defined sample of Australian parents of school and preschool-age children (Carlon et al., 2011). This was one of the first Australian studies of this nature and the first online survey study in which participants were recruited from a defined sample. Although the response rate was low, data were generally consistent with those collected in larger survey studies. The use of a defined sample and therefore the ability to calculate a return rate highlighted some of the possible methodological issues related to disseminating surveys widely to an unknown number of possible participants. Recommendations for future research were offered.

Chapter 3

Chapter 3 includes a review paper published in *Research in Autism Spectrum Disorders* (Carlon, Carter, & Stephenson, 2013). This paper provided the first review of parent reports of factors influencing their decision-making regarding interventions for their children with ASD. Sixteen studies including parent reports of factors in decision-making were examined. Advice and recommendations from others were frequently examined by researchers and nominated by parents as factors in decision-making. Other frequently nominated factors included those related to pragmatic issues, to the effectiveness of interventions, and research evidence. Research evidence was not nominated as frequently as some of the other factors. Although multiple factors were identified across the studies, data related to the level of importance that parents placed on different factors in their decision-making were very limited. In addition, limited Australian data were available.

Chapter 4

Chapter 4 includes two related qualitative papers, one of which is in press for the Australasian Journal of Special Education (Carlton, Stephenson, & Carter, in press), and one which has been submitted for publication (Carlton, Stephenson, & Carter, 2014a). With the intent to provide information to inform later survey research, interviews were conducted with Australian parents of preschool-age children with ASD. The population was restricted to parents of preschool-age children for two reasons: (a) there was some evidence to suggest that parents were likely to employ the interventions offered at the child's school once they started school, rather than actively choose to commence or continue to use similar interventions available outside of school (Akshoomoff, Stahmer, Corsello, & Mahrer, 2010; Le Grice & McMenamin, 2001; Thomas, Morrissey, & McLaurin, 2007); and (b) in Australia the Federal Government had implemented the "Helping Children With Autism (HCWA) package", which provided Autism Advisors, autism-specific playgroups, family workshops, an ASD website, and funding for parents to access early intervention services for children under seven years of age (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012). It appeared, therefore, that decision-making for Australian parents of children who had not yet started school may have been influenced by slightly different factors than for parents of children who were of school-age. There were very limited data available regarding sources used by parents in, and factors related to, the decision-making of Australian parents of preschool-age children with ASD. This exploratory qualitative study added to the very small Australian research base in the area.

Interviews were conducted with 12 parents of preschool-age children with ASD, and qualitative analysis of these interviews was undertaken in order to investigate how parents made decisions about intervention use. Results related to participants' impressions of the reliability or trustworthiness of different sources of information about interventions, and the perceived usefulness of the information provided are presented in Carlton, Stephenson, and Carter (in press). Parents reported using a range of information sources (consistent with previous survey research), and reported that the first-hand experience of other parents, their

perceptions of the source's intentions, a relationship with the source, and the presentation of information all influenced how reliable or trustworthy they considered sources to be. Sources that were considered to be trustworthy did not necessarily provide information that was useful to the parents. Common themes related to the usefulness of the information provided included that the information was of limited use, and conversely that the amount of information was overwhelming. Parents' stated that being connected to other sources was useful even when the primary source provided limited information. Some parents described sources who acted as guides in decision-making as particularly helpful.

The factors involved in the actual decision-making of the parents, including those identified as the "final criteria" in decisions to use and reject self-nominated interventions are presented in Carlon, Stephenson, and Carter (2014a). This was one of the few papers in which parents were asked about the importance that they placed on different factors in decision-making. For most decisions, parents identified one or more factors which were the "final criteria" in their decisions to commence or reject interventions. Factors identified by parents included those specific to the Australian context, such as the complex funding system, highlighting the importance of considering country-specific contextual factors in future research.

Chapter 5

Chapter 5 includes two related papers presenting findings from a survey with Australian parents regarding the importance of factors in decision-making about early intervention, one of which is in press for the Journal of Developmental and Physical Disabilities (Carlon, Carter, & Stephenson, in press), and one which has been submitted for publication (Carlon, Carter, Stephenson, & Sweller, 2014). Carlon, Carter, and Stephenson (in press) presented findings related to the importance of different explicitly declared decision-making factors. It was one of the few studies that investigated the weight that parents placed on different factors in their decision-making, and the first Australian study of this kind. For both decisions to use and to reject nominated interventions a number of factors, including the

child's individual needs, staff attributes, whether the intervention was ASD-specific, and intuition/gut feelings, were weighted more highly than research evidence. Although advice/recommendations had been frequently reported as influencing parent decision-making in previous research (Carlon et al., 2013), when the factors were grouped pragmatically the category of advice/recommendations was ranked significantly lower than all other categories. This finding suggests that factors that are frequently considered in decision-making may not necessarily carry the most weight in parents' final decisions to use and/or reject interventions.

Carlon, Carter, Stephenson, and Sweller (2014) explored the relationship between a number of implicit parent and child factors and the use of different interventions (using data collected in the same survey as those data presented in Carlon, Carter, & Stephenson, in press). The investigation of the possible relationships between the number and type of interventions used and implicit child and parent factors was the first study of this type with an entirely Australian sample. Consistent with other studies in the area, few significant relationships were found, suggesting that the decision-making of parents involves a complex interplay between different factors.

Chapter 6

Chapter 6 includes a paper submitted for publication to a peer reviewed journal (Carlon, Carter, & Stephenson, 2014). The findings of the research presented in Chapters 2 to 5 of this thesis indicated that parents did not appear to place as much importance on research evidence as on other factors in decision-making. It was unclear whether this was due to parents being unaware of the importance of research, unable to access reliable information about the efficacy of different interventions, or dismissive of the importance of research evidence. Carlon, Carter, and Stephenson (2014) present a pilot study of the effectiveness of a parent education DVD-based package that provided guided access to two websites with reliable information about the efficacy of interventions for ASD. The twelve parents who completed the trial provided positive feedback about the DVD-based package and generally felt more confident in making intervention decisions after using the package. The package did

not appear to influence the parents' desire to use interventions with varying levels of support, the level of importance placed on different factors in decision-making, nor the parents' understanding of the level of research support for different interventions. The parents' ratings of research support were related to their level of desire to use different interventions. The findings of this research raised questions about the effectiveness of websites such as Raising Children Network (2006-2014) in disseminating information about the efficacy of interventions to parents.

Chapter 7

This concluding chapter provides a summary of the findings of the research presented in the papers that comprise this thesis. Implications for future research and practice are discussed, and the original contribution of this research is highlighted.

Summary

In this chapter the purpose of the research contained in this thesis was introduced. Literature providing a background to and rationale for this research was presented. An overview of the structure and content of this thesis by publication was also provided.

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CHAPTER 2: INTERVENTIONS USED BY PARENTS OF CHILDREN WITH ASD

Chapter Overview

This chapter includes two papers, one published in the *Australasian Journal of Special Education* (Carlton, Stephenson, & Carter, 2014b)¹, and one published in *Special Education Perspectives* (Carlton, Carter, & Stephenson, 2011)^{2, 3}. Carlton, Stephenson, and Carter (2014b) presents the first systematic review of parental reports of interventions used with their children with ASD. Across the studies parents reported using a variety of interventions with differing levels of research support. There were few data from Australian samples. Recommendations for the conduct of future research are offered. The supplementary tables with details of the interventions examined in each of the 42 studies are presented in Appendices 1 and 2 of this chapter.

Carlton et al. (2011) presents a small pilot online survey study. This study added to the very limited Australian research base, and was the first online survey study of parents of children with ASD regarding intervention use which included the method of targeting a defined sample. It was conducted with parents of Australian children of both pre-school and school age children to facilitate the comparison of intervention use across different ages. Although the response rate was low, the findings were generally consistent with larger international studies in the area. Recommendations for future research were provided. A copy of the survey used in this study is provided in Appendix 3 of this chapter.

¹ Publication Status:

Carlton, S., Stephenson, J., & Carter, M. (2014b). 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

² Publication Status:

Carlton, S., Carter, M., & Stephenson, J. (2011). An internet survey of treatments used by Australian parents of children with autism spectrum disorders. *Special Education Perspectives*, 20, 40-57.

³ I was awarded the 2010 Lee Mills Teacher Training Encouragement Award by the Australian Association of Special Education for an earlier version of this paper.

Pages 20-47 of this thesis have been removed as they contain published material. Please refer to the following citation for details of the article contained in these pages.

Carlon, 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(1), 63-90.

DOI: [10.1017/jse.2014.4](https://doi.org/10.1017/jse.2014.4)

Pages 48-65 of this thesis have been removed as they contain published material. Please refer to the following citation for details of the article contained in these pages.

Carlon, S., Carter, M., & Stephenson, J. (2011). An internet survey of treatments used by Australian parents of children with autism spectrum disorders. *Special Education Perspectives*, 20(1), 40-57.

APPENDIX 1

Supplementary Table 1.

Intervention Use Reported in Studies Reviewed in Carlon, Stephenson, and Carter (2014b).

**Note: Due to the size of this table, it is presented in 3 sections.*

A key to the numbers representing studies and the symbols used in the table is presented before the table.

Supplementary Table 1.

Intervention Use Reported in Studies Reviewed in Carlon, Stephenson, and Carter (2014b).

Key

- | | |
|--|--|
| 1 = Aman et al., 1995 | 31 = Goin-Kochel et al. 2007 (for those with PDD-NOS) |
| 2 = Kohler, 1999 | 32 = Goin-Kochel et al. 2009 |
| 3 = Martin et al, 1999 | 33 = Hanson et al., 2007 |
| 4 = Study 1 in Smith & Antolovich, 2000 | 34 = Thomas, Ellis, et al., 2007*(overall use) |
| 5 = Study 2 in Smith & Antolovich, 2000 | 35 = Thomas, Ellis, et al., 2007* (use at school) |
| 6 = King et al, 2000 | 36 = Thomas, Ellis, et al., 2007* (use outside of school) |
| 7 = Erba, 2000 | 37 = Thomas, Morrissey, et al., 2007 (overall use) |
| 8 = Boyd & Corley, 2001 | 38 = Thomas, Morrissey, et al., 2007 (use at school) |
| 9 = LeGrice & McMenamin, 2001 | 39 = Thomas, Morrissey, et al., 2007(use outside of school) |
| 10 = Langworthy-Lam, 2002 | 40 = Cassidy et al., 2008 |
| 11 = Aman et al., 2003 | 41 = McLennan et al., 2008- (use at school, n=150) |
| 12 = Levy et al., 2003 | 42 = McLennan et al., 2008- (overall use, n=235) |
| 13 = Levine et al., 2004 (overall use) | 43 = Reffert, 2008 (use at school) |
| 14 = Levine et al., 2004- (use in school) | 44 = Reffert, 2008 (use outside of school) |
| 15 = Mansell & Morris, 2004 | 45 = Robinson, 2008 |
| 16 = Hume, Bellini, & Pratt, 2005 | 46 = Reghr & Feldman, 2009 |
| 17 = Witwer & Lecavalier, 2005 | 47 = Wong, 2009 |
| 18 = Green et al., 2006 | 48 = Akshoomoff et al., 2010- at school |
| 19 = Gurney et al, 2006 | 49 = Akshoomoff et al., 2010- outside school |
| 20 = McConachie & Robinson, 2006 | 50 = Al Anbar et al., 2010 |
| 21 = Renty & Roeyers, 2006 | 51 = Dardennes et al., 2011 |
| 22 = Harrington, Patrick et al, 2006 | 52 = Christon, Mackintosh, & Myers, 2010 |
| 23 = Harrington, Rosen et al, 2006 (for all diagnostic groups) | 53 = Senel, 2010 |
| 24 = Harrington, Rosen et al, 2006 (for those with autism) | 54 = Bowker et al., 2011- all diagnostic groups |
| 25 = Harrington, Rosen et al, 2006 (for those with PDD-NOS) | 55 = Bowker et al., 2011- autistic disorder |
| 26 = Harrington, Rosen et al, 2006 (for those with Asperger's syndrome) | 56 = Bowker et al., 2011- PDD-NOS |
| 27 = Wong & Smith, 2006 | 57 = Bowker et al., 2011- Asperger's Disorder |
| 28 = Goin-Kochel et al. 2007 (for all diagnostic groups) | 58 = Carter et al., 2011 |
| 29 = Goin-Kochel et al. 2007 (for those with autism) | 59 = Shattuck, 2011 |
| 30 = Goin-Kochel et al. 2007(for those with Asperger's syndrome) | Y = Use of the intervention was reported in the study |
| | 0 = It was reported that the intervention was not used |
| | A = The intervention was asked about in the study, but whether or not it was used was unreported. |

*Only data for children aged 9-11, not presented in Thomas, Morrissey, et al., 2007.

Supplementary Table 1.

Intervention Use Reported in Studies Reviewed in Carlon, Stephenson, and Carter (2014b).

Part 1

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
AAC; Augmentative and alternative communication; Augmentative communication						A										Y		Y										
ABA; Applied Behaviour Analysis; Behaviour therapy				Y	Y				Y									Y										Y
Abilify; Aripiprazole																												Y
Academic tutoring													Y	Y														
Acupuncture/Acupressure																												
Acupuncture							Y											Y									0	
Adaptive Physical Education																												
Adderall; Amphetamine salts											Y							Y				A						Y
Allegra; Fexofenadine																												Y
Allergen-restricted diet																	Y					Y						
Alpha Agonists			Y														Y											
Alpha Lipoic Acid																						Y						
Alternative/complementary therapy; Complementary and alternative therapies; CAM; Biological therapies						A						Y										Y	Y	Y	Y	Y	Y	
Alternative therapies/medicine; Alternative therapies																		Y										
Alternative medical systems																											Y	
Alternative treatments							Y											Y										
Amino acids																												
Amantadine; Symmetrel										Y	Y																	Y
Ambrotose																												Y
Amphetamines				Y																								
Animal therapy												Y																
Antibiotics																							Y	Y	Y	0		
Anticholinergics	Y										Y																	
Anticonvulsants; Anti-epileptics; AEDs	Y			0						Y	Y						Y					Y						
Antidepressants	Y		Y	Y						Y	Y						Y					Y						Y
Antifungals																						Y	Y	Y	Y	Y		
Antihistamine																		Y	Y									
Antihypertensives	Y		Y							Y	Y																	
Anti-infectives												Y																
Antiparkinson/antispasmodic; Antiparkinsonian agents										Y							Y											
Antipsychotics				Y						Y	Y						Y											

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Anti-Yeast Treatments																												
Anthroposophic medicine																												
Anxiolytics			Y	0																								Y
Anxiolytics/sedatives/hypnotics	Y									Y	Y						Y											
Any Agent (psychotropic or other)	Y									Y	Y																	
Aromatherapy																		Y									Y	
Artichoke																						Y						
Art therapy																												
Assistive Technology; Assisted Technology													Y	Y														
Atomoxetine; Strattera																	Y											Y
Atypical antipsychotics																												Y
Atypical Neuroleptics			Y																			Y						
Auditory Integration Training- Berard Method							Y																					
Auditory Integration Training; Auditory Integration Therapy				Y			Y		Y			Y						Y				Y						Y
Auditory Integration Training- Tomatis Method; Tomatis program							Y																					Y
Auditory/sound treatment																												
Aversive therapy																												
Avoidance of red dyes; Elimination of dyes																												Y
Axid/Nizatidine																												Y
Ayurvedic Medicine																												
Azrin 24-hour toilet training																		Y										
Baudhuin Preschool																		Y										
Bee Pollen																												
Behavioural/educational/ alternative therapies																												Y
Behavioural optometrist																						Y						
Behaviour management or parent training															Y													
Behaviour supports																Y												
Behaviour therapist		Y																										
Benadryl; Diphenhydramine										Y	Y											Y						
Benztropine; Cogentin										Y	Y																	Y
Beta Blockers			Y														Y											
Bethanechol																		Y										Y
Bio-energy and Scio																												
Biological and dietary treatments																												
Biological-based therapies; Biologically based therapies																											Y	

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Biological treatments																							Y	Y	Y	Y		
Biomedical Rx (non-specific)																												
Biomedical treatment				Y																								
Biometrics																												
Biotin																						Y						
Blue green algae																												
Body-based relaxation therapies																										Y		
Bolles Sensory Learning Method																		Y										
Brain gym																												
Brushing											Y																	
Buspar; Buspirone	Y		Y							Y	Y						Y	Y										Y
Caffeine-Free Diet																										Y		
Calcium																						A	A	A	A	A	Y	
Calcium Butrate																												Y
Carbamazepine; Tegretol; Carbatrol	Y		Y							Y	Y							Y				A						Y
Carbohydrate-restricted diet																						Y						
Carnitine																							Y	Y	Y	Y		
Carnosine																												Y
Casein-Free Diet				Y			Y					Y					Y	Y				Y	Y	Y	Y	Y	Y	
Casein-Free or Dairy-Free Diet																												Y
Catnip							Y																					
Cerebrolysin																												
Chamomile																												
Chelation/antibiotic																												
Chelation; Chelation for lead or mercury; Detox (chelation); Detoxification (chelation method)												Y						Y				Y	Y	Y	Y	0		Y
Chemet; Succimer																												Y
Child Care; Day care; Nursery school																						Y						
Child development nursery																				A								
Chiropractic						A	Y																Y	Y	Y	Y	Y	Y
Chiropractics/Herbal therapy				Y																								
Chiropractic/osteopathy																												
Chloral Hydrate	Y																											
Chlorpromazine; Thorazine	Y																	Y										
Chocolate-Free Diet				Y																								
Citalopram; Celexa																	Y											Y
Classroom aide; Educational assistant or teacher's aide		Y														Y												
Clathration																		Y										
Clomipramine; Anafranil	Y			Y																								Y

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Clonazepam	Y		Y							Y																		
Clonidine; Catapres	Y		Y	Y						Y	Y						Y	Y										Y
Clonopin																		Y										
Clozapine																		Y										
Cod liver oil												Y					Y											
Cognitive/behavioural therapy																		Y										
Combined Programs																		Y										
Communication therapies/systems																												
Conductive Education																		Y										
Conventional therapies																												
Corn-restricted diet																						Y						
Counselling						A										Y			A									
Cranial Electrical Stimulation																												
Cranial Osteopathy															Y													
Cranial Vascular Therapy				Y																								
Craniosacral Manipulations; Craniosacral Therapy						A	A											Y										
Craniosacral treatment, myofascial release																												
Creon; Pancreatin																												Y
Cytobuddies																												
Dairy and Wheat-Free Diet					Y																							
Dairy, Wheat, and Yeast-Free Diet					Y																							
Dairy-Free Diet				Y	Y												Y											
Dance Therapy																		Y										
DDAVP; Desmopressin acetate																												Y
Defeat Autism Now (DAN) approach																												
Delay Vaccinations																							Y	Y	Y	Y		
Denver approach																												
Desyrel; Trazodone																												Y
Detoxification																		Y										
Detrol; Tolterodine tartrate																												Y
Developmental therapy																												
Dextroamphetamine; Dexedrine/d-Amphetamine; Dextrostat	Y		Y	Y						Y	Y						Y	Y										Y
Dietary Restriction (not gluten or casein)																												Y
Dietary Restrictions; Elimination diets; Diets; Special(ised) diets; Change in diet; Modified diets; Alternative diets				Y	Y										Y		Y	Y				Y					Y	
Dietary supplements																						Y						
Diets/supplements																							Y	Y	Y	Y		

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Diflucan; Fluconazole																		Y										Y
Digestive Enzymes																						Y	Y	Y	Y	Y	Y	
Dilantin; Phenytion sodium																												Y
Dimethylethanolamine; DMAE										Y	Y																	
Dimethylglycine; DMG	Y						Y			Y	Y						Y	Y				Y						Y
Dog Therapy																												
Dolphin Therapy; Dolphin Swim Therapy							A											Y				Y						
Doman-Delacato Patterning (Institute for Human Potential); Patterning							A											Y										
Drug and diet therapies																												Y
DTT; Discrete Trial Training; Lovaas; Discrete Trial Training (Lovaas)							Y								Y	Y		Y										
Early Childhood Education						A																						
Early Intensive Behavioral Intervention								Y																				
Early Years Course															Y													
Early intervention services; Early-Intervention (Generic- not ASD specific)																												Y
Echinacea																											0	
Eden Program																		Y										
Educational and therapy interventions																												
Educational techniques																												
Educative treatments/Educational techniques																												
EEG																												
EMG																												
Effexor; Venlafaxine																												Y
Electro-aversive therapy (Faradic skin shock)																		Y										
Energy Healer																						Y						
Energy therapies																												
Enzyme Potentiated Desensitization																												
Equestrian Therapy; Hippotherapy; Therapeutic Horseback Riding				Y			A															Y	Y	Y	Y	Y	Y	
Essential Fatty Acids; Fatty Acids; Oils/fatty acids																		Y					Y	Y	Y	Y	Y	
Evening primrose oil																												
Exelon; Rivastigmine tartrate																												Y
Extended Breastfeeding																		Y										
Facilitated Communication				Y			Y											Y				Y						
Famvir; Fanciclovir																												Y
Fast Forward; Fast ForWord							Y											Y										
Feingold Diet				Y			A											Y										Y
Fish oil																												

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Flexyx neurotherapy system																												
Floortime; Greenspan Model				Y			A									Y		Y										Y
Fluoxetine; Prozac	Y		Y	Y						Y	Y						Y	Y				A						Y
Fluvoxamine; Luvox			Y	Y							Y																	Y
Focalin																												
Folic Acid							A															Y	A	A	A	A		
Food supplements																												
Gabapentin										Y																		
Gammaglobulin; Immunoglobulin infusions; Intravenous immunoglobulin; IVIG				Y														Y				Y						
Garlic; Garlic oil																						Y					0	
Gastrointestinal medications												Y																
Gentle Teaching				Y														Y										
Geodon; Ziprasidone																												Y
Giant Steps																		Y										
Gingko biloba																												
Ginseng																												
Glutathione peroxidase																						Y						
Gluten and Casein-Free Diet												Y					Y											Y
Gluten or Casein-Free Diet, or both																												Y
Gluten-Free Diet							Y					Y					Y	Y				Y	Y	Y	Y	Y	Y	
Gluten/wheat-free diet				Y																								Y
Guanfacine; Tenex										Y							Y	Y										Y
Guided Imagery/Hypnosis																												
Haloperidol; Haldol	Y		Y															Y				A						Y
Hanen; "More than Words" course																				Y								
Healer/healing touch																												
Herbal Remedies; Herbal medicine; Herbal products						A																						
Higashi															Y			Y										
Holding Therapy				0			A											Y										
Homeopathy; Homeopathic remedies						A	Y							Y				Y				Y	Y	Y	Y	0	Y	
Humanistic play treatment				Y																								
Hydroxyzine	Y																											
Hyperbaric Oxygen Treatment																						A	A	A	A	A		
Imipramine; Tofranil	Y		Y	Y														Y										Y
Immune System Therapy																												
Inclusion Supports; Support at mainstream school															Y	Y												
Individual counselling/psychotherapy																												

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Individual Tutoring								Y																				
Integrated Movement Therapy																		Y										
Intensive behavioural intervention or ABA																												
Interactive Metronome																		Y										
Irlen lenses																		Y										
Iron																												
Joint Action Routines																		Y										
Kaplan Visual Therapy (special eyeglasses)				Y																								
Kava																												
Ketogenic diet																						Y						
KidsPlex																												
Kinesiology																												
Lactose-free diet																	A											
Lamotrigine; Lamictal											Y																	Y
L-Carnosine Powder																						Y						
LEAP																		Y										
Lekotek therapy																		Y										
Lexapro																												Y
L-Glutamine																		Y										
Lindamood Bell																		Y										
Lithium	Y		Y							Y	Y						Y	Y										Y
Lorazepam; Ativan										Y							Y											Y
Low GI Diet																											Y	
Magnesium																		Y				Y					Y	
Magnetic Therapy																												
Manganese																						Y						
Manipulative and body-based therapies; Manipulations and body-based methods																											R	
Manual Integrative Therapy																						Y						
Massage belt or chair																												
Massage therapy/Shiatsu						A																						
Massage; Infant Massage; Bodywork							Y											Y					Y	Y	Y	Y	Y	
Massage/reflexology																												
Medical, dietary or CAM interventions																												
Medical services						A																						
Medical Treatment; Medical Procedures																Y		A										
Medication; Medicine; Pharmaceuticals; Drugs; Medical agents	Y		Y				Y		Y		Y							Y				Y						
Medicine prescribed by a doctor; Prescription drugs; Prescription medication																			Y									

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Medication and supplements																												
Meditation/hypnosis; Meditation/relaxation response																												
Medication unrelated (e.g. Ventolin)																												
Mega-Vitamin Therapy; Megadose Vitamin; MegaVitamins					Y		Y			Y							Y	Y				Y						
Melatonin							A			Y	Y	Y					Y	Y					Y	Y	Y	Y	Y	Y
Mental health services																												
Metabolic treatments																												
Methylphenidate- Sustained Release										Y							Y											
Methylphenidate; Ritalin; Metadate; Concerta	Y		Y	Y						Y	Y						Y	Y				A						Y
Metoprolol; Lopressor; Toprol											Y																	
Mind-body and psychological therapies																											Y	
Mind-body interventions																												
Milk Thistle																						Y						
Mineral supplements	A																										Y	
Mineral and vitamin supplements																											Y	
Miralax; Polyethylene glycol																												Y
Miscellaneous herbal medication																												Y
Miscellaneous GI medication; Miscellaneous Gastro Intestinal medication																												Y
Miscellaneous medication; Other medication	Y									Y	Y																	Y
Miscellaneous- specific medication																												Y
Mobile Therapy		Y																										
Mood or behaviour medication																												
Mood Stabilisers	Y		Y							Y	Y						Y											Y
Moxibustion																												
Multi-disability services																					Y							
Multisensory Environments (Snoezelen)																		Y										
Music Therapy				Y			A		Y							Y		Y									Y	Y
Musical Therapy																												
Music and Dance therapy																						Y						
Naltrexone																		Y										
Naturopathy; Naturopathic remedies																											0	
Neural Therapy																		Y										
Neurofeedback; Biofeedback																		Y										Y
Neuroleptics	Y		Y	A																								
Neurontin																						A						Y
No Additives or Preservatives																											Y	

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Non-contact therapeutic touch																												
Non-specialist Nursery																				A								
Noradrenegic Agonists																	Y											
Nonbiologicals												Y																
Norpramin; Desipramine																												Y
Nortriptyline			Y																									
Nutritional supplements																	Y										Y	
Nystatin																		Y										Y
Occupational Therapy		Y		Y		Y	Y	Y	Y				Y	Y	Y	Y		Y	A									Y
Olanzapine; Zyprexa			Y							Y	Y						Y											Y
Omega fatty acids/Omega-3 fatty acids/Omega-3 oil																						Y					Y	Y
One-on-one aide or assistant; child's own aide																												
Opiate Blockers	Y									Y	0						Y											
Options Program; Options Therapy				Y			A								Y			Y										Y
Osteopathy; Osteopathic manipulation																		Y										
Other behavioural interventions (not EIBI)																												
Other CAM therapy																							Y	Y	Y	Y		
Other dietary supplements																												
Other (non-specific) treatments																												
Other skills based																		Y										
Paroxetine				Y						Y								Y										
Paxil; Seroxat															Y			Y										Y
Peanut-restricted diet																						Y						
PECS; Picture Exchange Communication System							Y								Y			Y										Y
Pemoline; Cylert	Y																	Y										
Pentoxifylline																		Y										
Pepcid																		Y										Y
Pet therapy																						Y						
Phenol-restricted diet																						Y						
Phenytoin; Dilantin	Y																	Y										
Physical Therapy; Physiotherapy		Y		Y		A	Y						Y	Y		Y		Y	A									Y
Physiological																		Y										
Play therapy									Y																			
Playgroup																				A								
Playgroup (integrated)							Y																					
Playgroup (specialised)																				A								
Pomadine				Y																								
Positive Behavioural Support																												
Pragmatics Training																												
Prayer; Prayer/Blessing							Y																					

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Prayer/Shaman																												
Prednisone																												Y
Preschool		Y						Y								Y												
Pre-school communication group																				A								
Pressure and vestibular stimulation					Y																							
Pressure and tactile stimulation					Y																							
Pressure and vestibular and tactile stimulation					Y																							
Probiotics																		Y				Y	Y	Y	Y	Y		
Propranolol; Inderal	Y		Y							Y	Y							Y										
Protein supplements																												
Psychiatric services																												
Psychic healing																												
Psychoanalysis				Y																								
Psychological/mental health services						A							Y	Y														
Psychology/psychometry						A																						
Psychomotor therapy																												
Psychotherapy				Y																								
Psychotropic Medication; Psychotropic drugs	Y		Y							Y	Y						Y											
Psychotropic or anticonvulsant medication	Y									Y	Y																	
Psychotropic medication or vitamins for autism	Y									Y	Y																	
Psychotropic medication or vitamins for autism or anticonvulsants	Y									Y	Y																	
Pulmicort; Budesonide																												Y
Pycnogenol																												
Pyridoxine																		Y										
Qi Gong																												
Rapid Prompting																		Y										
RDI (Relationship Development Intervention)																												
Recreation therapy; recreational therapy						A										Y												
Reduced L-Glutathione																		Y										
Reflexology																												
Regular day care																												
Reiki; Reike																		Y			Y							
Reiki/healing																												
Relationship-based treatments																		Y										
Remeron; Mirtazapine																												Y
Restores																												
Rhythmic entrainment interventions																		Y										

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Risperidone; Risperdal			Y	Y						Y	Y						Y	Y				A						Y
Rolfing																		Y										
Saccromyces bonlardii																						Y						
Salicylate-restricted diet																						Y						
Secretin							Y			0		Y			Y		Y	Y				Y	Y	Y	Y	Y		Y
Seizure-control medications																												Y
Selenium																											Y	
Self-Injurious Behavior Inhibiting System (SIBIS)																		Y										
Senna																												Y
Sensorimotor treatment				Y																								
Sensory/motor therapies																												
Sensory Integration; Sensory Integration Therapy				Y	Y		Y									Y		Y				Y	Y	Y	Y	Y	Y	Y
Sensory Therapies																												
Seroquel																						A						Y
Sertraline; Zoloft			Y							Y	Y						Y	Y				A						Y
Serzone; Nefazodone																												Y
Shaman							Y																					
Sign Language							Y																					
Skills training based on principles of ABA																		Y										
Skullcap																												
Social Skills Training							Y																					Y
Social Stories							Y											Y										Y
Social Supports																Y												
Social therapies																												
Spa/Hot Spring																												
Special education																												
Special Exercises																												
Specialised eye glasses																												
Specialised preschool																												
Special Therapy such as physical, occupational or speech therapy																			Y									
Special treatments or approaches for ASD																												
Speech therapy; Speech-Language Therapy; Speech Pathology		Y		Y	Y	Y	Y	Y	Y				Y	Y	Y	Y		Y	A	Y								Y
Spiritual healing																											Y	
Sporanox																		Y										
SSRI's			Y																									
Standard Therapies																		Y										
Stimulants	Y		Y							Y	Y						Y					Y						Y
St. John's Wort																												

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Strawberry Extract																											0	
Sucrose-free diet				Y																								
Sugar-restricted or sugar-free diet; avoidance of sugar																	Y					Y					Y	Y
Sumycin; Tetracycline																						Y						Y
Super Nu-Thera										Y							Y					Y						
Supplements																												
Squeeze machine																												
Swimming																												
Tactile stimulation					Y																							
Tai Chi																												
Taichi/ Reiki																												
Taurine																						Y						
TEACCH							Y								Y			Y										Y
Therapeutic listening																												
Thioridazine; Mellaril	Y		Y	Y						Y	Y																	
Thioxanthene; Navane																						A						
Thymus Extract																						Y						
TMG; Trimethylglycine																												Y
Topiramate; Topamax																	Y											Y
Traditional Chinese Medicine; Chinese Medicine																						Y						
Traditional Neuroleptics			Y																									
Transfer Factor																		Y										
Tranquiliser																						A	A	A	A	A		
Tricyclic Antidepressants			Y																									
Trileptal ; Oxcarbazepine																												Y
Tryptophan																						Y						
Tuina therapy																												
Tumbletots																				A								
Typical Neuroleptics																						Y						
Vaccination Withdrawal; Withhold immunisations; No vaccinations												Y											Y	Y	Y	Y		
Vagal nerve stimulation; Vagus nerve stimulation																		Y										
Valerian																												
Valium; Diazepam											Y							Y										Y
Valproic Acid; Valproate; Divalproex; Depakote	Y		Y							Y	Y						Y	Y										Y
Van Dijk approach																		Y										
Vancomycin; Vancin																		Y										Y

Treatment/Intervention	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Vegan Diet																												
Vegetarian diet; Meat-free diet																												Y
Vestibular stimulation					Y																							
Vision Therapy																												
Visual communication strategies																												
Visual Integration Training																		Y										
Visual Schedules																		Y										
Visual training																						Y						
Vitamin A																		Y				A						
Vitamin B																											Y	
Vitamin B12																						A						
Vitamin B12 and Magnesium																											Y	
Vitamin B6	Y									Y	Y						Y	Y				A						
Vitamin B6 and Magnesium	Y			Y	Y		Y																				Y	
Vitamin B6 and Magnesium and DMG					Y																							
Vitamin C							A											Y				A					Y	
Vitamin D																											0	
Vitamin E																						A						
Vitamins and nutritional supplements																	Y											
Vitamins; Vitamin therapy; Vitamin supplements; Special Vitamins	Y				Y	A				Y	Y	Y						Y									Y	
Vitamins/minerals; Vitamins and minerals																												
Vitamin or mineral supplements																												
Vitamins for Autism Only; Autism supplements	Y									Y	Y																	
Watsu																		Y										
Weight loss/get rid of toxic substances																												
Weighted vest/blanket																		Y										
Wellbutrin; Bupropion																												Y
Wild oat seed																												
Wheat and Yeast-Free Diet					Y																							
Wheat-free diet					Y																							
White noise																												
Xanax																		Y										Y
Yeast-Free Diet				Y														Y				Y					Y	
Yoga																												
Yoga/dancing/relaxation																												
Zinc																						Y						
Ziprasidone																	Y											
Zyrtec																												Y

Supplementary Table 1.

*Intervention Use Reported in Studies Reviewed in Carlon, Stephenson, and Carter (2014b).**Part 2*

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
AAC; Augmentative and alternative communication; Augmentative communication																										
ABA; Applied Behaviour Analysis; Behaviour therapy	Y	Y	Y	Y	A	Y			Y			Y			Y	Y		0	Y			Y	Y			Y
Abilify; Aripiprazole				Y																						
Academic tutoring																										
Acupuncture/Acupressure					Y																					
Acupuncture							0			0									Y						Y	
Adaptive Physical Education							Y			Y										Y	0					
Adderall; Amphetamine salts				Y	A																					
Allegra; Fexofenadine				Y																						
Allergen-restricted diet																										
Alpha Agonists																										
Alpha Lipoic Acid																										
Alternative/complementary therapy; Complementary and alternative therapies; CAM; Biological therapies					Y			Y			Y								Y					Y	Y	
Alternative therapies/medicine; Alternative therapies																										Y
Alternative medical systems					Y														Y							
Alternative treatments														Y												
Amino acids																									A	
Amantadine; Symmetrel				Y																						
Ambrotose				Y																						
Amphetamines																										
Animal therapy																								Y		
Antibiotics																										
Anticholinergics																										
Anticonvulsants; Anti-epileptics; AEDs																										
Antidepressants	Y	Y	Y	Y																						
Antifungals																										
Antihistamine																										
Antihypertensives																										
Anti-infectives																										
Antiparkinson/antispasmodic; Antiparkinsonian agents																										
Antipsychotics																										
Anti-Yeast Treatments																									Y	

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Anthroposophic medicine					Y																					
Anxiolytics	Y	Y	0	Y																						
Anxiolytics/sedatives/hypnotics																										
Any Agent (psychotropic or other)																										
Aromatherapy																										
Artichoke																										
Art therapy					A																					
Assistive Technology; Assisted Technology																		Y								
Atomoxetine; Strattera				Y																						
Atypical antipsychotics	Y	Y	Y	Y																						
Atypical Neuroleptics																										
Auditory Integration Training- Berard Method																										
Auditory Integration Training; Auditory Integration Therapy	Y	Y	Y	Y	Y			Y			Y							Y						Y	Y	
Auditory Integration Training- Tomatis Method; Tomatis program	Y	Y	Y																							
Auditory/sound treatment																										
Aversive therapy								0			0															
Avoidance of red dyes; Elimination of dyes				Y																						
Axid/Nizatidine				Y																						
Ayurvedic Medicine																			A							
Azrin 24-hour toilet training																										
Baudhuin Preschool																										
Bee Pollen																			Y							
Behavioural/educational/alternative therapies	Y	Y	Y																							
Behavioural optometrist																										
Behaviour management or parent training																										
Behaviour supports																										
Behaviour therapist																										
Benadryl; Diphenhydramine																										
Benzotropine; Cogentin				Y																						
Beta Blockers																										
Bethanechol				Y																						
Bio-energy and Scio																								Y		
Biological and dietary treatments				Y																						
Biological-based therapies; Biologically based therapies					Y														Y							
Biological treatments																										
Biomedical Rx (non-specific)																										

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Biomedical treatment																										
Biometrics					A																					
Biotin																										
Blue green algae					A																					
Body-based relaxation therapies																										
Bolles Sensory Learning Method																										
Brain gym																									Y	
Brushing																										
Buspar; Buspirone				Y																						
Caffeine-Free Diet																										
Calcium																									A	
Calcium Butrate				Y																						
Carbamazepine; Tegretol; Carbatrol				Y	A																					
Carbohydrate-restricted diet																										
Carnitine																										
Carnosine				Y																						
Casein-Free Diet				Y				Y			Y															
Casein-Free or Dairy-Free Diet																										
Catnip																										
Cerebrolysin																									Y	
Chamomile					A																					
Chelation/antibiotic																			Y							
Chelation; Chelation for lead or mercury; Detox (chelation); Detoxification (chelation method)	Y	Y	Y	Y																		Y	Y	Y	Y	
Chemet; Succimer				Y																						
Child Care; Day care; Nursery school								Y			Y			Y												
Child development nursery																										
Chiropractic					Y													Y							Y	
Chiropractics/Herbal therapy																										
Chiropractic/osteopathy																			Y							
Chloral Hydrate																										
Chlorpromazine; Thorazine																										
Chocolate-Free Diet																										
Citalopram; Celexa				Y																						
Classroom aide; Educational assistant or teacher's aide													Y													
Clathration																										
Clomipramine; Anafranil				Y																						
Clonazepam																										

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Clonidine; Catapres				Y	A																					
Clonopin																										
Clozapine																										
Cod liver oil																										
Cognitive/behavioural therapy																										
Combined Programs																										Y
Communication therapies/systems								Y			Y															
Conductive Education																										
Conventional therapies					Y														Y							
Corn-restricted diet																										
Counselling																										
Cranial Electrical Stimulation								0			0															
Cranial Osteopathy																										
Cranial Vascular Therapy																										
Craniosacral Manipulations; Craniosacral Therapy					Y																			Y	Y	
Craniosacral treatment, myofascial release								0			Y															
Creon; Pancreatin				Y																						
Cytobuddies					A																					
Dairy and Wheat-Free Diet																										
Dairy, Wheat, and Yeast-Free Diet																										
Dairy-Free Diet																										
Dance Therapy					A																					
DDAVP; Desmopressin acetate				Y																						
Defeat Autism Now (DAN) approach						Y			Y																	
Delay Vaccinations																										
Denver approach						0			0																	
Desyrel; Trazodone				Y																						
Detoxification																										Y
Detrol; Tolterodine tartrate				Y																						
Developmental therapy																		Y								
Dextroamphetamine; Dexedrine/d-Amphetamine; Dextrostat				Y	A																					
Dietary Restriction (not gluten or casein)																										
Dietary Restrictions; Elimination diets; Diets; Special(ised) diets; Change in diet; Modified diets; Alternative diets					Y							Y						Y	Y			Y	Y	Y	Y	Y
Dietary supplements																										
Diets/supplements																										
Diflucan; Fluconazole				Y																						

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Digestive Enzymes																									A	
Dilantin; Phenyton sodium				Y																						
Dimethylethanolamine; DMAE																										
Dimethylglycine; DMG				Y																					A	
Dog Therapy								0			Y															
Dolphin Therapy; Dolphin Swim Therapy								0			0															
Doman-Delacato Patterning (Institute for Human Potential); Patterning																								Y		
Drug and diet therapies	Y	Y	Y																							
DTT; Discrete Trial Training; Lovaas; Discrete Trial Training (Lovaas)						0			Y						Y	Y										
Early Childhood Education																										
Early Intensive Behavioral Intervention																		Y								
Early Years Course																										
Early intervention services; Early-Intervention (Generic-not ASD specific)	Y	Y	Y	Y																						
Echinacea																										
Eden Program																										
Educational and therapy interventions																										
Educational techniques					Y																					
Educative treatments/Educational techniques																						Y				
EEG					A																					
EMG					A																					
Effexor; Venlafaxine				Y																						
Electro-aversive therapy (Faradic skin shock)																										
Energy Healer					A																					
Energy therapies					Y																					
Enzyme Potentiated Desensitization								0			Y															
Equestrian Therapy; Hippotherapy; Therapeutic Horseback Riding								Y			Y							Y		0	Y					
Essential Fatty Acids; Fatty Acids; Oils/fatty acids																									A	
Evening primrose oil					A																					
Exelon; Rivastigmine tartrate				Y																						
Extended Breastfeeding																										
Facilitated Communication								0			Y															
Famvir; Famciclovir				Y																						
Fast Forward; Fast ForWord								0			Y															
Feingold Diet				Y	A			0			Y															

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Fish oil					A																					
Flexyx neurotherapy system								0			0															
Floortime; Greenspan Model	Y	Y	Y	Y	A	Y			Y						Y			Y								
Fluoxetine; Prozac				Y	A																					
Fluvoxamine; Luvox				Y																						
Focalin					A																					
Folic Acid																										
Food supplements					Y																					
Gabapentin																										
Gammaglobulin; Immunoglobulin infusions; Intravenous immunoglobulin; IVIG																								Y		
Garlic; Garlic oil																										
Gastrointestinal medications																										
Gentle Teaching																										
Geodon; Ziprasidone				Y																						
Giant Steps																										
Ginkgo biloba					A																					
Ginseng					A																					
Glutathione peroxidase																										
Gluten and Casein-Free Diet																										
Gluten or Casein-Free Diet, or both	Y	Y	Y	Y																						
Gluten-Free Diet				Y				Y			Y															
Gluten/wheat-free diet				Y																						
Guanfacine; Tenex				Y	A																					
Guided Imagery/Hypnosis					Y																					
Haloperidol; Haldol				Y																						
Hanen; "More than Words" course																										
Healer/healing touch					Y																					
Herbal Remedies; Herbal medicine; Herbal products					Y													Y	A					Y		
Higashi					A																					
Holding Therapy								0			Y															
Homeopathy; Homeopathic remedies																			Y					Y		
Humanistic play treatment																										
Hydroxyzine																										
Hyperbaric Oxygen Treatment																							Y	Y		
Imipramine; Tofranil				Y																						
Immune System Therapy								0			Y															
Inclusion Supports; Support at mainstream school																										
Individual counselling/psychotherapy																	Y									

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Individual Tutoring																	Y									
Integrated Movement Therapy																										
Intensive behavioural intervention or ABA														Y												
Interactive Metronome																										
Irlen lenses																										
Iron																								A		
Joint Action Routines																										
Kaplan Visual Therapy (special eyeglasses)																										
Kava					A																					
Ketogenic diet																										
KidsPlex					A																					
Kinesiology																										
Lactose-free diet																										
Lamotrigine; Lamictal				Y																						
L-Carnosine Powder																										
LEAP																										
Lekotek therapy																										
Lexapro				Y																						
L-Glutamine																										
Lindamood Bell																										
Lithium				Y																						
Lorazepam; Ativan				Y																						
Low GI Diet																										
Magnesium																								A		
Magnetic Therapy																							Y			
Manganese																										
Manipulative and body-based therapies; Manipulations and body-based methods																			Y							
Manual Integrative Therapy																			A							
Massage belt or chair																										
Massage therapy/Shiatsu																										
Massage; Infant Massage; Bodywork					Y																			Y		
Massage/reflexology																			A							
Medical, dietary or CAM interventions																										
Medical services																										
Medical Treatment; Medical Procedures																										0
Medication; Medicine; Pharmaceuticals; Drugs; Medical agents					A			Y			Y			Y			Y					Y	Y			Y

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Medicine prescribed by a doctor; Prescription drugs; Prescription medication					Y													Y								
Medication and supplements								Y			Y															
Meditation/hypnosis; Meditation/relaxation response					Y														A							
Medication unrelated (e.g. Ventolin)																										
Mega-Vitamin Therapy; Megadose Vitamin; MegaVitamins																										
Melatonin				Y																						
Mental health services																										
Metabolic treatments																						Y				
Methylphenidate- Sustained Release																										
Methylphenidate; Ritalin; Metadate; Concerta				Y	A																					
Metoprolol; Lopressor; Toprol																										
Mind-body and psychological therapies																										
Mind-body interventions					Y														Y							
Milk Thistle																										
Mineral supplements																										
Mineral and vitamin supplements																										
Miralax; Polyethylene glycol				Y																						
Miscellaneous herbal medication				Y																						
Miscellaneous GI medication; Miscellaneous Gastro Intestinal medication				Y																						
Miscellaneous medication; Other medication	Y	Y	Y	Y																						
Miscellaneous- specific medication				Y																						
Mobile Therapy																										
Mood or behaviour medication																										
Mood Stabilisers	Y	Y	Y	Y																						
Moxibustion																			A							
Multi-disability services																										
Multisensory Environments (Snoezelen)																										
Music Therapy	Y	Y	Y	Y	A		Y	0	Y	Y	Y							Y		Y	Y	Y	Y	Y		
Musical Therapy																									Y	
Music and Dance therapy																										
Naltrexone																										
Naturopathy; Naturopathic remedies																										
Neural Therapy																										
Neurofeedback; Biofeedback	Y	Y	Y	Y	Y																				Y	
Neuroleptics																										
Neurontin				Y																						
No Additives or Preservatives					A																					

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Non-contact therapeutic touch					A																					
Non-specialist Nursery																										
Noradrenergic Agonists																										
Nonbiologicals																										
Norpramin; Desipramine				Y																						
Nortriptyline																										
Nutritional supplements																										
Nystatin				Y																						
Occupational Therapy	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y		Y	Y					
Olanzapine; Zyprexa				Y																						
Omega fatty acids/Omega-3 fatty acids/Omega-3 oil				Y	A																					
One-on-one aide or assistant; child's own aide															Y		Y									
Opiate Blockers																										
Options Program; Options Therapy	Y	Y	0	Y																						
Osteopathy; Osteopathic manipulation					Y																			0		
Other behavioural interventions (not EIBI)																		0								
Other CAM therapy																										
Other dietary supplements																								Y		
Other (non-specific) treatments																									Y	
Other skills based																									Y	
Paroxetine																										
Paxil; Seroxat				Y	A																					
Peanut-restricted diet																										
PECS; Picture Exchange Communication System	Y	Y	Y	Y	A			Y			Y											Y	Y			
Pemoline; Cylert					A																					
Pentoxifylline																										
Pepcid				Y																						
Pet therapy																										
Phenol-restricted diet																										
Phenytoin; Dilantin																										
Physical Therapy; Physiotherapy	Y	Y	Y	Y			Y	0	Y	Y	Y			Y	Y	Y		Y								
Physiological																										Y
Play therapy								Y			Y															
Playgroup																										
Playgroup (integrated)																										
Playgroup (specialised)																										
Pomadine																										
Positive Behavioural Support				Y																						

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Pragmatics Training																	Y									
Prayer; Prayer/Blessing																			Y							
Prayer/Shaman					Y																					
Prednisone				Y																						
Preschool																										
Pre-school communication group																										
Pressure and vestibular stimulation																										
Pressure and tactile stimulation																										
Pressure and vestibular and tactile stimulation																										
Probiotics																								A		
Propranolol; Inderal																										
Protein supplements																								A		
Psychiatric services																				0	Y					
Psychic healing					A																					
Psychoanalysis																										
Psychological/mental health services																										
Psychology/psychometry																										
Psychomotor therapy																						Y	Y			
Psychotherapy																										
Psychotropic Medication; Psychotropic drugs																										
Psychotropic or anticonvulsant medication																										
Psychotropic medication or vitamins for autism																										
Psychotropic medication or vitamins for autism or anticonvulsants																										
Pulmicort; Budesonide				Y																						
Pycnogenol					A																					
Pyridoxine																										
Qi Gong					A																					
Rapid Prompting																										
RDI (Relationship Development Intervention)																		Y								
Recreation therapy; recreational therapy																										
Reduced L-Glutathione																										
Reflexology																								Y		
Regular day care																		Y								
Reiki; Reike					A																					
Reiki/healing																								Y		
Relationship-based treatments																									Y	
Remeron; Mirtazapine				Y																						
Restores					A																					
Rhythmic entrainment interventions																										

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Risperidone; Risperdal				Y	A																					
Rolfing																										
Saccromyces bonlardii																										
Salicylate-restricted diet																										
Secretin				Y	Y			0			0							Y						Y		
Seizure-control medications				Y																						
Selenium																									A	
Self-Injurious Behavior Inhibiting System (SIBIS)																										
Senna				Y																						
Sensorimotor treatment																										
Sensory/motor therapies								Y			Y															
Sensory Integration; Sensory Integration Therapy	Y	Y	Y	Y	A			Y			Y						Y	Y	Y					Y		
Sensory Therapies					Y																					
Seroquel				Y																						
Sertraline; Zoloft				Y	A																					
Serzone; Nefazodone				Y																						
Shaman																										
Sign Language																										
Skills training based on principles of ABA																										
Skullcap					A																					
Social Skills Training	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y						Y			Y	Y	Y	Y			
Social Stories	Y	Y	Y	Y																						
Social Supports																										
Social therapies								Y			Y															
Spa/Hot Spring																			Y							
Special education																										Y
Special Exercises					Y																					
Specialised eye glasses								Y			Y															
Specialised preschool																		Y								
Special Therapy such as physical, occupational or speech therapy																										
Special treatments or approaches for ASD												Y														
Speech therapy; Speech-Language Therapy; Speech Pathology	Y	Y	Y	Y	A	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y	Y	Y	Y			
Spiritual healing					A																					
Sporanox																										
SSRI's																										
Standard Therapies																										Y

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Stimulants	Y	Y	Y	Y																						
St. John's Wort					A																					
Strawberry Extract																										
Sucrose-free diet																										
Sugar-restricted or sugar-free diet; avoidance of sugar				Y	A																					
Sumycin; Tetracycline				Y																						
Super Nu-Thera																										
Supplements								Y			Y															
Squeeze machine								0			0															
Swimming																		Y								
Tactile stimulation																										
Tai Chi					A																					
Taichi/ Reiki																			A							
Taurine																										
TEACCH	Y	Y	Y	Y	A	Y			Y			Y			Y							Y	Y			
Therapeutic listening																		0								
Thioridazine; Mellaril																										
Thioxanthene; Navane																										
Thymus Extract																										
TMG; Trimethylglycine				Y																				A		
Topiramate; Topamax				Y																						
Traditional Chinese Medicine; Chinese Medicine																			Y							
Traditional Neuroleptics																										
Transfer Factor																										
Tranquiliser																										
Tricyclic Antidepressants																										
Trileptal ; Oxcarbazepine				Y																						
Tryptophan																										
Tuina therapy																			A							
Tumbletots																										
Typical Neuroleptics																										
Vaccination Withdrawal; Withhold immunisations; No vaccinations																										
Vagal nerve stimulation; Vagus nerve stimulation					Y																					
Valerian					A																					
Valium; Diazepam				Y																						
Valproic Acid; Valproate; Divalproex; Depakote				Y	A																					
Van Dijk approach																										
Vancomycin; Vancoin				Y																						
Vegan Diet					A																					

Treatment/Intervention	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54
Vegetarian diet; Meat-free diet				Y																						
Vestibular stimulation																										
Vision Therapy																				Y	Y					
Visual communication strategies												Y														
Visual Integration Training																										
Visual Schedules																										
Visual training																										
Vitamin A																									A	
Vitamin B																										
Vitamin B12																									A	
Vitamin B12 and Magnesium																										
Vitamin B6					A																				A	
Vitamin B6 and Magnesium																										
Vitamin B6 and Magnesium and DMG																										
Vitamin C					A																				A	
Vitamin D																										
Vitamin E																									A	
Vitamins and nutritional supplements																										
Vitamins; Vitamin therapy; Vitamin supplements; Special Vitamins																		Y	Y			Y	Y	Y		Y
Vitamins/minerals; Vitamins and minerals					Y																				Y	
Vitamin or mineral supplements																			A							
Vitamins for Autism Only; Autism supplements																										
Watsu																										
Weight loss/get rid of toxic substances																			Y							
Weighted vest/blanket																										
Wellbutrin; Bupropion				Y	A																					
Wild oat seed					A																					
Wheat and Yeast-Free Diet																										
Wheat-free diet					A																					
White noise					A																					
Xanax				Y																						
Yeast-Free Diet					A																					
Yoga																									Y	
Yoga/dancing/relaxation																			A							
Zinc					A																				A	
Ziprasidone																										
Zyrtec				Y																						

Supplementary Table 1.

Intervention Use Reported in Studies Reviewed in Carlon, Stephenson, and Carter (2014b).

Part 3

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
AAC; Augmentative and alternative communication; Augmentative communication						2	0	1
ABA; Applied Behaviour Analysis; Behaviour therapy	Y	Y	Y	Y		15	1	1
Abilify; Aripiprazole						2	0	0
Academic tutoring						1	0	0
Acupuncture/Acupressure						1	0	0
Acupuncture						4	3	0
Adaptive Physical Education						3	0	0
Adderall; Amphetamine salts						4	0	2
Allegra; Fexofenadine						2	0	0
Allergen-restricted diet						2	0	0
Alpha Agonists						2	0	0
Alpha Lipoic Acid						1	0	0
Alternative/complementary therapy; Complementary and alternative therapies; CAM; Biological therapies						10	0	1
Alternative therapies/medicine; Alternative therapies	Y	Y	Y			2	0	0
Alternative medical systems						3	0	0
Alternative treatments						3	0	0
Amino acids						0	0	1
Amantadine; Symmetrel						4	0	0
Ambrotose						2	0	0
Amphetamines						1	0	0
Animal therapy						2	0	0
Antibiotics						1	0	0
Anticholinergics						2	0	0
Anticonvulsants; Anti-epileptics; AEDs						5	0	0
Antidepressants						9	0	0
Antifungals						2	0	0
Antihistamine						2	0	0
Antihypertensives						4	0	0
Anti-infectives						1	0	0
Antiparkinson/antispasmodic; Antiparkinsonian agents						2	0	0
Antipsychotics						4	0	0
Anti-Yeast Treatments						1	0	0
Anthroposophic medicine						1	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Anxiolytics						3	1	0
Anxiolytics/sedatives/hypnotics						4	0	0
Any Agent (psychotropic or other)						3	0	0
Aromatherapy						2	0	0
Artichoke						1	0	0
Art therapy						0	0	1
Assistive Technology; Assisted Technology						2	0	0
Atomoxetine; Strattera						3	0	0
Atypical antipsychotics						2	0	0
Atypical Neuroleptics						2	0	0
Auditory Integration Training- Berard Method						1	0	0
Auditory Integration Training; Auditory Integration Therapy						14	0	0
Auditory Integration Training- Tomatis Method; Tomatis program						2	0	0
Auditory/sound treatment				Y		1	0	0
Aversive therapy						0	2	0
Avoidance of red dyes; Elimination of dyes						2	0	0
Axid/Nizatidine						2	0	0
Ayurvedic Medicine						0	0	1
Azrin 24-hour toilet training						1	0	0
Baudhuin Preschool						1	0	0
Bee Pollen						1	0	0
Behavioural/educational/alternative therapies						1	0	0
Behavioural optometrist						1	0	0
Behaviour management or parent training						1	0	0
Behaviour supports						1	0	0
Behaviour therapist						1	0	0
Benadryl; Diphenhydramine						3	0	0
Benztropine; Cogentin						4	0	0
Beta Blockers						2	0	0
Bethanechol						3	0	0
Bio-energy and Scio						1	0	0
Biological and dietary treatments						1	0	0
Biological-based therapies; Biologically based therapies						3	0	0
Biological treatments						1	0	0
Biomedical Rx (non-specific)				Y		1	0	0
Biomedical treatment						1	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Biometrics						0	0	1
Biotin						1	0	0
Blue green algae						0	0	1
Body-based relaxation therapies						1	0	0
Bolles Sensory Learning Method						1	0	0
Brain gym						1	0	0
Brushing						1	0	0
Buspar; Buspirone						8	0	0
Caffeine-Free Diet						1	0	0
Calcium						1	0	3
Calcium Butrate						2	0	0
Carbamazepine; Tegretol; Carbatrol						7	0	2
Carbohydrate-restricted diet						1	0	0
Carnitine						1	0	0
Carnosine						2	0	0
Casein-Free Diet				Y		12	0	0
Casein-Free or Dairy-Free Diet						1	0	0
Catnip						1	0	0
Cerebrolysin						1	0	0
Chamomile						0	0	1
Chelation/antibiotic						1	0	0
Chelation; Chelation for lead or mercury; Detox (chelation); Detoxification (chelation method)				Y		11	0	0
Chemet; Succimer						2	0	0
Child Care; Day care; Nursery school				Y		5	0	0
Child development nursery						0	0	1
Chiropractic				Y		8	0	1
Chiropractics/Herbal therapy						1	0	0
Chiropractic/osteopathy						1	0	0
Chloral Hydrate						1	0	0
Chlorpromazine; Thorazine						2	0	0
Chocolate-Free Diet						1	0	0
Citalopram; Celexa						3	0	0
Classroom aide; Educational assistant or teacher's aide						3	0	0
Clathration						1	0	0
Clomipramine; Anafranil						4	0	0
Clonazepam						3	0	0
Clonidine; Catapres						9	0	1
Clonopin						1	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Clozapine						1	0	0
Cod liver oil						2	0	0
Cognitive/behavioural therapy						1	0	0
Combined Programs	Y	Y	Y			2	0	0
Communication therapies/systems						2	0	0
Conductive Education						1	0	0
Conventional therapies						2	0	0
Corn-restricted diet						1	0	0
Counselling						1	0	2
Cranial Electrical Stimulation						0	2	0
Cranial Osteopathy						1	0	0
Cranial Vascular Therapy						1	0	0
Craniosacral Manipulations; Craniosacral Therapy						4	0	2
Craniosacral treatment, myofacial release						1	1	0
Creon; Pancreatin						2	0	0
Cytobuddies						0	0	1
Dairy and Wheat-Free Diet						1	0	0
Dairy, Wheat, and Yeast-Free Diet						1	0	0
Dairy-Free Diet						3	0	0
Dance Therapy						1	0	1
DDAVP; Desmopressin acetate						2	0	0
Defeat Autism Now (DAN) approach						2	0	0
Delay Vaccinations						1	0	0
Denver approach						0	2	0
Desyrel; Trazodone						2	0	0
Detoxification	Y	Y	0			2	0	0
Detrol; Tolterodine tartrate						2	0	0
Developmental therapy						1	0	0
Dextroamphetamine; Dexedrine/d-Amphetamine; Dextrostat						9	0	1
Dietary Restriction (not gluten or casein)				Y		2	0	0
Dietary Restrictions; Elimination diets; Diets; Special(ised) diets; Change in diet; Modified diets; Alternative diets	Y	Y	Y			16	0	0
Dietary supplements						1	0	0
Diets/supplements						1	0	0
Diflucan; Fluconazole						3	0	0
Digestive Enzymes						3	0	1
Dilantin; Phenyton sodium						2	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Dimethylethanolamine; DMAE						2	0	0
Dimethylglycine; DMG						9	0	1
Dog Therapy						1	1	0
Dolphin Therapy; Dolphin Swim Therapy						2	2	1
Doman-Delacato Patterning (Institute for Human Potential); Patterning						2	0	1
Drug and diet therapies						1	0	0
DTT; Discrete Trial Training; Lovaas; Discrete Trial Training (Lovaas)						6	1	0
Early Childhood Education						0	0	1
Early Intensive Behavioral Intervention						2	0	0
Early Years Course						1	0	0
Early intervention services; Early-Intervention (Generic- not ASD specific)				Y		3	0	0
Echinacea						0	1	0
Eden Program						1	0	0
Educational and therapy interventions				Y		1	0	0
Educational techniques						1	0	0
Educative treatments/Educational techniques						1	0	0
EEG						0	0	1
EMG						0	0	1
Effexor; Venlafaxine						2	0	0
Electro-aversive therapy (Faradic skin shock)						1	0	0
Energy Healer						1	0	1
Energy therapies						1	0	0
Enzyme Potentiated Desensitization						1	1	0
Equestrian Therapy; Hippotherapy; Therapeutic Horseback Riding						8	0	1
Essential Fatty Acids; Fatty Acids; Oils/fatty acids				Y		4	0	1
Evening primrose oil						0	0	1
Exelon; Rivastigmine tartrate						2	0	0
Extended Breastfeeding						1	0	0
Facilitated Communication						5	1	0
Famvir; Fanciclovir						2	0	0
Fast Forward; Fast ForWord						3	1	0
Feingold Diet						5	1	2
Fish oil						0	0	1
Flexyx neurotherapy system						0	2	0
Floortime; Greenspan Model				Y		10	0	2
Fluoxetine; Prozac						9	0	2
Fluvoxamine; Luvox						5	0	0
Focalin						0	0	1

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Folic Acid						1	0	2
Food supplements						1	0	0
Gabapentin						1	0	0
Gammaglobulin; Immunoglobulin infusions; Intravenous immunoglobulin; IVIG						4	0	0
Garlic; Garlic oil						1	1	0
Gastrointestinal medications						1	0	0
Gentle Teaching						2	0	0
Geodon; Ziprasidone						2	0	0
Giant Steps				Y		2	0	0
Gingko biloba						0	0	1
Ginseng						0	0	1
Glutathione peroxidase						1	0	0
Gluten and Casein-Free Diet				Y		4	0	0
Gluten or Casein-Free Diet, or both						2	0	0
Gluten-Free Diet				Y		11	0	0
Gluten/wheat-free diet						3	0	0
Guanfacine; Tenex						5	0	1
Guided Imagery/Hypnosis						1	0	0
Haloperidol; Haldol						5	0	1
Hanen; "More than Words" course				Y		2	0	0
Healer/healing touch						1	0	0
Herbal Remedies; Herbal medicine; Herbal products						3	0	2
Higashi						2	0	1
Holding Therapy						2	2	1
Homeopathy; Homeopathic remedies				Y		9	0	1
Humanistic play treatment						1	0	0
Hydroxyzine						1	0	0
Hyperbaric Oxygen Treatment						2	0	2
Imipramine; Tofranil						6	0	0
Immune System Therapy						1	1	0
Inclusion Supports; Support at mainstream school						2	0	0
Individual counselling/psychotherapy						1	0	0
Individual Tutoring						2	0	0
Integrated Movement Therapy						1	0	0
Intensive behavioural intervention or ABA						1	0	0
Interactive Metronome						1	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Irlen lenses						1	0	0
Iron						0	0	1
Joint Action Routines						1	0	0
Kaplan Visual Therapy (special eyeglasses)						1	0	0
Kava						0	0	1
Ketogenic diet						1	0	0
KidsPlex						0	0	1
Kinesiology				Y		1	0	0
Lactose-free diet						0	0	1
Lamotrigine; Lamictal						3	0	0
L-Carnosine Powder						1	0	0
LEAP						1	0	0
Lekotek therapy						1	0	0
Lexapro						2	0	0
L-Glutamine						1	0	0
Lindamood Bell						1	0	0
Lithium						8	0	0
Lorazepam; Ativan						4	0	0
Low GI Diet						1	0	0
Magnesium						3	0	1
Magnetic Therapy						1	0	0
Manganese						1	0	0
Manipulative and body-based therapies; Manipulations and body-based methods						2	0	0
Manual Integrative Therapy						1	0	0
Massage belt or chair						0	0	1
Massage therapy/Shiatsu						0	0	1
Massage; Infant Massage; Bodywork						6	0	0
Massage/reflexology						0	0	1
Medical, dietary or CAM interventions				Y		1	0	0
Medical services						0	0	1
Medical Treatment; Medical Procedures						1	1	1
Medication; Medicine; Pharmaceuticals; Drugs; Medical agents	Y	Y	Y			14	0	1
Medicine prescribed by a doctor; Prescription drugs; Prescription medication						3	0	0
Medication and supplements						2	0	0
Meditation/hypnosis; Meditation/relaxation response						1	0	1
Medication unrelated (e.g. Ventolin)				Y		1	0	0
Mega-Vitamin Therapy; Megadose Vitamin; MegaVitamins						6	0	0
Melatonin						9	0	1

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Mental health services					Y	1	0	0
Metabolic treatments						1	0	0
Methylphenidate- Sustained Release						2	0	0
Methylphenidate; Ritalin; Metadate; Concerta						9	0	2
Metoprolol; Lopressor; Toprol						1	0	0
Mind-body and psychological therapies						1	0	0
Mind-body interventions						2	0	0
Milk Thistle						1	0	0
Mineral supplements						1	0	1
Mineral and vitamin supplements						1	0	0
Miralax; Poyethylene glycol						2	0	0
Miscellaneous herbal medication						2	0	0
Miscellaneous GI medication; Miscellaneous Gastro Intestinal medication						2	0	0
Miscellaneous medication; Other medication						5	0	0
Miscellaneous- specific medication						2	0	0
Mobile Therapy						1	0	0
Mood or behaviour medication				0		0	1	0
Mood Stabilisers						7	0	0
Moxibustion						0	0	1
Multi-disability services						1	0	0
Multisensory Environments (Snoezelen)						1	0	0
Music Therapy				Y		15	0	2
Musical Therapy						1	0	0
Music and Dance therapy						1	0	0
Naltrexone						1	0	0
Naturopathy; Naturopathic remedies				Y		1	1	0
Neural Therapy						1	0	0
Neurofeedback; Biofeedback						5	0	0
Neuroleptics						2	0	0
Neurontin						2	0	1
No Additives or Preservatives						1	0	1
Non-contact therapeutic touch						0	0	1
Non-specialist Nursery						0	0	1
Noradrenergic Agonists						1	0	0
Nonbiologicals						1	0	0
Norpramin; Desipramine						2	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Nortriptyline						1	0	0
Nutritional supplements						2	0	0
Nystatin						3	0	0
Occupational Therapy				Y		20	0	1
Olanzapine; Zyprexa						6	0	0
Omega fatty acids/Omega-3 fatty acids/Omega-3 oil						4	0	1
One-on-one aide or assistant; child's own aide						2	0	0
Opiate Blockers						3	1	0
Options Program; Options Therapy						5	0	1
Osteopathy; Osteopathic manipulation						2	1	0
Other behavioural interventions (not EIBI)						0	1	0
Other CAM therapy						1	0	0
Other dietary supplements						1	0	0
Other (non-specific) treatments	Y	Y	Y			4	0	0
Other skills based	Y	Y	Y			5	0	0
Paroxetine						3	0	0
Paxil; Seroxat						4	0	1
Peanut-restricted diet						1	0	0
PECS; Picture Exchange Communication System						9	0	1
Pemoline; Cylert						2	0	1
Pentoxifylline						1	0	0
Pepcid						3	0	0
Pet therapy						1	0	0
Phenol-restricted diet						1	0	0
Phenytoin; Dilantin						2	0	0
Physical Therapy; Physiotherapy						13	0	2
Physiological	Y	Y	Y			2	0	0
Play therapy						3	0	0
Playgroup				Y		1	0	1
Playgroup (integrated)						1	0	0
Playgroup (specialised)						0	0	1
Pomadine						1	0	0
Positive Behavioural Support						1	0	0
Pragmatics Training						1	0	0
Prayer; Prayer/Blessing						2	0	0
Prayer/Shaman						1	0	0
Prednisone						2	0	0
Preschool				Y		4	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Pre-school communication group						0	0	1
Pressure and vestibular stimulation						1	0	0
Pressure and tactile stimulation						1	0	0
Pressure and vestibular and tactile stimulation						1	0	0
Probiotics						3	0	1
Propranolol; Inderal						5	0	0
Protein supplements						0	0	1
Psychiatric services						1	0	0
Psychic healing						0	0	1
Psychoanalysis						1	0	0
Psychological/mental health services						1	0	0
Psychology/psychometry						0	0	1
Psychomotor therapy						2	0	0
Psychotherapy						1	0	0
Psychotropic Medication; Psychotropic drugs						5	0	0
Psychotropic or anticonvulsant medication						3	0	0
Psychotropic medication or vitamins for autism						3	0	0
Psychotropic medication or vitamins for autism or anticonvulsants						3	0	0
Pulmicort; Budesonide						2	0	0
Pycnogenol						0	0	1
Pyridoxine						1	0	0
Qi Gong						0	0	1
Rapid Prompting						1	0	0
RDI (Relationship Development Intervention)				Y		2	0	0
Recreation therapy; recreational therapy						1	0	1
Reduced L-Glutathione						1	0	0
Reflexology						1	0	0
Regular day care						1	0	0
Reiki; Reike						2	0	1
Reiki/healing						1	0	0
Relationship-based treatments	Y	Y	Y			2	0	0
Remeron; Mirtazapine						2	0	0
Restores						0	0	1
Rhythmic entrainment interventions						1	0	0
Risperidone; Risperdal						8	0	2
Rolfing						1	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Saccromyces bonlardii						1	0	0
Salicylate-restricted diet						1	0	0
Secretin						12	3	0
Seizure-control medications						2	0	0
Selenium						1	0	1
Self-Injurious Behavior Inhibiting System (SIBIS)						1	0	0
Senna						2	0	0
Sensorimotor treatment						1	0	0
Sensory/motor therapies						2	0	0
Sensory Integration; Sensory Integration Therapy						16	0	1
Sensory Therapies						1	0	0
Seroquel						2	0	1
Sertraline; Zoloft						7	0	2
Serzone; Nefazodone						2	0	0
Shaman						1	0	0
Sign Language						1	0	0
Skills training based on principles of ABA						1	0	0
Skullcap						0	0	1
Social Skills Training						9	0	0
Social Stories						4	0	0
Social Supports						1	0	0
Social therapies						2	0	0
Spa/Hot Spring						1	0	0
Special education	Y	Y	Y			1	0	0
Special Exercises						1	0	0
Specialised eye glasses						2	0	0
Specialised preschool						1	0	0
Special Therapy such as physical, occupational or speech therapy						1	0	0
Special treatments or approaches for ASD						1	0	0
Speech therapy; Speech-Language Therapy; Speech Pathology				Y	Y	26	0	2
Spiritual healing						1	0	1
Sporanox						1	0	0
SSRI's						1	0	0
Standard Therapies	Y	Y	Y			2	0	0
Stimulants						8	0	0
St. John's Wort						0	0	1
Strawberry Extract						0	1	0
Sucrose-free diet						1	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Sugar-restricted or sugar-free diet; avoidance of sugar						5	0	1
Sumycin; Tetracycline						2	0	0
Super Nu-Thera						3	0	0
Supplements						2	0	0
Squeeze machine						0	2	0
Swimming				Y		2	0	0
Tactile stimulation						1	0	0
Tai Chi						0	0	1
Taichi/ Reiki						0	0	1
Taurine						1	0	0
TEACCH						11	0	1
Therapeutic listening						0	1	0
Thioridazine; Mellaril						5	0	0
Thioxanthene; Navane						0	0	1
Thymus Extract						1	0	0
TMG; Trimethylglycine						2	0	1
Topiramate; Topamax						3	0	0
Traditional Chinese Medicine; Chinese Medicine						2	0	0
Traditional Neuroleptics						1	0	0
Transfer Factor						1	0	0
Tranquiliser						0	0	2
Tricyclic Antidepressants						1	0	0
Trileptal ; Oxcarbazepine						2	0	0
Tryptophan						1	0	0
Tuina therapy						0	0	1
Tumbletots						0	0	1
Typical Neuroleptics						1	0	0
Vaccination Withdrawal; Withhold immunisations; No vaccinations				Y		3	0	0
Vagal nerve stimulation; Vagus nerve stimulation						2	0	0
Valerian						0	0	1
Valium; Diazepam						4	0	0
Valproic Acid; Valproate; Divalproex; Depakote						8	0	1
Van Dijk approach						1	0	0
Vancomycin; Vancin						3	0	0
Vegan Diet						0	0	1
Vegetarian diet; Meat-free diet						2	0	0

Treatment/Intervention	55	56	57	58	59	Number of studies reporting use	Number of studies reporting no use (0% usage rates)	Number of studies asking about use only (actual use unknown)
Vestibular stimulation						1	0	0
Vision Therapy						1	0	0
Visual communication strategies						1	0	0
Visual Integration Training						1	0	0
Visual Schedules						1	0	0
Visual training						1	0	0
Vitamin A						1	0	2
Vitamin B						1	0	0
Vitamin B12						0	0	2
Vitamin B12 and Magnesium						1	0	0
Vitamin B6						5	0	3
Vitamin B6 and Magnesium						5	0	0
Vitamin B6 and Magnesium and DMG						1	0	0
Vitamin C						2	0	4
Vitamin D						0	1	0
Vitamin E						0	0	2
Vitamins and nutritional supplements						1	0	0
Vitamins; Vitamin therapy; Vitamin supplements; Special Vitamins	Y	Y	Y	Y		14	0	1
Vitamins/minerals; vitamins and minerals						2	0	0
Vitamin or mineral supplements						0	0	1
Vitamins for Autism Only; Autism supplements						3	0	0
Watsu						1	0	0
Weight loss/get rid of toxic substances						1	0	0
Weighted vest/blanket						1	0	0
Wellbutrin; Bupropion						2	0	1
Wild oat seed						0	0	1
Wheat and Yeast-Free Diet						1	0	0
Wheat-free diet						1	0	1
White noise						0	0	1
Xanax						3	0	0
Yeast-Free Diet						4	0	1
Yoga						1	0	0
Yoga/dancing/relaxation						0	0	1
Zinc						1	0	2
Ziprasidone						1	0	0
Zyrtec						2	0	0

APPENDIX 2

Supplementary Table 2.

*Reported Rates of Use of Interventions Frequently Reported Across Studies Reviewed in
Carlon, Stephenson, and Carter (2014b)*

**Note: Due to the size of the table, it has been presented in 3 parts.*

A key to the numbers representing studies and the symbols used in the table is presented
before the table.

Supplementary Table 2

Reported Rates of Use of Interventions Frequently Reported Across Studies Reviewed in Carlson, Stephenson, and Carter (2014b).

Key

- | | |
|--|--|
| 1 = Aman et al., 1995 | 30 = Goin-Kochel et al. 2007(for those with Asperger's syndrome) |
| 2 = Kohler, 1999 | 31 = Goin-Kochel et al. 2007 (for those with PDD-NOS) |
| 3 = Martin et al, 1999 | 32 = Goin-Kochel et al. 2009 |
| 4 = Study 1 in Smith & Antolovich, 2000 | 33 = Hanson et al., 2007 |
| 5 = Study 2 in Smith & Antolovich, 2000 | 34 = Thomas, Ellis, et al., 2007*(overall use) |
| 6 = King et al, 2000 | 35 = Thomas, Ellis, et al., 2007* (use at school) |
| 7 = Erba, 2000 | 36 = Thomas, Ellis, et al., 2007* (use outside of school) |
| 8 = Boyd & Corley, 2001 | 37 = Thomas, Morrissey, et al., 2007 (overall use) |
| 9 = LeGrice & McMenamin, 2001 | 38 = Thomas, Morrissey, et al., 2007 (use at school) |
| 10 = Langworthy-Lam, 2002 | 39 = Thomas, Morrissey, et al., 2007(use outside of school) |
| 11 = Aman et al., 2003 | 40 = Cassidy et al., 2008 |
| 12 = Levy et al., 2003 | 41 = McLennan et al., 2008- (use at school, n=150) |
| 13 = Levine et al., 2004 (overall use) | 42 = McLennan et al., 2008- (overall use, n=235) |
| 14 = Levine et al., 2004- (use in school) | 43 = Reffert, 2008 (use at school) |
| 15 = Mansell & Morris, 2004 | 44 = Reffert, 2008 (use outside of school) |
| 16 = Hume, Bellini, & Pratt, 2005 | 45 = Robinson, 2008 |
| 17 = Witwer & Lecavalier, 2005 | 46 = Reghr & Feldman, 2009 |
| 18 = Green et al., 2006 | 47 = Wong, 2009 |
| 19 = Gurney et al, 2006 | 48 = Akshoomoff et al., 2010- at school |
| 20 = McConachie & Robinson, 2006 | 49 = Akshoomoff et al., 2010- outside school |
| 21 = Renty & Roeyers, 2006 | 50 = Al Anbar et al., 2010 |
| 22 = Harrington, Patrick et al, 2006 | 51 = Dardennes et al., 2011 |
| 23 =Harrington, Rosen et al, 2006 (for all diagnostic groups) | 52 = Christon, Mackintosh, & Myers, 2010 |
| 24 = Harrington, Rosen et al, 2006 (for those with autism) | 53 = Senel, 2010 |
| 25 = Harrington, Rosen et al, 2006 (for those with PDD-NOS) | 54 = Bowker et al., 2011- all diagnostic groups |
| 26 = Harrington, Rosen et al, 2006 (for those with Asperger's syndrome) | 55 = Bowker et al., 2011- autistic disorder |
| 27 = Wong & Smith, 2006 | 56 = Bowker et al., 2011- PDD-NOS |
| 28 = Goin-Kochel et al. 2007 (for all diagnostic groups) | 57 = Bowker et al., 2011- Asperger's Disorder |
| 29 = Goin-Kochel et al. 2007 (for those with autism) | 58 = Carter et al., 2011 |
| | 59 = Shattuck, 2011 |
| | R = Use of the intervention was reported, but rates of use were unavailable |

*Only data for children aged 9-11, not presented in Thomas, Morrissey, et al., 2007.

Supplementary Table 2

Reported Rates of Use of Interventions Frequently Reported Across Studies Reviewed in Carlon, Stephenson, and Carter (2014b).

Part 1

Intervention		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
ABA; Applied Behaviour Analysis; Behaviour therapy	Current use				100	100													36.4	
	Past use																		22.7	
	Lifetime use				26.4 ^b					80										
Alternative/complementary therapy; Complementary and alternative therapies; CAM; Biological therapies	Current use	R																		
	Past use																			
	Lifetime use												31.7							
Antidepressants	Current use	6.1		32.1							21.7	21.6						21.2		
	Past use																			
	Lifetime use				19.8															
Auditory Integration Training; Auditory Integration Therapy	Current use																		9.1	
	Past use																		21	
	Lifetime use				29.8			10		20			R							
Casein-Free Diet	Current use																	0.8	26.8	
	Past use																		18.5	
	Lifetime use				6.6			19.2					R							
Chelation; Chelation for lead or mercury; Detox (chelation); Detoxification (chelation method)	Current use																		7.4	
	Past use																		7.8	
	Lifetime use												1.5							
Dietary Restrictions; Elimination diets; Diets; Special(ised) diets; Change in diet; Modified diets; Alternative diets	Current use																	15.1	26.8	
	Past use																		R	
	Lifetime use				49.6	29.2										35				
Dimethylglycine; DMG	Current use	5									2.7	R						1.7	14	
	Past use																		27.4	
	Lifetime use							25.5												
Floortime; Greenspan Model	Current use																		13	
	Past use																		16.3	
	Lifetime use				9.9												20.5			
Gluten-Free Diet	Current use																	1.7	23.1	
	Past use																		21.7	
	Lifetime use							17					R							
Homeopathy; Homeopathic remedies	Current use																		10.2	
	Past use																		12.1	
	Lifetime use							1.5								5.5				

Intervention		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Medication; Medicine; Pharmaceuticals	Current use	53.3 ^a		55								65 ^a							52.5	
	Past use																		R	
	Lifetime use			68.8				3.7		20										
Melatonin	Current use										2.9	3.4						2.8	10.8	
	Past use																		14.6	
	Lifetime use												3							
Music Therapy	Current use																		16	
	Past use																		18.5	
	Lifetime use				3.3					20							23.1			
Occupational Therapy	Current use		48				56		13					32.2	26				R	
	Past use								50											
	Lifetime use				4.1			69.7		40						39	83.1			
PECS; Picture Exchange Communication System	Current use																		27.6	
	Past use																		31.1	
	Lifetime use							45								8				
Physical Therapy; Physiotherapy	Current use		8											17.3	13.7				R	
	Past use																			
	Lifetime use				1.7			25.1									29.7			
Secretin	Current use										0							2.8	1.6	
	Past use																		11.3	
	Lifetime use							14.5					6			10				
Sensory Integration; Sensory Integration Therapy	Current use																		38.2	
	Past use																		33.2	
	Lifetime use				56.2	41.7		42.8									40			
Social Skills Training	Current use																			
	Past use																			
	Lifetime use							44.3												
Speech therapy; Speech-Language Therapy; Speech Pathology	Current use		88				72		63					74.6	73.1				70	
	Past use								56										23.2	
	Lifetime use				85.1	79.2		90		40						87	89.2			
TEACCH	Current use																		15.7	
	Past use																		14.9	
	Lifetime use							39.4								21				
Vitamins; Vitamin therapy; Vitamin supplements; Special Vitamins	Current use	R									R	R						17.3	42.6	
	Past use																		R	
	Lifetime use				R	45.8							12.5							

^aIncluding vitamins for autism; ^bNo behavioural interventions in addition to the Early Intensive Behavioural Intervention

Supplementary Table 2

*Reported Rates of Use of Interventions Frequently Reported Across Studies Reviewed in Carlon, Stephenson, and Carter (2014b).**Part 2*

Intervention		20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40
ABA; Applied Behaviour Analysis; Behaviour therapy	Current use									33	40.2	20.4	40			9			17			R
	Past use																					
	Lifetime use									47	55.2	34.9	51.3	47								
Alternative/complementary therapy; Complementary and alternative therapies; CAM; Biological therapies	Current use																	R			R	
	Past use																					
	Lifetime use			R	92	R	R	R	52						74							
Antidepressants	Current use									15.7	11.9	24.8	17.5									
	Past use																					
	Lifetime use			37						22.1	18.9	29.2	23.8	28.4								
Auditory Integration Training; Auditory Integration Therapy	Current use									5.4	5.3	5	9.6					4			3	
	Past use																					
	Lifetime use			23						18.4	22.5	15.7	16.4	18.4	2							
Casein-Free Diet	Current use								12									6			12	
	Past use								8													
	Lifetime use			60	50	56.8	51.7	13						R								
Chelation; Chelation for lead or mercury; Detox (chelation); Detoxification (chelation method)	Current use									2.9	4.5	0	2.9									
	Past use																					
	Lifetime use			13	8.1	5.4	13.8	0		6.7	9	4.9	4.3	6.7								
Dietary Restrictions; Elimination diets; Diets; Special(ised) diets; Change in diet; Modified diets; Alternative diets	Current use																					R
	Past use																					
	Lifetime use			69					R						38							
Dimethylglycine; DMG	Current use																					
	Past use																					
	Lifetime use			37						R				R								
Floortime; Greenspan Model	Current use									15	21	5.1	19.7			5			10			
	Past use																					
	Lifetime use									26.9	33.7	18.4	31.5	26.9								
Gluten-Free Diet	Current use								18									6			10	
	Past use								12													
	Lifetime use			66	52.7	56.8	55.2	25						R								
Homeopathy; Homeopathic remedies	Current use								2													
	Past use								2													
	Lifetime use			3	16.2	18.9	17.2	0														

Intervention		20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40
Medication; Medicine; Pharmaceuticals	Current use																	68			40	
	Past use																					
	Lifetime use			53																		
Melatonin	Current use								8													
	Past use								8													
	Lifetime use				21.6	18.9	24.1	25		R				R								
Music Therapy	Current use								2	15.7	21.3	9.1	18.6				6	0	R	7	6	
	Past use								2													
	Lifetime use									26.9	36.4	13	27.4	26.9								
Occupational Therapy	Current use									52.6	67.2	29.6	63.6			R	42	11	R	64	14	
	Past use																					
	Lifetime use									75.4	85.8	56.2	85.9	75.4								
PECS; Picture Exchange Communication System	Current use									31.9	48.1	5.1	32.9					10			23	
	Past use																					
	Lifetime use									48.2	68	10.1	53.5	48.2								
Physical Therapy; Physiotherapy	Current use									15.4	20.4	6.3	22.5				6	0	R	11	2	
	Past use																					
	Lifetime use									30.5	38.5	22.2	31.5	30.5								
Secretin	Current use																	0			0	
	Past use																					
	Lifetime use			34	9.5	8.1	10.3	13		R				R	8							
Sensory Integration; Sensory Integration Therapy	Current use								12	37.4	46.9	22.4	53.5					12			21	
	Past use								12													
	Lifetime use			3	50	48.6	51.7	50		53.2	62.5	36.7	70.3	53.2								
Social Skills Training	Current use									43	44.3	59.8	49.3			R	46	24	R	28	12	
	Past use																					
	Lifetime use									50.9	48.1	73.5	58.3	50.9								
Speech therapy; Speech-Language Therapy; Speech Pathology	Current use	78								64.1	84.4	36.8	76.4				65	10		83	19	92.2
	Past use	R																				
	Lifetime use									84.1	95.3	66.3	94.8	84.1								
TEACCH	Current use									11.9	19	4.2	8.5			62			55			R
	Past use																					
	Lifetime use									18.4	27.5	9.4	12.7	18.4								
Vitamins; Vitamin therapy; Vitamin supplements; Special Vitamins	Current use																					
	Past use																					
	Lifetime use			60					R													

Supplementary Table 2

Reported Rates of Use of Interventions Frequently Reported Across Studies Reviewed in Carlon, Stephenson, and Carter (2014b).

Part 3

Intervention		41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59
ABA; Applied Behaviour Analysis; Behaviour therapy	Current use			17.1	37.1			7.5			40.4	39.7			37	57.4	38.2	4.5	11.9	
	Past use														12.1				3.6	
	Lifetime use						0 ^b													
Alternative/complementary therapy; Complementary and alternative therapies; CAM; Biological therapies	Current use							40.8					51							
	Past use																			
	Lifetime use												71	R						
Antidepressants	Current use																			
	Past use																			
	Lifetime use																			
Auditory Integration Training; Auditory Integration Therapy	Current use												3.6							
	Past use																			
	Lifetime use						4.3						16.1	10.5						
Casein-Free Diet	Current use																		29.8	
	Past use																			
	Lifetime use																			
Chelation; Chelation for lead or mercury; Detox (chelation); Detoxification (chelation method)	Current use										6.7	6.4	5.2						2.4	
	Past use																			
	Lifetime use												10.9	50						
Dietary Restrictions; Elimination diets; Diets; Special(ised) diets; Change in diet; Modified diets; Alternative diets	Current use							2.5			19.1	19.2	14.1		13.7	50.4	43.6	6		
	Past use														19.2					
	Lifetime use						56.5						29.4	79						
Dimethylglycine; DMG	Current use																			
	Past use																			
	Lifetime use																			
Floortime; Greenspan Model	Current use			2.9															3.6	
	Past use																		1.2	
	Lifetime use						8.7													
Gluten-Free Diet	Current use																		31	
	Past use																			
	Lifetime use																			
Homeopathy; Homeopathic remedies	Current use							5											7.1	
	Past use																			
	Lifetime use													10.5						

Intervention		41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59
Medication; Medicine; Pharmaceuticals	Current use		17								27	26.9			14.6	45.4	39	15.6		
	Past use														19.9					
	Lifetime use					54.9														
Melatonin	Current use																			
	Past use																			
	Lifetime use																			
Music Therapy	Current use								7	1	13.5	11.5	7.7						7.1	
	Past use																		1.2	
	Lifetime use						8.7													
Occupational Therapy	Current use	73	78	60	62.9				59	17									33.3	
	Past use																		21.4	
	Lifetime use					92.2	52.2													
PECS; Picture Exchange Communication System	Current use										24.7	25.6								
	Past use																			
	Lifetime use																			
Physical Therapy; Physiotherapy	Current use		14	25.7	17.1															
	Past use																			
	Lifetime use						13													
Secretin	Current use												0.4							
	Past use																			
	Lifetime use						13						6.5							
Sensory Integration; Sensory Integration Therapy	Current use							42.5												
	Past use																			
	Lifetime use					53.8	43.5							60.5						
Social Skills Training	Current use								21	34	21.3	19.2								
	Past use																			
	Lifetime use					73.1														
Speech therapy; Speech-Language Therapy; Speech Pathology	Current use	78	88	71.4	65.7				76	4	R	R							61.9	9.1
	Past use																		42.9	
	Lifetime use					90.4	69.6													
TEACCH	Current use			14.3							38.2	38.5								
	Past use																			
	Lifetime use																			
Vitamins; Vitamin therapy; Vitamin supplements; Special Vitamins	Current use							10			22.5	21.8	19.8		8.7	48.8	41.2	10	32.1	
	Past use														13.2					
	Lifetime use						56.5						27							

APPENDIX 3

Full survey used in Carlon, Carter, & Stephenson (2011).

Treatments for Autism Survey

1. Information and Consent page

You are invited to participate in a study of the range of treatments used by parents of children with Autism Spectrum Disorders (ASD) who are of school or preschool age. The purpose of the study is to examine the number and types of different approaches used by Australian parents in the treatment of their children with ASD. It is expected that this research will give us a clearer understanding of the types of choices made by parents and provide a basis for improving information available to parents.

The study is being conducted by Sarah Carlon, a postgraduate student at the Macquarie University Special Education Centre (MUSEC) (Ph: _____). The study is being undertaken to meet the requirements of Special Education Project Stage 2 under the supervision of Associate Professor Mark Carter (Ph: _____), and Associate Professor Jennifer Stephenson (ph _____) of MUSEC.

If you decide to participate, you will be asked to complete an anonymous, brief online survey about the treatments you have used and/or currently use with your preschool or school-aged child. It will take around 15 minutes to complete. The survey can be accessed by clicking next at the bottom of this page. We ask that you do not pass this address onto anyone else, as we would like to have an indication of the number of invited parents who have chosen to participate.

Participants in the study will be given the opportunity to provide contact details to go into a draw to win one of two \$100 Coles/Myer gift vouchers. Participation in this study and the provision of contact details for the draw are both entirely voluntary. If you choose to provide your contact details for the prize draw after completing the survey these may be entered on a separate page of the survey site - your identity will not be linked to the survey you complete.

You will also be provided with the opportunity to indicate whether you are interested in participating in a follow-up study focussing on the factors contributing to the choices of treatments for your child. Indicating your interest does not commit you to participating in the follow-up study. The researchers will simply contact you at a later date by post or email to invite you to participate.

Any information or personal details gathered in the course of the study are confidential (except as required by law). As the survey is anonymous, no individual will be identified in any publication of the results. Only the researchers directly involved will have access to the data collected for the purposes of this study. A summary of the results of the data will be posted on the Macquarie University Special Education Centre website (<http://www.musec.mq.edu.au/home.aspx>) and passed on to Aspect.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Human Research Ethics Committee through the Director, Research Ethics (telephone 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Yours sincerely,

Sarah Carlon BEd(ECE), M Spec.Ed
Postgraduate Research Student

Mark Carter PhD
Associate Professor

Jennifer Stephenson PhD
Associate Professor

To complete the survey please click "next"

2. About your child

Treatments for Autism Survey

1. My child is:

- ☐ 5 years old or younger
- ☐ 6-10 years old
- ☐ 11-14 years old
- ☐ 15-20 years old
- ☐ Over 21 years old

2. My child is currently receiving:

- ☐ Preschool services
- ☐ School services
- ☐ Post-school services

3. My child is:

- ☐ Male
- ☐ Female

4. My child is best described as having:

- ☐ Asperger's Syndrome or high functioning autism
- ☐ Moderate autism
- ☐ Severe autism (nonverbal)
- ☐ Other developmental disability (please specify)

3. About you

1. I am:

- ☐ Male
- ☐ Female

2. My education level is:

- ☐ Did not complete Higher School Certificate (left high school prior to completing Higher School Certificate or equivalent)
- ☐ Higher School Certificate or equivalent (finished high school)
- ☐ Beyond High School

3. Our geographic location is:

State:

Country:

Treatments for Autism Survey

4. Are you registered with Aspect in Australia?

- ☐ Yes
☐ No

4. Nonbiological treatments- Educational/Therapy Approaches

Please indicate whether or not you have ever used the following treatments:

1. Applied Behaviour Analysis

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

2. Auditory Integration Training

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

3. Augmentative Alternative Communication

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

4. Auslan/Makaton/Manual signing

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

5. Azrin 24-hour toilet training

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

6. Bolles Sensory Learning

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

7. Child care services

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

8. Cognitive/Behavioural Therapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

9. Conductive Education

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

10. Early intervention program (generic/not autism specific)

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

11. Electroaversive therapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

Treatments for Autism Survey

12. Facilitated Communication

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

13. Fast For Word

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

14. Floor Time

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

15. Functional Communication Training

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

16. Gentle Teaching

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

17. Interactive Metronome

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

18. Irlen Lenses

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

19. Integrated Movement Therapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

20. Joint Action Routines (JAR)

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

21. Lindamood-Bell

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

22. Lovaas Therapy/Discrete-Trial Training

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

23. Music Therapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

24. Neurofeedback (biofeedback)

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

Treatments for Autism Survey

25. Occupational Therapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

26. Picture Exchange Communication System (PECS)

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

27. Playgroup

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

28. Physical Therapy/Physiotherapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

29. Rapid Prompting Method

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

30. Sensory Integration

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

31. Self-Injurious Behaviour Inhibiting System (SIBIS)

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

32. Social Stories

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

33. Speech Therapy

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

34. Swimming

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

35. Van Dijk Approach

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

36. Visual Integration Training

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

37. Visual schedules

- ☐ Yes, currently ☐ In the past, but not now ☐ No, never

Treatments for Autism Survey

38. Weighted vests/blankets

☐ Yes, currently

☐ In the past, but not now

☐ No, never

39. Other(s)

5. Nonbiological treatments- Alternative Medicine

Please indicate whether or not you have ever used the following treatments:

1. Acupuncture

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Aromatherapy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Chiropractic

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Craniosacral Manipulation

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Dance Therapy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

6. Dolphin Therapy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

7. Extended Breastfeeding

☐ Yes, currently

☐ In the past, but not now

☐ No, never

8. Holding Therapy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

9. Homeopathy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

10. Infant Massage

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

11. Kinesiology

☐ Yes, currently

☐ In the past, but not now

☐ No, never

12. Naturopathy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

13. Neural Therapy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

14. Osteopathy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

15. Rhythmic Entertainment Intervention

☐ Yes, currently

☐ In the past, but not now

☐ No, never

16. Rolfing

☐ Yes, currently

☐ In the past, but not now

☐ No, never

17. Watsu

☐ Yes, currently

☐ In the past, but not now

☐ No, never

18. Other(s)

6. Nonbiological treatments- Packaged Programs

Please indicate whether or not you have ever used the following treatments:

1. Baudhuin Preschool

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Early Start Denver Model

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Eden Program

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Giant Steps

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

5. Higashi School

☐ Yes, currently

☐ In the past, but not now

☐ No, never

6. Institute for Human Potential (Doman-Delacato Patterning)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

7. LEAP

☐ Yes, currently

☐ In the past, but not now

☐ No, never

8. Options

☐ Yes, currently

☐ In the past, but not now

☐ No, never

9. More Than Words: The Hanen Program

☐ Yes, currently

☐ In the past, but not now

☐ No, never

10. Relationship Development Intervention (RDI)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

11. TEACCH

☐ Yes, currently

☐ In the past, but not now

☐ No, never

12. Other(s)

7. Nonbiological treatments- Miscellaneous

Please indicate whether or not you have ever used:

1. Multisensory Environments (e.g. Snoezelen)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Other(s)

8. Biological treatments- Antipsychotics

Please indicate whether or not you have ever used the following treatments:

1. Clozapine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Haldol

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

3. Risperdal

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Thorazine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

9. Biological treatments- Anticonvulsants

Please indicate whether or not you have ever used the following treatments:

1. Depakote

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Dilantin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Klonopin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Tegretol

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

10. Biological treatments- Antidepressants

Please indicate whether or not you have ever used the following treatments:

1. Paxil

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Prozac

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Tofranil

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

4. Zoloft

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

11. Biological treatments- Antianxiety

Please indicate whether or not you have ever used the following treatments:

1. Ativan

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Buspar

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Valium

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Xanax

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

12. Biological treatments- Stimulants

Please indicate whether or not you have ever used the following treatments:

1. Adderall

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Cylert

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Dexedrine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Ritalin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

Treatments for Autism Survey

13. Biological treatments- Antivirals

Please indicate whether or not you have ever used the following treatments:

1. Intravenous Immunoglobulin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Pentoxifylline

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Transfer Factor

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Other(s)

14. Biological treatments- Antibiotics

Please indicate whether or not you have ever used the following treatment/s:

1. Vancomycin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Other(s)

15. Biological treatments- Antagonists

Please indicate whether or not you have ever used the following treatment/s:

1. Naltrexone

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Other(s)

16. Biological treatments- Antifungals

Please indicate whether or not you have ever used the following treatments:

1. Diflucan

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

2. Nystatin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Sporanox

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Other(s)

17. Biological treatments- Digestive Aids

Please indicate whether or not you have ever used the following treatments:

1. Bethanechol

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Pepcid

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Probiotics (e.g. *L. acidophilus*, *S. boulardii*, etc.)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Secretin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

18. Biological treatments- Vitamin Supplements

Please indicate whether or not you have ever used the following treatments:

1. Vitamin B6

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Vitamin A

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Vitamin C

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Dimethylglycine (DMG)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

5. Essential Fatty Acids (cod liver oil, flax seed oil, etc.)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

6. L-Glutamine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

7. Magnesium

☐ Yes, currently

☐ In the past, but not now

☐ No, never

8. Megavitamin Therapy

☐ Yes, currently

☐ In the past, but not now

☐ No, never

9. Pyridoxine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

10. Other(s)

19. Biological treatments- Diets

Please indicate whether or not you have ever used the following treatments:

1. Casein-Free

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Feingold

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Gluten-Free

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Yeast-Free

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Other(s)

20. Biological treatments- Detoxification

Please indicate whether or not you have ever used the following treatments:

Treatments for Autism Survey

1. Chelation

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Clathration

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Reduced Glutathione

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Other(s)

21. Biological treatments- Sleep Aids

Please indicate whether or not you have ever used the following treatments:

1. Antihistamines (Benadryl, etc.)

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Melatonin

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Other(s)

22. Biological treatments- Miscellaneous

Please indicate whether or not you have ever used the following treatments:

1. Clonidine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

2. Fenfluramine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

3. Inderal

☐ Yes, currently

☐ In the past, but not now

☐ No, never

4. Lithium

☐ Yes, currently

☐ In the past, but not now

☐ No, never

5. Tenex

☐ Yes, currently

☐ In the past, but not now

☐ No, never

Treatments for Autism Survey

6. Withholding of MMR Vaccine

☐ Yes, currently

☐ In the past, but not now

☐ No, never

7. Other(s)

23. Comments

Please provide any comments in the box below.

Click "done" to complete the survey.

1. Comments:

CHAPTER 3: DECLARED FACTORS RELATED TO INTERVENTION DECISIONS MADE BY PARENTS OF CHILDREN WITH ASD

Chapter Overview

This chapter includes a review paper published in *Research in Autism Spectrum Disorders* (Carlon, Carter, & Stephenson, 2013)^{1, 2}. Given that parents access interventions with varying levels of research support, how they came to these decisions was of interest. This paper was the first review of factors declared by parents of children with ASD as related to their intervention decision-making. Declared factors were defined as those specifically identified by parents as being related to their decisions. While these may have included sources of information about interventions, this was only the case if the parent reported that the source had influenced their decision-making (e.g., by providing advice or recommendations). A range of different factors were reported across the 16 reviewed studies, but data regarding the level of importance placed by parents on different factors in their decision-making were very limited. In addition, there were few data collected from Australian samples.

Due to a publishing error, Table 2 was shaded incorrectly in the original article. Therefore, an erratum published in the journal is included as an appendix to this chapter.

¹ Publication Status:

Carlon, S., Carter, M., & Stephenson, J. (2013). A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions. *Research in Autism Spectrum Disorders*, 7, 369-381. doi: 10.1016/j.rasd.2012.10.009

² I was awarded the 2015 Jennifer Bowes Prize for Outstanding Higher Degree Research Publication by the Macquarie University Institute of Early Childhood for this paper.



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Research in Autism Spectrum Disorders

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A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions

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ABSTRACT

The range of interventions available for children with autism spectrum disorders (ASD) has increased in recent years. This has led to an interest in the decision-making process related to intervention choices for parents of children with ASD. The present paper reviewed 16 studies examining the factors declared by parents as affecting their decision-making. Frequently nominated factors included recommendations from others, the availability, accessibility, and cost of interventions, the availability and use of other interventions, and research evidence. Few studies presented data regarding the impact of research evidence or the relative importance of factors when making decisions. Further research related to professionals' recommendations for interventions, the weight parents place on different factors, and the influence of research evidence is recommended.

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1. Introduction

Autism spectrum disorders (ASD) are pervasive neurological disorders characterised by impairments in the domains of language and social interaction along with restricted or repetitive interests and/or behaviours (American Psychiatric Association, 2000). When parents receive their child's diagnosis, and throughout their child's life, parents make decisions about which interventions to use with their child. This has been described by some parents as a difficult and overwhelming process (Valentine, 2010). There are currently a great number of intervention options for children with ASD, including many empirically unsupported and controversial interventions (Metz, Mulick, & Butter, 2005; National Autism Center, 2009; Odom, Boyd, Hall, & Hume, 2010). Given the different interventions available to parents, parent decision-making about intervention use has become a topic of increasing interest.

There have been a number of reviews of research findings in recent years dedicated to assessing the research evidence in support of different interventions for ASD (e.g., National Autism Center, 2009; Odom et al., 2010; Roberts & Prior, 2006). It might be expected that parents would choose interventions that are known to be effective, but recent surveys of parents revealed that parents often use a variety of interventions concurrently, including both interventions with empirical support and those without such support (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Regehr & Feldman, 2009; Thomas, Morrissey, & McLaurin, 2007). This leads to the question of what factors contribute to parents' decisions to use, or not use, certain interventions.

Recent reviews of parent's treatment decisions and decision support needs regarding medical treatment for children across a variety of areas (e.g., surgery, transplantation, immunization, end of life treatment decisions, and managing acute or long term medical conditions) have revealed a number of factors that parents have identified as influencing their decision-making (Jackson, Cheater, & Reid, 2008; Lipstein, Brinkman, & Britto, 2012). These factors included recommendations from medical professionals, school staff, family members, or other community members with disease-specific experience, and formal or informal networks (Jackson et al., 2008; Lipstein et al., 2012). Social factors, such as embarrassment, have also been identified by parents as influencing their decision-making, along with past experience and the outcomes of past decisions (Jackson et al., 2008). The child's preferences for treatment and the parent's expectations or goals for their child, and parents emotions, beliefs, and values have also been identified as factors influencing decision-making (Lipstein et al., 2012).

Parents of children with ASD may possibly identify similar factors as influencing their decisions about interventions; however it is likely that factors in decision-making will be somewhat different for parents of children with ASD because in this case the parents play the major role in decision-making regarding interventions to use with their children (Valentine, 2010). Rather than being guided by professionals (such as doctors in the case of medical conditions, for example), parents are given a greater degree of freedom of choice. In Australia, for example, the Federal Government offers funding to parents of children with ASD to access an approved range of early intervention services. It is the parent's role to make the decision regarding which intervention to use from the approved list of over 20 different interventions (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012).

The factors that have been explicitly stated by parents as being related to their decision-making are declared decision-making factors. The decision-making process may also be influenced by factors that parents may not be aware of (implicit underlying factors), such as parental causal beliefs about ASD and parental education levels (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Dardennes et al., 2011; Erba, 2000). Data about the factors influencing parent decision-making could be helpful in gaining a better understanding of the range of issues considered by parents in their decision-making for interventions. In turn, this could be used as a foundation for providing better services and/or information to help parents make informed decisions about intervention use.

The influence of both declared and implicit underlying factors on intervention decision-making for parents of children with ASD have been examined by researchers (Al Anbar et al., 2010; Birkin, Anderson, Seymour, & Moore, 2008; Bowker, D'Angelo, Hicks, & Wells, 2011; Christon, Mackintosh, & Myers, 2010; Dardennes et al., 2011; Erba, 2000; Loomis, 2007; Miller, Schreck, Mulick, & Butter, 2012), but to date there have been no attempts to review this research or synthesise the findings. Researchers have used a variety of research methods, both quantitative (Bowker et al., 2011; Miller et al., 2012) and qualitative (Loomis, 2007; Valentine et al., 2010) to explore parental decision-making for interventions. Additionally,

researchers have used a variety of approaches, ranging from asking about decision-making for single interventions (Birkin et al., 2008), to intervention decision-making in general for a range of interventions (Miller et al., 2012). If the factors declared by parents as being related to their decision-making triangulate across different methodologies and approaches, then this will provide converging evidence about which factors are important in parental decision-making.

The present study provides a review of the literature on the declared factors in decision-making related to the use of educational, therapy, medical or complementary and alternative medicine (CAM) interventions by parents of children with ASD. Specifically, the following questions will be addressed:

- (1) What is the range of decision-making factors identified by parents of children with ASD?
- (2) Which factors are most commonly identified by parents?
- (3) Which factors do parents identify as the most important in the decision-making process?

2. Method

2.1. Inclusion and exclusion criteria

Papers were included in the review if they: (1) presented data (qualitative or quantitative); (2) data were collected from parents of children with ASD; and (3) included factors *explicitly* declared by parents as influencing the decision-making process related to the use of educational, therapy, medical or CAM interventions. There were no restrictions placed on the geographic area in which the data were collected or on the year of publication of the study. Papers were excluded if they discussed decision-making related to interventions, but did not include data collected from parents of children with ASD.

2.2. Search procedure

The CINAHL, ERIC, psycINFO, PubMed, ScienceDirect, Scopus, and Web of Science databases were searched using a combination of a diagnostic descriptor (autis* OR ASD), AND a treatment descriptor (treatment OR intervention), AND a parent descriptor (parent OR family OR families), AND a decision-making descriptor (decision making OR choice). The initial search resulted in 157 papers, and the abstracts of these papers were examined independently by the first and second authors using the inclusion and exclusion criteria above. Agreement of 98.7% was reached on papers to be shortlisted for inclusion in the review. Disagreements were resolved by consensus after looking at the full papers, and 11 papers were shortlisted for inclusion. Ancestral searches were conducted and a further 23 papers were shortlisted for inclusion, along with an additional four studies which were identified from an ongoing review of parental reports of interventions used with their children with ASD.

The first and second authors each examined the full papers of the 38 shortlisted papers to confirm that they met the inclusion and exclusion criteria, and reached 100% agreement on the papers for inclusion. Sixteen studies were included in the final analysis.

2.3. Data extraction and coding procedures

Each study was coded for: (a) design (qualitative or quantitative); (b) number of participants; (c) participant characteristics; (d) location of participants; (e) interventions discussed; (f) method of data collection; and (g) findings regarding declared decision-making factors. Data were coded by the first author and checked for accuracy by the third author. All disagreements were resolved by discussion.

3. Results

3.1. Study description

In seven of the studies quantitative data were collected via surveys, questionnaires or interviews (Bowker et al., 2011; Christon et al., 2010; Hanson et al., 2007; Miller et al., 2012; Senel, 2010; Study 2 in Smith & Antolovich, 2000; Wong & Smith, 2006). In two studies, interviews were used to collect both quantitative and qualitative data (Study 1 in Birkin et al., 2008; Le Grice & McMenamin, 2001), and in the remaining seven studies qualitative data were collected via interviews. The number of participants ranged from 6 to 970, with a mean of 133.8 (median = 43.5, *SD* = 246.6). Wong and Smith (2006) included a control group of 50 parents of children without ASD whose decision-making regarding CAM interventions was compared to that of the 50 parents of children with ASD.

In 12 of the studies, at least one of the study aims was to collect data about one or more factors related to parental decision-making for using, choosing not to use, or discontinuing interventions. In the remaining four studies, data related to parental decision-making were collected to supplement other study aims, such as evaluating the post-diagnosis support offered to parents of children with ASD and collecting data about patterns of treatment use or parent's experiences with interventions (Rajkovic et al., 2010; Valentine, 2010; Valentine et al., 2010; Wong & Smith, 2006).

Table 1
Declared decision-making factors.

	Study												Total number of studies reporting	
	Bowker et al. (2011)	Miller et al. (2012)	Smith and Antolovich (2000)	Le Grice and McMenamin (2001)	Loomis et al. (2007)	Rajkovic et al. (2010)	Shyu et al. (2010)	Valentine (2010)	Christon et al. (2010)	Hanson et al. (2007)	Wong Smith (2006)	Lynch (2004) and Smith (2006)	Study 1 in Birkin et al. (2008)	Study 2 in Birkin et al. (2008)
Interventions considered														
Interventions in general/overall	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
A range of individual interventions	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
CAM interventions only														
Dietary interventions and/or supplements only														
The EarlyBird Program (parent training) only														
Study design														
Qualitative interviews/focus groups	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Quantitative surveys/interviews	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Number of participants														
970	400	24	6	11	18	13	49	49	248 ^a	112	100 ^b	14	77 ^c	12
Declared decision-making factors														
Recommendations	100%	✓		✓	✓	✓	✓	✓	100%	30%	100%	✓	22.0%	12
Availability and/or accessibility	✓		✓	✓	✓	✓	✓	✓	7.9%	✓	✓	✓	✓	10
Cost/affordability	✓		✓	✓	✓	✓	✓	✓	17.8%	✓	✓	✓	✓	8
Child's progress or lack thereof/parent satisfaction with intervention	37.7%		✓	✓	✓	✓	✓	✓	27.3%	✓	✓	✓	✓	7
Use of and perceived effectiveness of other interventions		✓	✓	✓	✓	✓	✓	✓				✓	9.8%	7
Specific needs of the child		✓	✓	✓	✓	✓	✓				✓	✓	✓	6
Research evidence		✓	✓	✓	✓	✓	✓			66% ^d		✓	✓	5
Time constraints		✓	✓	✓	✓	✓	✓	✓	9.5%				31.7%	5
Access to funding for interventions		✓	✓	✓	✓	✓	✓	✓					✓	4
Availability of alternative interventions		✓	✓	✓	✓	✓	✓	✓			✓		✓	4
Child's resistance to or preference for the intervention						✓	✓		10.4%		✓			4
Treatment side effects/adverse effects	17.4%			✓	✓	✓	✓	✓		✓				4
Compatibility with other interventions		✓		✓	✓	✓	✓	✓						3
Family impact				✓	✓	✓	✓							2
Child's age				✓	✓	✓							19.5%	2
Belief that the treatment is no longer needed, or that the child had completed all it had to offer	10.3%								8.8%					2
Parent's hope for improvement/a cure				✓						50% ^d		✓		2
Whether parent feels ready/wants to attend													✓	1
Program expectations													✓	1
Parent's shyness or language barriers													✓	1
Safety of prescribed medicine										84% ^d				1

Perceived amount of parental control over intervention	54% ^d	1
Cultural/family/religious traditions	13% ^d	1
Preference for "natural" therapy	39% ^d	1
Preference for holistic approach	14% ^d	1
Expected duration of the intervention		1
Knowledge and skills from parent's own professional training/parent's own past experiences		1
Results of lab testing		1
Parental beliefs about child's probable reaction to intervention		1
Parent's belief that their child should maintain a "normal" life		1
Risk of harm		1
Parental belief that what works for one child with ASD may or may not work for another		1
Possible benefits of the intervention		1
Gut feelings/whether an intervention "makes sense" to the parent		1
Possibility of future guilt if not tried		1
Effects of discontinuing intervention		1
Parent's willingness to take risk		1
Co-morbid disorders/illnesses		1
Flexibility of delivery approach		1
Fit of parent/child with therapist		1
Parent required to choose		1
Whether the intervention is autism-specific		1
The training or experience of the staff		1
Personal values/family practices		1
Opportunities for parent involvement		1

Note: Shaded cells indicate that the factor was specifically asked about by the researchers. Unshaded cells indicate parents provided information in response to an open-ended question. Ticks indicate that the factor was identified in the study. Where available, the percentage of parents nominating the factor is provided.

^a Percentages below refer to the sub-category of 176 participants who indicated that they used CAM interventions.

^b Percentages below refer to the sub-category of 26 participants who indicated that they chose not to participate in the EarlyBird Program.

^c Percentages below refer to the sub-category of 36 participants who indicated that they chose not to participate in the EarlyBird Program.

^d Percentage of those who answered this question that rated the factor as important in choosing treatment.

3.2. Declared decision-making factors

Table 1 gives an overview of the decision-making factors that were identified by parents across the studies, ranked by frequency of the number of studies in which they were identified. Shaded cells indicate that the factor was directly asked about by the researchers and unshaded cells indicate parents provided information in response to an open-ended question. Quantitative studies were examined for data related to the percentage of participants nominating a factor and this is provided where available.

Recommendations from others was the most frequently reported factor across the studies. Other frequently reported factors across all studies were availability and/or accessibility of interventions, cost/affordability, the parent's perception of the child's progress/satisfaction with an intervention, and the use and perceived effectiveness of other interventions. Specific findings related to commonly reported declared decision-making factors will be presented below.

3.2.1. Recommendations

Recommendations were the most frequently reported declared decision-making factor, reported in 12 of the studies with all participants nominating recommendations in three studies. Recommendations to use interventions were specifically asked about in each of the quantitative studies that addressed this factor. Recommendations not to use interventions were only reported by parents in two qualitative studies (Loomis, 2007; Valentine et al., 2010). The reported sources of recommendation are shown in Table 2. Where information about the percentage of participants identifying a source was available from more than one study, considerable differences were found between the studies. Other parents were the most frequently reported source of recommendation (reported in seven studies) and the most common reason given for choosing CAM interventions reported by Christon et al. (40.3%; 2010) and Senel (30%; 2010).

Recommendations from medical doctors were reported in six studies. They were rated as an important reason for using CAM interventions by 67% of the participants in Hanson et al. (2007), and stated as a reason for using CAM interventions by 39% of the participants in Christon et al. (2010) and 23% of those in Wong and Smith (2006). Other frequently reported sources of recommendation were the Internet and books/authors on autism.

Professionals other than medical doctors were only identified in one study, but in this case 85.4% of participants reported that recommendations by professionals influenced their decision-making (Miller et al., 2012).

Most studies examined only identified the sources of recommendations, but Hanson et al. (2007) asked parents to rate a series of statements, including those about different sources of recommendation, in terms of their importance when choosing interventions. A total of 67% of participants rated recommendations from physicians as important, 53% recommendations from friends, family, or other parents, and 4% recommendations from a health food store. Smith and Antolovich (2000) asked parents which source was most influential in their decision-making. Forty seven percent of those using speech therapy and 36% of those using sensory integration identified recommendations from professionals as most influential in their decision-making; 5% of those using speech therapy, 57% of those using diets, and 18% of those using vitamins identified other parents as most influential; and 14% of those using diets and 27% of those using vitamins identified authors on autism as most influential.

3.2.2. Availability/accessibility

The availability of and/or accessibility to interventions were a factor identified by parents in 10 of the studies, including nine studies in response to open-ended questions. Availability was identified as a particular issue for interventions provided through public health systems in Taiwan and Australia, and for families living in remote areas in Australia (Shyu, Tsai, & Tsai, 2010; Valentine et al., 2010). Bowker et al. (2011) did not differentiate the factors of cost and accessibility, and the third most common reason nominated for terminating interventions (13.2%) was that the intervention was no longer available due to these factors. A lack of accessibility was also identified as a reason for discontinuing CAM interventions (Christon et al., 2010; Wong & Smith, 2006).

3.2.3. Cost

Cost as a factor was reported in eight studies, including five qualitative studies. Particular emphasis was placed on the cost of high intensity interventions such as Applied Behaviour Analysis (ABA) and autism specific schools in Valentine et al. (2010), and this was related to parent's decisions not to use these interventions. The second most common reason selected for discontinuing CAM interventions in Christon et al. (2010) was cost, nominated by 17.8% of participants (averaged across the interventions).

3.2.4. Perceptions of progress or satisfaction

Parents' perceptions of their child's progress or satisfaction with an intervention was a factor identified by parents in relation to terminating interventions in seven studies, including six in response to an open-ended question. The most common reason selected for discontinuing CAM interventions reported in Christon et al. (2010) was that the parents felt that the treatment did not work. Similarly, lack of progress was the most common reason overall (37.7%) given for discontinuing interventions in the study of Bowker et al. (2011), and also the most common reason given for discontinuing medications, vitamins, alternative diets, and special education. Parents interviewed by Rajkovic et al. (2010) reported discontinuing the use of interventions at home that had been successful in the school environment because they were not effective in the home.

Table 2
Sources of recommendation.

Study reporting												Total number of studies reporting
Milleret al. (2012)	Christon et al. (2010)	Hanson et al. (2007)	Senel (2010)	Wong and Smith (2006)	Le Grice and McMenamin (2001)	Loomis (2007)	Shyu et al. (2010)	Study 2 in Smith and Antolovich (2000)	Valentine (2010)	Valentine et al. (2010)	Lynch (2004)	
Interventions considered												
Interventions in general/overall	✓		✓	✓	✓			✓	✓	✓	✓	
CAM interventions only		✓	✓					✓				
A range of individual interventions												
Dietary interventions and/or supplements only												
Source of recommendation												
Other parents	75.2%	40.3%	✓	30.0%		✓	✓	✓		✓		7
Medical doctors	✓	39.0%	67.0%		23.0%		✓	✓			✓	6
Books/authors on autism	85.6%	22.5%			15.0%			✓	✓			4
Internet/websites/online chat groups		40.3%	✓		23.0%		✓			✓		4
Friends/relatives					35.0%		✓					3
School teams/educators	67.8%	8.1%				✓						3
Occupational therapists	✓				27.0%	✓						3
Speech therapists	✓					✓				✓		3
Service providers						✓						2
CAM practitioners						✓					✓	2
Dieticians/nutritionists						✓						2
Chiropractors												1
Pharmacists												1
Television		7.9%										1
Support groups/disability newsletters		17.1%										1
Conferences/workshops												1
Professionals other than medical doctors	85.4%	22.1%										1
Psychologists	✓											1
Behaviour analysts	✓											1
Physical therapists	✓											1
Audiologists	✓											1
Fortune teller								✓				1
Health food store				4.0%								1

Note: Shaded cells indicate that the source was specifically asked about by the researchers. Unshaded cells indicate parents provided information in response to an open-ended question. Ticks indicate that the source was identified in the study. Where available, the percentage of parents nominating the source is provided.

environment. Parental satisfaction with interventions was also linked to the child's willingness to comply with the intervention program (Loomis, 2007; Rajkovic et al., 2010) and concerns about causing the child pain or discomfort (Loomis, 2007; Shyu et al., 2010).

3.2.5. Use and effectiveness of other interventions

The current use of other interventions and their perceived effectiveness were identified as factors influencing decision-making in seven studies in response to an open-ended question. In two studies parents reported that they did not seek to use new interventions because they were already using interventions that were effective (Birkin et al., 2008; Shyu et al., 2010). By comparison it was reported in Loomis (2007) that the perceived effectiveness of one alternative intervention led to one parent trying more alternative interventions. Parents in four of the studies sought out new interventions when they thought that progress was slow or that the interventions they were using were ineffective (Loomis, 2007; Rajkovic et al., 2010; Study 2 in Smith & Antolovich, 2000; Valentine et al., 2010). Additionally, it was reported in two studies that parents discontinued interventions because similar interventions were offered in the school environment and they were happy to access these as an alternative to the interventions they were using outside of school (Le Grice & McMenamin, 2001; Valentine et al., 2010).

3.2.6. Needs of the child

The specific needs of the child were identified by parents as a factor influencing decision-making in six studies in response to an open-ended question. The use of specific interventions to target symptoms commonly associated with ASD such as speech therapy to target communication/language needs and social skills training and play therapy to target peer interaction skills/peer difficulties were reported across a number of the studies (Le Grice & McMenamin, 2001; Loomis, 2007; Rajkovic et al., 2010; Study 2 in Smith & Antolovich, 2000). CAM interventions, such as diets and vitamins, were reported to be used to target physical symptoms associated with gastro-intestinal problems, either identified by alternative health professionals or the parents. These treatments were also used to treat the symptoms of ASD in general, or problems such as challenging behaviour, ritualistic behaviour, concentration/attention difficulties, communication/speech, tactile sensitivity, and to improve the child's developmental levels and general health (Loomis, 2007; Lynch, 2004; Study 2 in Smith & Antolovich, 2000; Wong & Smith, 2006).

3.2.7. Research evidence

Research evidence was identified as a decision-making factor by parents in five of the 16 studies, including four in response to an open-ended question. In Study 2 in Smith and Antolovich (2000), 29% of those using diets and 45% of those using vitamins stated that they were doing so due to research evidence. The role of service providers in offering information about research was reported in Le Grice and McMenamin (2001) and Valentine (2010), who also noted that some parents were becoming research literate in order to inform their intervention decision-making. Three out of the 11 parents interviewed in Loomis (2007) discussed the importance of research evidence in their decision-making, while others dismissed its importance. Nonetheless, Hanson et al. (2007) reported that 66% of participants rated a preference for a scientifically proven therapy as being an important factor in decision-making.

3.2.8. Time constraints

Time constraints were identified by parents in five studies, including four in response to an open-ended question. The most common reason (31.7%) that parents chose not to use the EarlyBird program (Study 1 in Birkin et al., 2008) was that the program was not available at a convenient time. Christon et al. (2010) indicated that almost one tenth of those who discontinued CAM interventions did so due to time constraints.

3.2.9. Funding

In four studies parents identified access to funding for interventions as a decision-making factor. In Study 2 in Smith and Antolovich (2000) parents who rated the efficacy of speech therapy or sensory integration as low chose to continue these interventions because they received funding for them.

3.2.10. Availability of other interventions

The availability of other interventions was identified in four of the qualitative studies. The availability of other interventions was reported to be restricted for parents living in regional and remote areas (Valentine, 2010; Valentine et al., 2010). Long waiting lists and a lack of availability of public services, such as speech therapy and occupational therapy, were reported to influence parent's choices to use private services by Valentine et al. (2010) and alternative interventions by Shyu et al. (2010).

3.2.11. Child's resistance to the intervention

The child's resistance to the intervention was identified as a reason for discontinuing CAM interventions by those terminating interventions (Christon et al., 2010; Shyu et al., 2010; Wong & Smith, 2006). Rajkovic et al. (2010) included reports of parents discontinuing interventions such as the Picture Exchange Communication System (PECS) and social skills programs because the child did not like the intervention and refused to comply.

3.2.12. Side effects

Treatment side effects or adverse effects from interventions were identified in four studies, including three in response to an open-ended question. Treatment side effects were identified by parents as a reason for discontinuing medications and vitamins in Loomis (2007), and fears about causing the child pain as a reason for discontinuing acupuncture in Shyu et al. (2010). The three most common factors rated as important in choosing CAM treatments in Hanson et al. (2007) were the safety of prescribed medicine (84%), concerns about side effects of prescription therapy (83%), and experiences of unacceptable side effects of prescription therapy (73%). Additionally, 17.4% of those in Bowker et al. (2011) who reported discontinuing interventions did so due to side effects or finding the treatment aversive.

3.2.13. Compatibility with other interventions

The compatibility of new interventions with those currently being used was identified as a factor related to commencing interventions in three of the studies. In Study 2 in Smith and Antolovich (2000) one parent reported changing speech therapists in order to co-ordinate the therapy with an ABA approach. The consistency of delivery approaches with ABA was also identified as a decision-making factor in Rajkovic et al. (2010) and Valentine et al. (2010).

4. Discussion

A number of factors were identified by parents as being related to their decisions to either commence using interventions, terminate the use of interventions, or both. The factors reported most frequently across the studies can be grouped into those related to recommendations from others, factors related to pragmatic issues, factors related to the effectiveness of interventions, and research evidence. These will now be addressed followed by limitations of the review.

4.1. Recommendations

Recommendations were the most frequently reported declared factor. This was not surprising given that recommendations from others were commonly identified factors related to the medical decisions of parents (Jackson et al., 2008; Lipstein et al., 2012). Recommendations were reported in qualitative and quantitative studies, both when they were explicitly asked about and in response to open-ended questioning. Other parents were the most frequently reported sources of recommendation across the studies, indicating that personal, and probably anecdotal, recommendations are sought frequently by parents of children with ASD. Additionally, Smith and Antolovich (Study 2, 2000) found the most common reasons given for obtaining speech therapy, diets, and sensory integration, were recommendations (from service providers, other parents, authors on autism, or a combination of these sources).

Although professionals, service providers, and associations/peak bodies have been reported as common sources of information about interventions (Al Anbar et al., 2010; Christon et al., 2010; Erba, 2000; Loomis, 2007; Miller et al., 2012; Rajkovic et al., 2010; Valentine et al., 2010), they appear to be somewhat reluctant to give recommendations not to use ineffective interventions. In only two of the studies (both qualitative; Loomis, 2007; Valentine et al., 2010) were there reports of professional recommendations *not* to use an intervention. In a recent examination of websites of eight national autism organisations (from Australia, Canada, New Zealand, South Africa, the UK, and the US) it was found that all websites contained a disclaimer regarding the information they provided to parents indicating that they did not endorse any particular interventions (Stephenson, Carter, & Kemp, 2012). This indicates that such bodies may be avoiding making recommendations to parents at all. Similarly, Valentine et al. (2010) reported that peak bodies and professionals were reluctant to present information to parents about the interventions with empirical support (such as ABA) for fear of presenting parents with options that they could not afford. The lack of evidence of professionals making recommendations *against* interventions may reflect a reluctance to alienate parents, given the heated controversy that surrounds some interventions.

Medical doctors were identified as a frequent source of recommendations across the studies examined. A recent survey of medical professionals in North America revealed that primary care providers (family practitioners, paediatricians, and neurologists) were less likely to endorse special education services than professionals from an autism-specific service (Heidgerken, Geffken, Modi, & Frakey, 2005). Furthermore, Golnik, Ireland, & Borowsky (2009) reported that primary care physicians were less confident in working with children with ASD than those with neurodevelopmental conditions and other chronic conditions. It is of interest that 67% of participants in Hanson et al. (2007) rated recommendations from medical doctors as important in choosing to use CAM interventions. In addition, 39% of those in Christon et al. (2010) and 23% of those in Wong and Smith (2006) indicated that they used CAM interventions because of doctors' recommendations. This suggests that at least some doctors are recommending the use of interventions without sound empirical support. These findings highlight the importance of medical professionals, particularly generalist medical practitioners, having up to date and accurate information on interventions relevant to ASD. The reasons why professionals make recommendations, both for and against the use of interventions, or decline to make recommendations, warrants further investigation.

Information on the weighting of sources of recommendation in decision-making was considered in two studies (Hanson et al., 2007; Study 2 in Smith and Antolovich, 2000). Hanson et al. (2007) reported that 67% of participants rated a physician's recommendation as important, 53% rated recommendations from friends, family, or other parents as important, and 4% recommendations from a health food store. Smith and Antolovich (Study 2; 2000) asked parents which source was most

influential in their decision-making. Forty seven percent of those using speech therapy and 36% of those using sensory integration identified recommendations from professionals as most influential in their decision-making; 5% of those using speech therapy, 57% of those using diets, and 18% of those using vitamins identified other parents as most influential; and 14% of those using diets and 27% of those using vitamins identified authors on autism as most influential. Nevertheless, while we have extensive information on the range of sources consulted by parents, there are relatively limited data on the relative importance of these sources. Systematic examination of the weighting that parents place on different sources of recommendation should be considered a priority issue in future research.

4.2. Pragmatic issues

Other frequently reported declared factors were related to pragmatic issues. These included the availability/accessibility of interventions and of alternative interventions, the cost of interventions and funding available, the specific needs of the child, time constraints, and the compatibility of the intervention with other currently used interventions. A number of these factors may be related to each other, such as the cost of an intervention, the availability of funding, and availability or lack thereof of alternative interventions. These factors are likely to be considered by parents in combination, and whether they are ultimately more important to parents than other factors, such as recommendations or research evidence, is currently unknown and could be explored in future research.

It is interesting that some pragmatic factors, such as the availability or accessibility of interventions and their cost were not identified in reviews of parental medical decision-making for children across areas such as surgery, transplantation, immunization, end of life treatment decisions, and managing acute or long term medical conditions (e.g., Jackson et al., 2008; Lipstein et al., 2012). This confirmed the initial proposal that factors related to decisions for parents of children with ASD would be somewhat different than for those making medical decisions for their children. However, the opening hours and location of general practitioners were identified as a barrier to parent control over medical decision-making, suggesting that accessibility may be a related issue (Jackson et al., 2008). Nevertheless, given that most of the interventions available to families of children with ASD are not medically based, it is not surprising that pragmatic factors identified in the current study differed. Parents of children with attention deficit hyperactivity disorder, however, have identified availability, accessibility, cost, and funding available through health insurance as factors influencing their decision-making about interventions, including the use of medications (Bussing et al., 2012; Fiks, Hughes, Gafen, Guevara, & Barg, 2011).

4.3. Effectiveness of interventions

Some frequently reported factors were parent's satisfaction with an intervention (including perception of the child's progress or lack thereof), the use and perceived effectiveness of other interventions, treatment side effects or adverse effects, and the child's resistance to, or preference for, the intervention.

Again, parents are likely to consider a number of these factors in combination. How satisfied a parent is with an intervention may be related to the parent's initial expectation of the intervention and their reason for using the intervention. For example, a parent may be satisfied with an ineffective intervention simply because it provides them with respite (Le Grice & McMenamin, 2001). Smith and Antolovich (2000) and Hume, Bellini, & Pratt, 2005 suggested that positive ratings of interventions by parents may be related to parents investing time and money into an intervention and therefore wanting it to be effective. Parents may tend to be more satisfied with, and likely to continue using, interventions in which they have already invested a large amount of resources. The extent to which parental satisfaction with interventions is reflective of the actual efficacy of the intervention and how much other factors (such as time and money already invested, access to funding for the intervention, the cost of the intervention, and the child's apparent level of enjoyment of the intervention) influence the parent's perceptions is unclear.

4.4. Research evidence

In a study that considered sources of information about ASD interventions, Erba (2000) noted that although some parents reported hearing about interventions from research, it was not clear what they meant when they reported using "research". Given the common use of the term, it is possible that in some cases parents were reporting their own act of information-seeking as "research", rather than referring to information presented in empirical studies. Additionally, Smith and Antolovich (Study 2, 2000) reported that a subset of parents indicated that research was the reason that diets and vitamins were chosen. In this case "research" seems to refer to the claims of efficacy of dietary interventions and vitamins, possibly accessed through non-technical publications or the Internet, or that the parents personally sought out information (and considered this research). Neither of these interventions has been reported to have clear empirical support in recent research reviews (Millward et al., 2008; Mulloy et al., 2010, 2011; Nye & Brice, 2005; Roberts & Prior, 2006).

While there was evidence that at least some parents reported placing considerable weight on research when selecting interventions (Hanson et al., 2007; Le Grice & McMenamin, 2001; Loomis, 2007; Study 2 in Smith & Antolovich, 2000; Valentine, 2010), there is considerable evidence to indicate that many interventions used by parents are in fact not research-based (Bowker et al., 2011; Christon et al., 2010; Goin-Kochel et al., 2007; Green et al., 2006; Hanson et al., 2007). The extent

to which this apparent discrepancy is related to lack of accessible information on empirical research, misinterpretation of research or lack of regard for the importance of research remains an important open question.

Valentine (2010) and Le Grice and McMenamin (2001) discussed the role of service providers in sharing research evidence with parents. However, the extent to which professionals base their recommendations to parents on research evidence is not clear. The reasons for professionals not sharing recommendations, either for or against the use of interventions, based on empirical evidence is worthy of further examination.

4.5. Factors not frequently examined across studies

A large number of factors were examined in fewer than three studies. While these factors were not declared frequently it is likely that in some cases this was because parents were not asked about them. Typically, these factors were identified in qualitative studies, where they arose from open-ended questioning. Factors such as the impact of the intervention on the family, the hope for improvement or a cure, whether the intervention is ASD-specific, and the parent's "gut feelings" are all factors that may be related to parental decision-making but were not explicitly addressed in most studies. More explicit and direct examination of the frequency with which these factors affect decision-making and the degree of their influence would be appropriate.

5. Limitations

A number of limitations of this review should be acknowledged. The reviewed studies included a wide diversity of populations and research methodologies, both quantitative and qualitative, and each study also focused on slightly different issues (e.g., CAM interventions, empirically supported interventions, or specific individual interventions). The degree of specificity of analysis in the present study was inherently limited by the degree of specificity of the research issues presented in the original studies. While the quantitative studies generally presented data from larger samples, these data were limited at times by the specific focus of questions asked in each of the studies. Qualitative studies typically provided richer data on a greater number of factors related to decision-making, but generalizability may have been more limited. The methodology of studies also varied considerably with some researchers explicitly asking parents about a range of factors and others using open-ended questions. Thus, the frequency with which factors were identified may be influenced by the nature and form of questions asked by researchers. While these limitations should be acknowledged, it should also be noted that some decision-making factors were reported consistently across varied research samples and methodologies, providing converging evidence that they may be frequently considered in parental decision-making. The research examined in the review primarily provided information on the existence of factors, but there was very limited data (quantitative or qualitative) on their degree of influence.

Where possible, data related to the number of participants identifying a decision-making factor or recommendation source were extracted from the quantitative studies for comparison across the studies. This was not possible in some cases for a number of reasons, for example in Study 2 in Smith and Antolovich (2000), data were reported for the participants for four different interventions, and the number of parents overall identifying each factor or source was not available. Additionally, in some studies factors were considered together and individual rates were not available (e.g., availability and cost in Bowker et al., 2011), and in many cases data related to how many participants identified factors were not presented. This made comparing rates of identification across the different populations difficult. Furthermore, the diversity in methodologies, populations, and research issues of focus, as discussed above, may explain the considerable differences in the percentage of parents identifying various sources of recommendation in the studies in which these data were available.

While this paper focused on the declared decision-making factors, a number of possible implicit underlying factors have also been identified such as causal beliefs about ASD (Al Anbar et al., 2010; Dardennes et al., 2011), the child's diagnosis (Bowker et al., 2011; Christon et al., 2010; Hanson et al., 2007), and parental education levels (Erba, 2000; Hanson et al., 2007; Wong & Smith, 2006). An important direction for future research is to investigate the correspondence and relationships between these two types of factors, potentially providing an integrative understanding of a full range of factors that influence parental decision-making.

Finally, this paper identified factors declared by parents as influencing their decision-making for interventions but did not explore the decision-making process in itself. The use of a theoretical framework in the future to explore the decision-making process of parents of children with ASD, and how the consideration of different factors fit into such a framework, would be beneficial in reaching a better understanding of how parents make these complex decisions.

6. Conclusion

The current review identified a range of factors that parents stated as influencing their decision-making. The most common factors identified included recommendations from others, those related to pragmatic issues, those related to the effectiveness of interventions, and research evidence. Despite the diversity of methodology and samples these factors were identified across a number of studies. However, very limited data were available on the weighting of different decision-making factors in the decision-making process. This review has highlighted the importance of professionals having accurate and up-to-date information about interventions relevant to ASD because parents may seek advice from them. Additionally, it

has provided important directions for future research including investigating why professionals make recommendations for or against the use of interventions, or decline to make recommendations, and the extent to which they base these recommendations on research evidence. The research base would also be strengthened by investigation of the relationship between explicit declared and implicit underlying factors to provide a complete picture of the decision-making process of parents. Most importantly, future research should focus on the systematic investigation of the level of importance that parents place on different factors in their decision-making, including factors identified in a small number of the reviewed studies.

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APPENDIX

Carlon, S., Carter, M., & Stephenson, J. (2013). Erratum to: "A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions" [Res. Autism Spectrum Disord. 7 (2013) 369-381]. *Research in Autism Spectrum Disorders*, 7, 502-503. doi: 10.1016/j.rasd.2013.01.001



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Erratum to: “A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions” [Res. Autism Spectrum Disord. 7 (2013) 369–381]

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The publisher regrets that an error has occurred in the above paper. Table 2 on page 375 was shaded incorrectly. The amended Table 2 is reproduced correctly on the next page.

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Table 2
Sources of recommendation.

	Study reporting											Total number of studies reporting
	Miller et al. (2012)	Christon et al. (2010)	Hanson et al. (2007)	Senel (2010)	Wong and Smith (2006)	LeGrice and McMenamin (2001)	Loomis (2007)	Shyu et al. (2010)	Study 2 in Smith and Antolovich (2000)	Valentine (2010)	Valentine et al. (2010)	
Interventions considered	✓											
Interventions in general/overall		✓		✓	✓							
CAM interventions only			✓								✓	
A range of individual interventions						✓	✓	✓	✓	✓		
Dietary interventions												✓
and/or supplements only												
Source of recommendation												
Other parents	75.2%	40.3%	✓	30.0%			✓		✓		✓	7
Medical doctors	✓	39.0%	67.0%		23.0%		✓					6
Books/authors on autism	85.6%	22.5%			15.0%		✓		✓			4
Internet/websites/online chat groups		40.3%			23.0%		✓			✓		4
Friends/relatives			✓		35.0%		✓					3
School teams/educators	67.8%	8.1%				✓						3
Occupational therapists	✓				27.0%	✓						3
Speech therapists	✓					✓			✓			3
Service providers							✓			✓		2
CAM practitioners							✓				✓	2
Dieticians/nutritionists							✓					2
Chiropractors	✓				15.0%							1
Pharmacists					4.0%							1
Television		7.9%										1
Support groups/disability newsletters		17.1%										1
Conferences/workshops		22.1%										1
Professionals other than medical doctors												1
Psychologists	85.4%											1
Behaviour analysts	✓											1
Physical therapists	✓											1
Audiologists	✓											1
Fortune teller	✓							✓				1
Health food store			4.0%									1

Note: Shaded cells indicate that the source was specifically asked about by the researchers. Unshaded cells indicate parents provided information in response to an open-ended question. Ticks indicate that the source was identified in the study. Where available, the percentage of parents nominating the source is provided.

CHAPTER 4: EXPLORATION OF DECISION-MAKING BY AUSTRALIAN PARENTS OF PRESCHOOL-AGE CHILDREN WITH ASD

Chapter Overview

This chapter includes two related papers. One is in press at the *Australasian Journal of Special Education* (Carlton, Stephenson, & Carter, in press)¹, and one has been submitted to a peer reviewed journal (Carlton, Stephenson, & Carter, 2014a)². An exploratory qualitative study was undertaken with Australian parents of preschool-age children with ASD with the intent to provide information to inform later survey research. The interview schedule used to collect data reported in both of the papers was developed using findings from the review studies presented in Chapters 2 and 3 of this thesis, and is presented in Appendix 1 of this chapter. In addition, a full list of possible themes and sub-themes used in the qualitative analysis are presented in Appendix 2.

Carlton, Stephenson, and Carter (in press) added to the very small Australian research base regarding sources of information used. It was the first paper to provide insight into why parents perceived different sources to be more or less reliable or trustworthy, and how useful they found information provided by different sources, including uniquely Australian sources such as Autism Advisors. In Carlton, Stephenson, and Carter (2014a) a range of factors influencing actual decisions of Australian parents were identified. While there was some overlap between the sources used (reported in Carlton, Stephenson, & Carter, in press) and factors considered, the decision-making factors were conceptualised as being identified by parents as having an influence on their decision-making. In comparison sources may have simply provided information, rather than exerted any influence on the parents' decisions.

Unlike previous qualitative research, parents identified criteria which played a role in the final

¹ Publication Status:

Carlton, S., Stephenson, J., & Carter, M. (in press). Parent perspectives on sources of information about autism interventions in Australia. *Australasian Journal of Special Education*.

² Publication Status:

Carlton, S., Stephenson, J., & Carter, M. (2014a). "Can you tell me how you came to your decision...?": A qualitative consideration of intervention decision-making of parents of preschoolers with autism spectrum disorder. Manuscript submitted for publication.

decisions to use or reject interventions, indicating that they placed greater weight on some factors compared to others. The data collected were used to inform later survey research.

Pages 151-179 of this thesis have been removed as they contain published material. Please refer to the following citation for details of the article contained in these pages.

Carlton, S., Stephenson, J., & Carter, M. (in press). Parent perspectives on sources of information about autism interventions in Australia. *Australasian Journal of Special Education*.

“Can You Tell Me How You Came to Your Decision...?": A Qualitative Consideration of Intervention Decision-Making of Parents of Preschoolers with Autism Spectrum Disorder.

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Abstract

Qualitative analysis of interviews conducted with twelve parents of preschool-age children with autism spectrum disorder (ASD) was undertaken. The parents reported how they chose to use, reject, continue using, and discontinue self-nominated interventions. They also indicated which criteria played a role in their final decisions to use and reject the nominated interventions. A range of different factors influenced intervention decisions, including some that were consistent with previous research. While the research revealed idiosyncratic and complex interplay between the factors, the most common criteria nominated as influencing the final decisions to use and/or reject interventions were those related to availability, logistic considerations, and service characteristics (such as the structure and delivery of the intervention program). Recommendations for future research are offered.

Keywords: autism spectrum disorder, choice, decision-making, intervention, parent

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“Can You Tell Me How You Came to Your Decision...?”: A Qualitative Examination of Intervention Decision-Making of Parents of Preschoolers with Autism Spectrum Disorder.

Parent reports of interventions used with children with autism spectrum disorder (ASD) have revealed that parents are typically using a number of interventions for ASD concurrently (Carlson, Stephenson, & Carter, 2014). Furthermore, it is common for parents to try and then discontinue interventions. For example, in both Goin-Kochel, Myers, and Mackintosh (2007) and Green et al. (2006), parents surveyed about their intervention use reported having used an average of eight different interventions in the past. These were in addition to the mean of 5.2 (Goin-Kochel et al., 2007) and seven (Green et al., 2006) interventions that the parents reported currently using. Even when data collection was restricted to parents of preschool-age children (2.2 - 5.0 years, $M = 3.5$ years), a mean of 1.4 educational and therapeutic interventions (range = 0 - 4) were reported to have been used in the past (Carter et al., 2011).

Parent decision-making about interventions has been reported to have been influenced by a variety of factors, including recommendations, cost and availability, and perceived effectiveness of interventions (Carlson, Carter, & Stephenson, 2013). Parents have commonly reported receiving recommendations from other parents of children with ASD, medical doctors and other professionals (such as occupational therapists and speech therapists), books or authors on autism, the internet, friends or relatives, and school teams or educators (Christon, Mackintosh, & Myers, 2010; Hanson et al., 2007; Hebert, 2014; Miller, Schreck, Mulick, & Butter, 2012; Wong & Smith, 2006).

It is logical for parents to consider the cost of interventions and possible access to additional funding when choosing interventions. It is not surprising that these pragmatic factors have been frequently nominated by parents as influencing decision-making (e.g. Bowker, D'Angelo, Hicks, & Wells, 2011; Christon et al., 2010; Hebert, 2014). Other nominated factors related to pragmatic issues included the availability of and/or accessibility

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to interventions, and time constraints (Christon, et al., 2010; Smith & Antolovich, 2000; Wong & Smith, 2006). Additionally, parents also reported taking into consideration the interventions currently being used, and whether they would be compatible with new interventions (Bowker et al., 2011; Christon et al., 2010; Smith & Antolovich, 2000; Wong & Smith, 2006).

Parent perceptions of the effectiveness of interventions in meeting their child's perceived needs or goals, parent satisfaction with the intervention, and the child's resistance to or preference for the intervention have been frequently reported to play a role in decisions regarding the continuation or discontinuation of interventions (Bowker et al., 2011; Christon et al., 2010; Wong & Smith, 2006). Additionally, the use and perceived effectiveness of other interventions and the possibility of treatment side effects or adverse effects were considered by parents when deciding whether to commence using new interventions (Hanson et al., 2007; Smith & Antolovich, 2000).

The level of research support for the intervention appears to be important to some parents in their intervention decision-making (Hanson et al., 2007). However, it should be noted that research evidence has not been reported as frequently across studies as other factors such as recommendations and pragmatic considerations (Carlon et al., 2013).

Data related to the weight of importance that parents place on different criteria in their decision-making are limited. Hanson et al. (2007) asked parents to rate the importance of a series of statements related to decision-making regarding their use of Complementary and Alternative Medicine (CAM) interventions. Issues related to safety and possible side effects of medications were rated as important by the greatest number of participants, followed by physician recommendation and the preference for a scientifically proven therapy. In addition, Smith and Antolovich (2000) reported that the first source from which parents of children using Applied Behavior Analysis (ABA) heard about supplemental interventions (speech therapy, megavitamins, sensory integration, and/or elimination diets) was not necessarily the

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most influential source in their decision to commence using these interventions. These survey findings indicate that parents appear to be weighing up a number of factors when making decisions about interventions to employ. In-depth qualitative investigation focusing on actual decisions of parents would allow for exploration of the range of different factors parents consider when making intervention decisions, the interplay between these factors, and whether they identify one or more of these as being critical to their final decision.

Existing research examining factors in parental decision-making has largely been conducted in North America. More specifically, there are limited Australian data related to factors identified by parents as influencing their intervention decision-making (Lynch, 2004; Rajkovic, Thompson, & Valentine, 2010; Valentine, 2010; Valentine, Rajkovic, Dinning, & Thompson, 2010) and existing studies have typically not addressed the range of different factors considered by parents of children with ASD in commencing and discontinuing a range of nominated specific interventions. Questions that are focused on parent decisions about specific interventions, rather than decision-making in general, offer the advantage of supporting parents to accurately recall what had influenced actual decisions rather than hypothesize about factors that might have been important in decision-making.

The unique structure of funding for interventions in Australia may mean that some factors may be more important to families living in Australia than those living in North America. In Australia, the Federal government offers some funding for parents of preschool-age children with ASD through the “Helping Children with Autism (HCWA) package”. This funding can be used to access interventions delivered by approved providers (Australian Government Department of Families, Housing, Community Services, and Indigenous Affairs, 2012). Additionally, individual State and Territory governments also fund both general and autism-specific early intervention programs in each state/territory, but the number of places may be limited and long waiting lists may apply.

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Some medical-based interventions, such as speech therapy and physiotherapy, may be provided in part through the public health systems in each state/territory. However, there are often long waiting lists to access these public services (Valentine, 2010). Private health insurance policies can cover part of the cost of visits to allied health professionals, such as speech pathologists and physiotherapist, and also CAM practitioners such as chiropractors. Unlike the private health insurance system in the United States, behavioral interventions are not covered by private health insurance.

The present paper is part of a larger exploratory qualitative study involving interviews with twelve parents. The purpose of the larger study is to examine both the sources of information used by parents in decision-making regarding intervention use for preschool-age children with ASD and the factors related to these decisions. In the present paper findings related to factors in decision-making are presented. Specifically, the following research questions are addressed: (a) How do parents decide whether to use or reject interventions?; (b) What factors in decision-making are most important in the final decision to use or reject an intervention?; and (c) How do parents decide whether to continue using or to discontinue interventions?

Method

As this research is part of a larger study, the description of the participants, instruments, procedure, and data collection has been adapted from Authors (2014).

Participants

Participants were 12 parents of preschool-age children with a diagnosed ASD in New South Wales (NSW) and the Australian Capital Territory (ACT). They responded to recruitment notices that were distributed by early intervention staff via email or in person to parents receiving early intervention services through Autism Spectrum Australia (Aspect), the largest provider of autism-specific early intervention in Australia.

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The participants were 11 mothers and one father, with education levels ranging from high school to postgraduate university degrees. The majority (seven) were aged between 35 and 44 years, four between 25 and 34 years, and one over 44 years. Annual family income levels were reported in 11 cases. Five families had income levels between \$40,000 and \$80,000; three between \$80,000 and \$120,000; and three over \$120,000 per year.

The children were four girls and eight boys, with a mean age of 4.0 years (range 3.0 - 4.9, $SD = 0.59$). Based on parent report, eleven were diagnosed with autism and one with pervasive developmental disorder - not otherwise specified (PDD - NOS). Parent ratings of the severity of ASD symptoms ranged from mild to severe.

Instruments

A copy of the questions used in the present report is available in the appendix. The questions focused on parent decisions about specific interventions rather than decision-making in general, in contrast to previous studies which have taken a broader approach to questioning (e.g., Hebert, 2014). This was to support parents to accurately recall what had influenced actual decisions rather than hypothesize about what may have been important in decision-making. In general terms, parents were asked about interventions they considered and decided not to use, interventions they were currently using, and interventions they had discontinued.

Procedure

Ethics approval for conducting the interviews, including the use of an incentive for participation, was obtained from the relevant ethics committees. Interviews were conducted by the first author, in person at one parent's request and via telephone in the other 11 cases. The interview schedule was used along with additional probe questions to clarify information provided by the interviewees, as needed. All interviews were audiotaped and later transcribed by the first author. This provided the opportunity for emergent insights into the themes present in the data (Patton, 2002). Transcripts were sent to the study participants to allow

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them to be checked for accuracy and some minor additions/changes were made to a small number of transcripts. The amended transcripts were used in the data analysis.

Data Analysis

The first author acted as the primary coder, using open coding (Strauss & Corbin, 1998) to identify emergent themes in the data. All transcripts were examined and a preliminary list of themes and sub-themes was developed. In addition, the three authors used deductive analysis (Patton, 2002) to identify possible themes and sub-themes from the interview questions, and added these to the list. The themes related to aspects of decision-making as explored in the interviews, such as factors in decision-making, reasons for continuing to use interventions, and actual and hypothetical reasons for discontinuing interventions. Themes also included those related to factual information, such as the type of intervention used, and whether it was used currently, used in the past, or heard of but never used.

The qualitative data analysis computer program TAMS Analyzer (Weinstein, 2011), was used to analyze the data. A list of possible themes and sub-themes was used in the final coding of the transcripts (available from the first author on request). Across the entire study, reliability was undertaken by the first two authors. They reached agreement of an average of 80.1% across three entire transcripts and all disagreements were resolved through consensus of the three authors. The remaining nine transcripts were coded by the first author.

The major themes, themes, and examples of sub-themes related to the factors impacting parent decision-making are presented in Table 1 (insert Table 1 about here). The authors noted that although the themes were related to different aspects of decision-making, there were commonalities between a number of sub-themes within different themes. For example, funding (or lack thereof) had been coded as an advantage of an intervention, a disadvantage of an intervention, a reason for discontinuing an intervention, a reason an intervention would hypothetically be discontinued in the future, and a reason for continuing to

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use an intervention. There were also a number of other sub-themes related to financial matters. The three authors re-grouped the sub-themes into themes related to factors in parent decision-making through a process of discussion until consensus was reached. In a number of cases these new themes appeared to be related and were grouped to form major themes.

Results

Interventions Used

Participants listed the interventions they were currently using, any that they had used in the past but discontinued, and interventions that they had heard about but not used. No restrictions were placed by the investigators on what may be considered an intervention, so the interventions reported represent the participants' interpretation of the term "intervention". The most common currently used interventions were autism-specific centre-based early intervention programs (10 participants); childcare, preschool, or kindergarten (8); occupational therapy (7); speech therapy (5); and generic (not autism-specific) centre-based early intervention programs (4). Those most commonly discontinued were speech therapy (9); occupational therapy (5); and dietary interventions (4). In some cases the discontinued intervention was recommenced using a different service provider (e.g. a different speech therapist): in others, the intervention was not used again. Those interventions most frequently heard of but not used were dietary interventions (9); applied behavior analysis (ABA; 7); Autism Behavioural Intervention (ABI [a home-based autism-specific program based on the principles of ABA]; 4); and medication (4).

Factors in Decision-Making

Participants discussed factors related to their decisions to commence using and to reject interventions. Parents were asked to reflect on decisions regarding specific interventions rather than discuss decision-making in general. Depending on each participant's interpretation of the term "intervention", some responses related to decisions about a type of intervention (e.g. ABA, speech therapy), and some responses related to decisions about using

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a particular service provider to deliver an intervention (e.g. the use of a specific speech therapist). In three cases parents mentioned a single factor related to their decision. However, for the majority of decisions, parents identified a number of decision-making factors and were asked “Which criteria played a role in your final decision to use/not to use this treatment/intervention?” Participants also explained how they chose to either continue using or discontinue interventions, and were asked the hypothetical question “What would influence you to stop using it?”

Themes identified in the participants’ responses are shown in Table 1. The factors identified as common themes in decisions to use, reject, and discontinue interventions are presented below. Those most frequently nominated as playing a role in the final decision to use and/or reject an intervention are presented first.

Availability, and accessibility/logistic considerations. The availability of the intervention was nominated by several parents as playing a role in their final decision to use and/or reject one or more interventions. Availability seemed especially important to parents for interventions which were subsidized by government funding (e.g. generic early intervention, ABI, and occupational therapy offered by service providers approved for HCWA package funding). Due to waiting lists for such interventions, however, the location offered was not always ideal but parents felt that they needed to accept the place, even if it involved personal inconvenience. Parent J explained “... I was lucky to get a spot because they have very limited places...I didn’t have a choice”. As a result, her daughter attended a generic early intervention program outside of her local area, which was inconvenient for her: “I leave her at 10 and I don’t go home, so I’m either wandering around the shops or I sit near there and read the paper”. Although she considered the other factors in her decision-making she prioritized availability.

However, for other interventions the accessibility and location of the intervention were particularly important for Parent J because her child with ASD had a sibling who had high

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support needs, and she needed to dedicate a certain amount of time to caring for him at home. This was one of the reasons that she chose to use home-based autism-specific early intervention and a childcare centre “a couple of streets away” from her house. Similarly, Parent E chose a local autism-specific playgroup and chose to administer acupuncture at home himself because it was convenient. A lack of accessibility also led to parents rejecting interventions, as Parent B explained: “Logistics is the issue for us and I felt that travelling time could be the issue.”

By comparison, some parents will travel a long way to access interventions. Parent I commuted approximately 1.5 hours each way one day per week to attend an autism-specific playgroup. She did so because she felt there was not an alternative closer to her, apart from a non-autism specific (generic) playgroup.

These factors also influenced parents’ decisions regarding discontinuation of interventions. Logistical considerations and time constraints led to Parents D and K discontinuing occupational therapy and Parent H discontinuing centre-based autism-specific early intervention. They were also offered as reasons that Parents E and G would hypothetically stop using interventions in the future.

Service characteristics and parents’ response to these. Parents A and L believed that an intervention being delivered in an autism specific environment was an advantage, and chose interventions and service providers based on this. In contrast, Parent G felt that this was not necessarily the case: “... the difference is that *Service Provider A* has children not only with autism but with different disabilities, so I thought it is good for my child to interact with different children with different levels of skills and knowledge” (generic centre-based early intervention).

Other parents identified specific aspects of the structure and delivery of interventions as playing a role in their final decision regarding use. Both Parents E and K identified the flexibility of the delivery of an autism-specific playgroup and of a home-based autism-

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specific early intervention program (respectively) as criteria in their final decision to use these interventions. The small group size was an important consideration in Parent B's decision to use a generic early intervention program.

Parents also discussed how their beliefs about different intervention approaches played a final role in their decisions to either use or reject interventions. Parents A and J, for example, did not use interventions based on the principles of ABA (ABI and ABA) because they did not think that their children would respond to that approach. For some parents the final decision was based on whether they believed in the efficacy of the intervention or the claims of the provider. Parents E, G, and H indicated that their final decisions not to use kinesiology, CAM interventions, and detoxification (respectively) were due to believing that the claims about them were not feasible.

The level of accountability offered for the intervention through monitoring and reporting were reasons that Parent B continued using speech therapy and Parent K continued using centre-based autism-specific early intervention. The specific strategies and approaches used within interventions also contributed to parents' decisions about the continuation of interventions. Parent I continued using an autism-specific playgroup because the approach was naturalistic, and Parents J and K discontinued speech therapy and occupational therapy (respectively) because they believed the therapists were using general (rather than autism-specific) strategies.

The structure of the program also influenced parent decision-making regarding discontinuation. Parent I explained why she stopped using music therapy: "She tried - she really, really tried but it was poorly organized so I stopped". Parent D stopped using a social skills program after six weeks because it was a fixed-time program. Additionally, Parents A (ABI), E and I (centre-based autism-specific early intervention) all predicted that they would stop using fixed-time intervention programs in the future. Staff turnover was the reason that Parent E stopped using ABA and also the hypothetical reason that Parent I would stop using

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occupational therapy with her current service provider. Other staff factors that influenced parents to continue using interventions were the availability of a teacher's aide at childcare (Parents A and L) and access to a multidisciplinary team of professionals (Parent B).

Child factors. Parents considered the individual characteristics and needs of their children in commencement decisions. This involved parents making predictions about how the intervention would relate to their child's specific needs, for example:

“...it just seemed like it was a step towards helping him transition to the school environment, it's like doing a mini afternoon of school, having to sit with other kids and listen, and do all of the activities he's instructed to do. So it was just going to be a good thing to do to get him ready for school.” (Parent H, autism-specific centre-based early intervention).

Parents also identified when they believed that an intervention would not address an area of need. Parents F, H, and K rejected dietary interventions, detoxification, and ABI (respectively) because they thought that the interventions would not suit their children's needs. Additionally, Parent I considered her child's age when commencing a dietary intervention.

The individual characteristics and needs of their children were also considered in continuation decisions. Once parents commenced using interventions they assessed their children's responses. For example, outcomes related to the child's communication, including improvements in expressive and receptive language, were stated as reasons for continuing to use a variety of interventions (speech therapy, autism-specific centre-based early intervention, autism-specific home-based early intervention, ABA, generic centre-based early intervention, childcare, autism-specific playgroup, and occupational therapy). Conversely, Parents E and H discontinued the use of ABA and Connect therapy respectively because they believed they were ineffective, and Parents C, D, G, J, and L all discontinued using specific speech therapists for the same reason. Furthermore, when asked “What would influence you to stop

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using it?” parents often predicted that their decision would be influenced by the effectiveness of the intervention. This included both if it were to be ineffective, or if it were to be effective and therefore no longer needed because the child had achieved the desired outcomes.

Along with the child’s response to the intervention in terms of actual or perceived effectiveness, the response in terms of cooperation, apparent enjoyment, and their relationship with staff were also important to a number of parents. For example, Parent B explained one of the reasons that she continued to use a particular speech therapist:

Then I realized that [*my child*] had taken a lot of time to get used to one therapist, and she’s not going to go with another one... because [*my child*] is still responsive to her. So it’s not all about me. I might not feel totally comfortable, it’s all about [*my child*] feeling comfortable with her.

Positive relationships between staff and children were also cited as reasons to continue using autism-specific centre-based early intervention (Parents D and G) and occupational therapy (Parent H). Additionally, Parents C, D, G, I, J, and L continued to use interventions because their children appeared happy or to enjoy the intervention. In contrast, staff expectations of children that parents believed were inappropriate led to parents discontinuing occupational therapy (Parents F and K), speech therapy (Parents F and G), and a generic playgroup (Parent I).

Cost and funding. Every parent identified cost as influencing their decision-making at some level, although Parent B commented “Cost is not an issue for us in most of the cases”. It is of note that Parent B’s family had an annual income of over \$120,000 with one child to support. For other parents, cost played a more vital role in their decision-making. Parent I, for example, described her disappointment surrounding her decision not to use an autism-specific early intervention program due to the cost:

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I offered my two days a week to the office, or mowing lawns, or whatever they needed to be done, it wasn't enough. My husband even offered to do their accounts because he's an accountant, but no, parents still need to fundraise the \$40,000 (per year).

Cost was often referred to by parents who considered using ABA. Parents C, D, F, and H all identified cost as playing a role in their final decision not to use it. Parents C, D, and F all stated that they would use ABA in the future if they had more money.

Interventions were not always rejected due to the cost. Parent I's final decision to use an occupational therapist involved not only consideration of the cost, but value for money: "The fact that if I was going to pay the money, I wanted to get the best out of it. So that's going the autism specific way". The cost of interventions also influenced parents' decisions regarding the continuation of interventions. Parent E discontinued using ABA for reasons including the cost, and Parent G decreased the intensity due to the restrictive cost. Parents also considered whether they would receive value-for-money when deciding whether to continue using interventions with specific service providers. Parents C, F, H, and L discontinued using interventions or service providers because they felt they were not worth the cost.

Funding was also a consideration for some parents. Specifically, being able to use the HCWA package funding played a role in the final decisions of Parents F and H to use specific service providers for occupational therapy and autism-specific centre-based early intervention (respectively). Additionally, not being able to use this funding with a generic early intervention service provider was the reason that Parent J decided not to use a generic early intervention program.

The impact of funding packages on continuation decisions was discussed by a number of parents. Parent H continued using an intervention that she thought was ineffective until the number of weeks that she had paid for upfront (using HCWA package funding) expired, and Parent J discontinued using a speech therapist because the therapist was not approved for the

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use of the HCWA package funding. Funding arrangements can be complex: for example, Parent H explained how accessing funding can lead to having to discontinue an intervention or change service providers:

...through Community Health, we got some free speech therapy so that's why we did it...and then when the FaHCSIA (HCWA package) money came through that stopped, because they said they couldn't give us anymore Community Health speech (therapy) until our FaHCSIA money was gone.

Parent H described then choosing other interventions which she could use the HCWA package funding to pay for. Parent C noted that she may need to discontinue interventions in the future when funding is no longer available: "Once the FaHCSIA [HCWA package] money runs out you only get five [visits to the speech therapist] rebated through Medicare every year". She also noted that she would discontinue using a NSW State Government supported behavioral intervention program, ABI, once the funded hours ran out.

Advice/recommendations. A number of parents reported receiving advice/recommendations about interventions from different sources. When asked "Is there anything that you think could help you to make good decisions about treatments or interventions?" Parents A and D both discussed the importance of advice from other parents. However, in practice, the recommendations that played a role in the final decisions of parents were all from professional sources. Parent D identified advice from a doctor as influencing her final decision to reject dietary interventions, and advice from pediatricians (Parents B and C), the autism advisor program (Parent A), a doctor (Parent D), and service providers (Parent H) were identified as final criteria in decisions to use autism-specific early intervention, childcare, a specific speech therapist, autism-specific centre-based early intervention, and a specific childcare centre (respectively).

Family impact. Parents considered the impact that the intervention would have on their family. One of the factors that played a role in Parent J's final decision to use home-based

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autism-specific early intervention was that she had another child at home with high support needs. Parent H also thought of her other children and the convenience to the family when making the final decision to send her son to a preschool next to his siblings' current school. The expected family inconvenience of implementing dietary restrictions resulted in Parents F and L rejecting dietary interventions.

The impact of interventions on their other children was also important when considering continuation of interventions. One of the reasons that Parent H discontinued a centre-based autism-specific early intervention program which included a parent component was that her son with autism had a twin sister whom she needed to take with her to the parent component whilst her son was involved in the intervention. Similarly, Parent J described how taking her daughter to a speech therapist had a negative impact on other family members:

... I had to drag [*my other child*] along, and I had to drag my mother in law along to stay with [*my other child*], and then I was in the room with her and I could hear him screaming so it was a big drama, that was one big issue that turned me off.

She consequently stopped using that speech therapist.

The impact of the intervention on the parents also influenced whether parents continued using interventions. Staff offering parent support (Parents B, I, and J) and training (Parents F and I) led to parents continuing to use interventions. Additionally, a lack of parent training led to Parent K discontinuing the use of an occupational therapist. Parents C and L both nominated the respite offered to them as a result of the use of childcare as a reason to continue using it.

Parent's beliefs and emotions. Some parents viewed certain interventions as “the only option”. Parent C stated that she believed speech therapy was “a necessity” and Parent G, when reflecting on her final decision to use ABA, stated “we just didn't see any other option”. Other parents described feeling that they should try any option: “Try anything- I have that opinion that I'll try anything once really” (Parent I, play therapy); “I thought ‘it's better

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than nothing, at the moment my child's not improving at all.' So I thought 'I've got to try something', because at that time I wasn't doing anything for her" (Parent L, Relationship Development Intervention [RDI] based occupational therapy)

Consideration of the possibility of future guilt was also reported by parents to have played a role in their decision-making. For example, it was the final consideration in Parent I's decision to use a special diet, who explained: "I couldn't not give this diet a try when so many are doing it, and then never know".

Parents also relied on their own intuition or "gut feelings" to guide them in their decision making. This was described by Parent F when asked "Are there any other factors that you feel are important to consider in the decision-making process?":

Know what you're looking for. If I was talking to a new mum, who's just had a child diagnosed, know what you're looking for, listen to your gut. Because I think parents know more, we may not know the procedures and the therapies, but we know the right person, what does and doesn't fit.

Staff characteristics and parent's perceptions of, and relationships with, staff. Staff experience of working with children with ASD led to the use of particular providers of occupational therapy (Parents I and K). That the staff were knowledgeable (Parent I, autism-specific playgroup), and the "skills of the teachers" (Parent L, generic early intervention) were other characteristics identified as criteria for commencing interventions.

Parent's perceptions of staff also influenced their final decision-making. Parent J believed the management of a childcare centre was professional and therefore chose to use that particular service provider. She also described how she was influenced by the service provider of an autism-specific early intervention program who spent time explaining the program to her: "I think she spent about 2 hours here, she was very positive and showed me all of the main points that they would go through and how they would help [*my child*]." She compared this to experiences with other service providers:

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Because a lot of people, the first thing they ask you is ‘Oh, how much FaHCSIA money [HCWA package funding] do you have?’, and when I hear that I think well you’re not really here for the interest of my daughter if you’re asking me about money.

Parent B also reported the perceived sincerity of a service provider of a generic early intervention program influencing her decision to use it.

Professional attributes of the staff, including expertise (Parent D, centre-based autism specific early intervention), knowledge (Parent K, occupational therapy), qualifications (Parent I, play therapy), and experience working with children with ASD (Parent I, play therapy) were reasons given for continuing to use interventions. Parents G and H discontinued using particular speech therapists, and Parents J and K particular occupational therapists because they believed the therapists lacked experience working with children with ASD. Additionally, Parent I stopped using music therapy because she thought the facilitator was inexperienced.

Parent perceptions of staff in relation to personality traits and perceived intentions also influenced their continuation decisions. One of the factors influencing Parent I to continue using play therapy was that the person implementing the therapy had “a really beautiful nature”. Similarly, Parent L described the teacher’s aide at the childcare centre as a “really nice woman” and one of the reasons that she continued to use the intervention. Parent K continued to use centre-based autism-specific early intervention because she believed that the staff members were committed to helping her child achieve set goals. Conversely, Parent K stopped using an occupational therapist because she perceived her as having a negative attitude.

Parent L also continued to use childcare because the staff member was open to input from others. In contrast, Parent J discontinued using a speech therapist because she felt that the therapist ignored parent input. Staff ignoring parent input was a reason given by Parent I that she would not recommend a discontinued music therapy program to other parents and a

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reason that Parent A would hypothetically discontinue speech therapy and childcare in the future.

Use and availability of other interventions. The decision to commence new interventions was influenced by the effectiveness of interventions that parents were currently using in some cases. Parent F was not satisfied with the occupational therapist she was using so commenced occupational therapy with the only other provider in her area approved for the use of HCWA funding. Conversely, Parent A was pleased with the home-based autism-specific early intervention program she was using and this was the reason she commenced using a centre-based program with the same service provider. This was also the case for parents who had used an intervention or service provider with a sibling of their child with ASD. For example, Parent A used a particular childcare provider because of past experience with a sibling, and Parent E stated that success in using acupuncture with his older son led to him commencing and continuing to use it with his younger son.

Parent A, however, rejected ABI because she was “already doing quite a few programs, it would be just too much if we were to do another one”. Parent K also rejected ABI because she thought her child was responding well to home-based autism-specific early intervention and that she would have to discontinue it if she commenced ABI. Parents H, K, and L stated that they were not looking for new interventions because they were satisfied with the interventions they were currently using.

The availability of alternative interventions and/or service providers, or lack thereof, was also considered by parents. When discussing making the final decision to use an RDI-based occupational therapist, Parent L reflected that “all of the well-known service providers that you ring up have long waiting lists” and the lack of an alternative led to her commencing this type of occupational therapy.

Parent F discontinued using an occupational therapist and a speech therapist when she found alternative therapists. Parent H also changed speech therapists; this was because she

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could access speech therapy through the public health system for free. Parent F discontinued the use of speech therapy and began using the Hanen program, which she saw as a better alternative. Other parents stopped using interventions once they commenced new interventions and saw results that they attributed to the new interventions. For example, Parent H explained why she discontinued using Connect Therapy: “that’s when we started using the Footprints program [ABI] and we just saw so much result in such a short time from Footprints that it was just like chalk and cheese”. Parents also considered the availability of alternative interventions when they predicted whether they would continue using an intervention. For example, Parents B, J, and K all stated that they would only discontinue the use of early intervention programs if their children were accepted into autism-specific schools.

Parents also considered whether the strategies used across interventions were consistent. Parent B continued using a speech therapist because the strategy used was based on the Hanen method and consistent with the approach used in the child’s centre-based autism-specific early intervention program. Parent C continued using speech therapy because the strategies used and goals being worked towards were consistent with those in the ABI program, and Parent L began training in the use of RDI because it was the approach used by her child’s occupational therapist. However, even if interventions are similar it does not necessarily mean that parents will continue using both of them. Parent K discontinued a home-based autism-specific early intervention program so that she could commence using ABI (another autism-specific home-based program), explaining “I don’t want the two happening at once because it’s just too much”.

Research evidence. Parents E and H were the only ones who considered research evidence in their final decisions about intervention use. They rejected kinesiology and detoxification (respectively) because they did not believe these interventions were supported by research evidence. In contrast, Parent L dismissed the importance of research evidence:

...other parents, and they would blindly just go along with what the mainstream thinking was, which was ABA is proven to be the best and only ABA can work, and it's not always the case. Everybody seems to be driven towards that end of the spectrum to try first, and in doing that it's such a waste of time for the child and the parent.

Discussion

The present exploratory study has provided preliminary insights into the decision-making of parents of preschoolers with ASD regarding a range of interventions chosen, rejected, and discontinued. The themes related to factors involved in the selection and rejection of interventions, including those seen as the “final criteria” in these decisions, and the themes involved in decisions regarding the continuation of interventions can be used to form the basis of further investigations with parents. These themes, along with recommendations for future research and the limitations of the study, will be discussed.

Factors in Decision-Making

The themes explored by the participants in this study included factors related to availability and logistics; service characteristics and parents' beliefs about/response to these; child factors; cost and funding; advice; family impact; parents' beliefs and emotions; staff characteristics and parents' perceptions of, and relationships with, staff; the use and availability of other interventions (including those used in the past); and research evidence. Although some of these types of factors have been examined in previous survey research (e.g. recommendations, availability/accessibility, and cost; Christon et al., 2010; Hanson et al., 2007; Miller et al., 2012; Smith & Antolovich, 2000; Wong & Smith, 2006), others have only been examined in qualitative studies, for example service characteristics such as whether the intervention is autism-specific (Valentine, 2010), parent emotions such as “gut feelings” and the possibility of future guilt (Hebert, 2014; Loomis, 2007), staff characteristics such as the training/experience of the staff (Hebert, 2014; Valentine, 2010), and the fit of the parent or child with the therapist (Hebert, 2014; Shyu, Tsai, & Tsai, 2010). Quantitative investigation

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of the variety of factors identified in the present study using a larger and more representative sample of parents in the future would provide a more complete picture of factors considered by parents in their decision-making.

Parents reported that a range of different factors influenced their decision-making, for most of the decisions described. Although there was clearly a complex idiosyncratic interplay of factors in decision-making by families, respondents were nevertheless able to nominate a specific factor that helped them make a final decision regarding using or rejecting nominated interventions. A pattern emerged in the present sample where the most common factors nominated as influencing the final decisions to use and/or reject interventions were those related to availability, logistic considerations, and service characteristics (such as the structure and delivery of the intervention program). Whether this pattern was representative would need to be investigated systematically with a larger sample. Access to services appeared to be a key issue for many families, which is consistent with previous Australian research (Valentine et al., 2010). Roberts et al. (2011) noted in a randomized control trial of early intervention service delivery types that there is a need for providers to offer different types of programs to suit individual child and family circumstances. As illustrated by Parent J's choices in the present study, although flexible service delivery options are sometimes available, this is not always the case. There is a need for providers to develop a range of service delivery options in the future.

In contrast to the present study in which the above factors were most frequently nominated as critical in decisions to use and reject interventions, Hebert (2014) reported that teachers and staff were the most important factor related to choosing an intervention program for the majority of the parents. Despite the apparent difference in the importance assigned to staff characteristics, it should be noted that some parents in the present study did nominate staff characteristics such as experience, knowledge and skills, along with parent perceptions of staff (which may have been related to what Hebert, 2014 described as interpersonal style),

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as critical factors in decisions to commence interventions. It should also be acknowledged that Hebert's (2014) sample included children of preschool and school age, in contrast to the present research, which was limited to preschool aged children. This may possibly account for the differences in findings. The present study also revealed that characteristics such as staff training and experience, and parent perceptions of staff were commonly considered in the continuation and discontinuation decisions of parents. The parent's perceptions of staff personality traits and intentions may be related to the interpersonal style of the staff, and as such this may have implications for the training of professionals with regard to the importance of effective communication with parents.

When asked about reasons for continuing or discontinuing interventions, parents identified similar themes to those identified as important in commencing interventions but with a somewhat different focus. For example, with regard to child factors, the parents focused on the child's actual response and assessment of outcomes rather than predicting the child's likely response. In a recent online survey, when parents were asked "What do you like/dislike about the treatments you're currently using?", over half of the participants responded with comments related to the effectiveness of treatments, indicating that the perceived effectiveness of interventions may be a significant consideration for many parents (Mackintosh, Goin-Kochel, & Myers, 2012). It appears logical that once a parent had made a decision to use an intervention, their child's apparent response to it would become a critical factor. However, in the present study, the child's relationship with, and response to, staff, and other outcomes such as respite were also offered by parents as reasons for continuation, highlighting the interplay of different factors that are considered in such decisions. These findings were consistent with larger survey research in the area (Bowker et al., 2011; Christon et al., 2010; Wong & Smith, 2006).

Cost was a factor that influenced the decisions of all of the parents in this study, including those regarding the rejection of conventional intervention approaches such as ABA

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and autism-specific early intervention programs. In comparison, Hebert (2014) reported that in the sample of parents living in the United States cost was primarily a significant issue specifically for families considering alternative interventions, such as CAM interventions and horseback riding. This difference in attitudes to cost may reflect differences in funding approaches to interventions for ASD and highlights the need to consider country-specific contextual issues in research regarding the decision-making of parents.

The experiences of parents in the present study in changing service providers and types of interventions used based on the funding support available highlighted the complexity of the funding system for parents of children with ASD in Australia. Future researchers could more systematically investigate the role of funding in parents' initial intervention and service provider decisions and also the role that funding plays in discontinuing interventions and changing service providers. An additional change to the Australian funding system that will require careful monitoring in terms of the impact on parent decision-making is the roll-out of the National Disability Insurance Scheme (NDIS). This scheme aims to provide individualized support to individuals, families, and carers of those with disabilities (National Disability Insurance Agency, 2014b). The funding of the intervention component of the HCWA package will be replaced with funding from the NDIS as the scheme is implemented across Australia over the coming years (National Disability Insurance Agency, 2014a). The impact of this funding change on parent decision-making could be assessed in future research.

Limitations

Some limitations of the present study should be acknowledged. This was an exploratory qualitative study of twelve parents of children in suburban areas of NSW and the ACT in Australia. They were all recruited through the same service provider, Aspect, and as such, generalization to other populations cannot be made. Parents were asked to nominate interventions to allow them to reflect on actual decision-making rather than hypothesize about what may be important in decision-making. The range of interventions for which decision-

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making was explored in this study is a reflection of the parents' interpretation of the term "interventions", so some of the interventions included are very broad. Furthermore, a number of the parents discussed decisions regarding the specific service delivery of an intervention rather than the use of the intervention in itself. This highlighted how much service delivery and staff factors, apart from the nature of the intervention, contributed to parents decisions about which interventions to employ.

Conclusion

This exploratory qualitative study revealed that parents are considering a range of different factors in their intervention decision-making. The decisions can be complex, and the majority of the time parents prioritize one or more factor(s) above others in their final decisions to use or reject interventions. Future research should focus on the systematic investigation of factors considered important by parents in decision-making and the role of the funding system in Australia in influencing intervention decisions.

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Table 1

Major themes, Themes, and Examples of Sub-themes Related Factors in the Decision-Making of Parents

Major theme	Theme	Examples of Sub-themes
Availability, accessibility and logistics	Availability	<i>Decision-making factor:</i> availability <i>Discontinued:</i> no longer eligible <i>Hypothetically, would discontinue:</i> changes in availability
	Accessibility/logistic considerations	<i>Advantage:</i> location <i>Decision-making factor:</i> time taken to travel to intervention location <i>Would use in future:</i> accessibility
Structure and delivery of the intervention program, accountability, and strategies and approaches used	Structure and delivery of the intervention program	<i>Advantage:</i> centre-based <i>Decision-making factor:</i> group size <i>Reason for continuing:</i> multidisciplinary staff team
	Strategies and approaches used	<i>Advantage:</i> individualized <i>Advantage:</i> the technique is family-centered <i>Discontinued:</i> general strategies
	Accountability	<i>Advantage:</i> monitoring <i>Reason for continuing:</i> feedback <i>Reason for continuing:</i> reporting
	Parent beliefs about the intervention	<i>Decision-making factor:</i> the difficulty of administering <i>Decision-making factor:</i> the parent's beliefs about the approach <i>Reason for continuing:</i> unique method
	Physical environment/resources	<i>Advantage:</i> physical environment provides comfort <i>Decision-making factor:</i> physical environment <i>Discontinued:</i> lack of resources
	Autism-specific	<i>Advantage:</i> autism-specific <i>Decision-making factor:</i> autism-specific <i>Discontinued:</i> general strategies
Child factors	Perceived, expected, or actual response	<i>Decision-making factor:</i> parent beliefs about child's response <i>Discontinued:</i> ineffective <i>Hypothetically, would discontinue:</i> no longer needed

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	Child's specific needs/development	<i>Advantage:</i> social interaction with other children <i>Decision-making factor:</i> relevance to child's developmental/functional area(s) of deficit <i>Reason for continuing:</i> behavioral outcomes
	Child's perceived enjoyment	<i>Reason for continuing:</i> child is happy
	Child's age	<i>Decision-making factor:</i> age <i>Disadvantage:</i> age <i>Hypothetically, would discontinue:</i> age
	Physical risks	<i>Decision-making factor:</i> physical risks <i>Would use in future:</i> improved safety
Provision of information and advice/recommendations	Advice/recommendations	<i>Decision-making factor:</i> advice from an Autism Advisor <i>Decision-making factor:</i> advice from other parents <i>Would use in future:</i> on doctor's recommendation
	Information sharing by service provider or others	<i>Decision-making factor:</i> information provided by a contact from the service provider <i>Decision-making factor:</i> whether information provided was feasible <i>Decision-making factor:</i> marketing
	Reputation/social validity	<i>Advantage:</i> reputation <i>Decision-making factor:</i> parent knew other children using the intervention <i>Decision-making factor:</i> reputation
Staff characteristics, parent perceptions of staff, and relationships with staff	Past experience	<i>Decision-making factor:</i> past experience before the child's diagnosis <i>Would use in future:</i> past experience <i>Would use in future:</i> sibling success
	Relationship with staff administering the intervention	<i>Advantage:</i> child's past experience with the staff administering the intervention <i>Discontinued:</i> unproductive child-staff relationship <i>Reason for continuing:</i> parent-staff relationship
	Personal and professional attributes of staff administering the intervention	<i>Advantage:</i> staff autism experience <i>Decision-making factor:</i> staff knowledge <i>Reason for continuing:</i> staff expertise

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	Parent perceptions of staff attitudes and intentions	<i>Advantage:</i> staff interest in child's progress <i>Discontinued:</i> staff member was negative <i>Reason for continuing:</i> perceived intentions of the staff member
Use and availability of other interventions	Use and availability of other interventions	<i>Decision-making factor:</i> the availability (or lack thereof) of alternative interventions <i>Decision-making factor:</i> Parent confidence in other interventions <i>Discontinued:</i> a better alternative was found
Family impact	Support for the parents and others working with the child	<i>Advantage:</i> social support for the parent <i>Discontinued:</i> no parent training/sharing of knowledge <i>Reason for continuing:</i> practical support for the parent
	Impact on the family	<i>Decision-making factor:</i> convenience to the family <i>Discontinued:</i> due to negative impact on the family <i>Reason for continuing:</i> respite for the parent
Research	Research	<i>Decision-making factor:</i> research evidence <i>Would use in future:</i> if supported by research
Cost and funding	Cost and funding	<i>Disadvantage:</i> cost <i>Would use in future:</i> money <i>Reason for Continuing:</i> funding available
Parents' personal beliefs and emotions	Parent beliefs	<i>Decision-making factor:</i> beliefs about importance of early intervention <i>Decision-making factor:</i> cultural beliefs <i>Decision-making factor:</i> belief that doing "something" to try to help is better than doing nothing at all
	Parent emotions	<i>Decision-making factor:</i> The possibility of future guilt <i>Decision-making factor:</i> Intuition/gut feelings <i>Decision-making factor:</i> The hope for a cure

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Appendix

Interview Questions

1. Can you tell me about the treatments or interventions that you are currently using with your child?

Who is delivering them? Are you doing it yourself or are using a service provider?

Which three of these treatments or interventions do you consider the most important for your child?

***For the three most important treatments/interventions repeat questions 2-4**

2. For treatment/intervention a can you tell me how you came to your decision to use it?

Where did you first hear about it?

Did you get information about it from anywhere else?

Did you receive conflicting information about this treatment/intervention? How did you decide which information was the most accurate?

What effects did you expect from the treatment/intervention?

What did you see as the pros or advantages of beginning this treatment/intervention?

What did you see as the cons? Did you think there were any risks?

Which criteria played a role in your final decision to use this treatment/intervention?

Do you intend to keep using this treatment/intervention?

3. What has influenced you to continue using this treatment/intervention?

What effects are you seeing?

4. What would influence you to stop using it?

5. Are there any treatments or interventions you have tried in the past but are no longer using?

***For the first three treatments listed repeat question 2, plus questions 6-8**

6. Why did you stop using the treatment/intervention?

8. What would influence you to start using it again in the future?

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9. Are there any treatments or interventions that you heard about and decided not to use?

Medical treatments? Dietary restrictions or nutritional supplements? Educational or therapy programs? Alternative therapies?

Is there one treatment or intervention you heard about and seriously considered using?

Is there one treatment or intervention that you heard about and were least likely to use?

10. For the treatment or intervention considered most seriously*, how did you come to the decision not to use it? (*Repeat question for the treatment or intervention least likely to use)

Where did you first hear about it?

Did you get information about it from anywhere else?

What did you see as the pros or advantages of beginning this treatment/intervention?

What did you see as the cons? Did you think there were any risks?

Did any of the following influence your decision: costs, availability or accessibility to the treatment or intervention, claims which you did not believe, you found an alternative you thought was better, difficulty of administering it, time constraints, was it not relevant to your child's needs?

Which criteria played a role in your final decision not to use this treatment/intervention?

What would influence you to change your mind and use the treatment/intervention in the future?

13. Is there anything that you think could help you to make good decisions about treatments or interventions?

14. Are there any other factors you feel are important to consider in the decision-making process?

APPENDIX 1

Full Interview Schedule Used in Carlon, Stephenson, and Carter (in press) and Carlon, Stephenson, and Carter (2014a)

Interview Schedule

1. Can you tell me about the treatments or interventions that you are currently using with your child?

- Who is delivering them? Are you doing it yourself or are using a service provider?
- How many hours per week are you using the treatment or intervention?
- Which three of these treatments or interventions do you consider the most important for your child?

**For the three most important treatments/interventions repeat questions 2-4*

2. For *treatment/intervention a* can you tell me how you came to your decision to use it?

- Where did you first hear about it?
- Did you get information about it from anywhere else?
- Did you receive information from friends or relatives, other parents, medical staff, the internet, magazines, teachers or service providers, books, conferences, research/journal articles, media programs, newsletters or any other sources you can think of?
- Did you receive conflicting information about this treatment/intervention? How did you decide which information was the most accurate?
- What effects did you expect from the treatment/intervention?
- What did you see as the pros or advantages of beginning this treatment/intervention?
- What did you see as the cons? Did you think there were any risks?
- Which criteria played a role in your final decision to use this treatment/intervention?
- Do you intend to keep using this treatment/intervention?

3. What has influenced you to continue using this treatment/intervention?

- What effects are you seeing?
- Would you recommend the treatment/intervention to other parents? Why?

4. What would influence you to stop using it?

5. Are there any treatments or interventions you have tried in the past but are no longer using?

**For the first three treatments listed repeat question 2, plus questions 6-8*

6. Why did you stop using the treatment/intervention?

7. Would you recommend the treatment/intervention to other parents? Why?

8. What would influence you to start using it again in the future?

9. Are there any treatments or interventions that you heard about and decided not to use?

- Medical treatments?

- Dietary restrictions or nutritional supplements?

- Educational or therapy programs?

- Alternative therapies?

- Is there one treatment or intervention you heard about and seriously considered using?

- Is there one treatment or intervention that you heard about and were least likely to use?

10. For *the treatment or intervention considered most seriously**, how did you come to the decision not to use it? (**Repeat question for the treatment or intervention least likely to use*)

- Where did you first hear about it?

- Did you get information about it from anywhere else?

- What did you see as the pros or advantages of beginning this treatment/intervention?

- What did you see as the cons? Did you think there were any risks?

- Did any of the following influence your decision: costs, availability or accessibility to the treatment or intervention, claims which you did not believe, you found an alternative you thought was better, difficulty of administering it, time constraints, was it not relevant to your child's needs?

- Which criteria played a role in your final decision not to use this

treatment/intervention?

- What would influence you to change your mind and use the treatment/intervention in the future?

11. Which sources do you believe offer you the most reliable and accurate information about current treatments and interventions available for your child?

- Do you think any of the following are reliable sources: friends or relatives, other parents, medical staff, the internet, magazines, teachers or service providers, books, conferences, research/journal articles, media programs, newsletters?

12. How reliable do you believe the following sources of information are (not reliable, not sure, somewhat reliable, very reliable)

- *List sources of information participant has indicated they have used.*

13. Is there anything that you think could help you to make good decisions about treatments or interventions?

14. Are there any other factors you feel are important to consider in the decision-making process?

APPENDIX 2

Full List of Possible Themes and Sub-Themes Used in Carlon, Stephenson, and Carter (in press) and Carlon, Stephenson, and Carter (2014a).

Advantage of the Intervention:

- Autism-specific
- Centre-based
- Early intervention
- Financial>cost
- Financial>funding:
- Flexibility
- History
- Home-based
- Inclusive
- Individualised
- Information
- Intensity
- Location
- Monitoring
- New approach
- Past experience>child>staff
- Physical environment>comfort
- Reputation
- Social>child>adult
- Social>child>child
- Social>parent
- Staff>caring
- Staff>connection
- Staff>demeanour
- Staff>development
- Staff>experience
- Staff>interest in progress
- Staff>knowledge
- Staff>multidisciplinary
- Staff>professional
- Staff>qualification
- Staff>understanding
- Support>child>school Readiness
- Support>emotional
- Support>practical>others
- Support>practical>parent
- Technique
- Technique>family-centred

Type of Intervention:

- Current
- Discontinued
- Heard of but never used
- Applied Behaviour Analysis (ABA)
- Autism Behavioural Intervention (ABI)
- Acupuncture
- Animal therapy
- Aqua therapy
- Biomedical
- CAM
- Centre-based
- Chelation
- Child care, preschool or kindergarten
- Connect therapy
- Discrete trial training
- Detoxification sauna
- Diets
- Dolphin therapy
- Autism-specific centre-based early intervention program
- Autism-specific home-based early intervention program

- Early intervention program at an autism-specific school
- Generic centre-based early intervention program
- Fast For Word computer program
- Floortime
- More than Words: The Hanen Program
- Holistic
- Hyperbaric chamber therapy
- iLs audio treatment program
- Interaction with typically developing siblings or peers
- iPad
- Kinesiology
- Medication
- Music therapy
- Neurofeedback
- Occupational therapy
- Parental therapy
- Picture Exchange Communication System (PECS)
- Autism-specific playgroup
- Generic/non-autism-specific playgroup
- Play therapy
- Relationship Development Intervention (RDI)
- Manual signing/sign language
- Social skills training
- SonRise
- Sound therapy
- Speech therapy
- Stem cell therapy
- Vitamins, minerals and supplements

Disadvantage of the intervention:

- Age
- Cost
- Intensity>low>time
- Irrelevant
- No funding
- Staff>number
- Staff>skills
- Staff>staff changes
- Time>parent
- Time>travel

Reasons for discontinuing intervention:

- Alternative
- Eligibility
- Family impact
- Financial>expensive
- Financial>not approved for Department of Families, Housing, Community Services and Indigenous Affairs funding
- Financial>Funding ran out
- Fixed time program
- General strategies
- Ineffective
- No parent training
- No regression
- Not needed
- Poorly organised
- Resistant>food

- Resistant>uncooperative
- Resources
- Staff>ASD experience
- Staff>child relationship
- Staff>expectations
- Staff>experience
- Staff>ignored parent input
- Staff>negative
- Staff>turnover
- Time

Decision-making factors:

- Alternatives available
- Child : staff ratio
- Family impact
- Group size
- Staff
- Staff>demeanour
- Staff>knowledge
- Staff>understanding
- Time>travel
- Worth trying
- Accessibility
- Administering>difficulty
- Administering>person
- Advice>Autism Advisor
- Advice>autism associations
- Advice>books
- Advice>counsellor
- Advice>Department of Education and Training Advisor
- Advice>doctor
- Advice>friends/relatives
- Advice>General Practitioner
- Advice>internet
- Advice>media
- Advice>medical professionals
- Advice>occupational therapist
- Advice>paediatrician
- Advice>parents
- Advice>research
- Advice>school
- Advice>service providers
- Advice>speech therapist
- Advice>teacher
- Advice>training
- Age
- Autism-specific
- Availability
- Availability>alternative
- Availability>intervention>location
- Availability>intervention>positions
- Child : staff ratio
- Contact>information
- Contact>intentions
- Contact>professional
- Contact>time
- Convenience>family
- Convenience>location
- Duration
- Emotions>guilt
- Emotions>gut feelings
- Emotions>other parents

- Financial>cost
- Financial>funding from NSW Department of Ageing Disability and Home Care
- Financial>funding from Department of Families, Housing, Community Services and Indigenous Affairs
- Financial>public health
- Financial>value
- Flexibility
- History
- Information received
- Information>feasibility
- Information>guide
- Intensity
- Marketing
- Other children already using the intervention
- Other interventions>attributing progress
- Other interventions>confidence
- Other interventions>intensity
- Other interventions>strategies
- Parental beliefs>aetiology of ASD
- Parental beliefs>approach
- Parental beliefs>change
- Parental beliefs>child's response
- Parental beliefs>cultural
- Parental beliefs>cure
- Parental beliefs>importance of early
- Parental beliefs>hope
- Parental beliefs>individuality
- Parental beliefs>only option
- Parental beliefs>need to "do something"
- Past experience>child>before diagnosis
- Past experience>child>service provider
- Past experience>child>staff
- Past experience>siblings
- Physical environment
- Physical environment>comfort
- Relevance>developmental area
- Relevance>physical symptoms
- Relevance>nutrition
- Research support
- Risk>behaviour
- Risk>physical
- Staff>autism experience
- Staff>caring
- Time
- Time>other activities

Expectations of the intervention:

- Alertness
- Child engagement
- Child flexibility
- Cognitive
- Communication
- Did not know what to expect
- Enjoyment
- Environment>accepting
- High
- Improve behaviour
- Improve delay
- Improve overall
- Improve physical symptoms
- Improve sensory processing/sensory

- sensitivity
- Individual support
- Language>expressive
- Language>receptive
- Parent training
- School readiness
- Settled
- Social
- Toilet training

Final criteria identified:

- Played a role in the parent's final decision to use the intervention.
- Played a role in the parent's final decision not to use the intervention.
- Only one criteria for selecting identified
- Only one criteria for rejecting identified

Would parent use the intervention in the future?:

- Yes
- No

Reasons the parent would use the intervention in the future:

- Accessibility
- Alternative discontinued
- Behavioural change
- Care for siblings
- Developmental area
- Doctor's recommendation
- Money
- Past experience
- Research evidence
- Staff experience

Hypothetical, the parent would discontinue the intervention:

- Alternative found
- Eligibility changed
- Family impact
- Financial>expensive
- Financial>funding
- Fixed time program
- Ineffective
- No regression
- Nothing would cause them to
- Not needed
- Resistant>food
- Resistant>uncooperative
- Staff>ASD experience
- Staff>expectations
- Staff>ignored parent input
- Staff changes
- Time constraints
- Unable to continue using it (for an unspecified reason)

Recommending interventions

- Would recommend ineffective intervention because children are individual
- Would not recommend a currently used intervention
- Would not recommend this intervention

- Would recommend this intervention

Reason for continuing to use an intervention:

- Affordable
- Approach>naturalistic
- Demeanour>cooperative
- Demeanour>happy
- Easy to administer
- Feedback
- Fun
- Funding
- Monitoring
- Other interventions>strategies compatible
- Outcomes>behaviour
- Outcomes>cognitive
- Outcomes>communication
- Outcomes>compliance
- Outcomes>confidence
- Outcomes>engagement
- Outcomes>language>expressive
- Outcomes>language>receptive
- Outcomes>milestones
- Outcomes>overall
- Outcomes>rules
- Outcomes>social
- Outcomes>unrestricted diet
- Reporting
- Respite
- Sibling success
- Staff>child relationship
- Staff>demeanor
- Staff>development
- Staff>experience
- Staff>expertise
- Staff>intentions
- Staff>multidisciplinary
- Staff>parent relationship
- Staff>qualifications
- Staff>teacher's aide
- Support>others
- Support>parent
- Unique method

Reasons for NOT recommending intervention:

- Alternative
- Cost
- Child : staff ratio
- Ignored parent input
- Ineffective
- Not autism-specific
- Poor relationship
- Research not a guarantee of effectiveness
- Resources
- Staff skills
- Strategies

Reasons for recommending interventions:

- Autism-specific
- Availability
- Caring
- Confidence
- Enjoyment
- Feedback

- Flexibility
- Individualised
- Intensity
- Multidisciplinary
- Parent training
- Part of life
- Philosophy
- Positive overall
- Reporting
- Reputation
- Routines
- School readiness
- Sibling success
- Social opportunities
- Staff>demeanor
- Staff>development
- Staff>expertise
- Staff>interest
- Staff>rapport
- Staff>sensitivity
- Success
- Support
- Trust staff
- Worth trying

Reliability of sources:

- Reliable
- Somewhat reliable
- Unreliable

Sources of information about interventions:

- Autism Advisor
- Books
- Conference
- Counsellor
- The NSW government Department of Ageing, Disability and Home Care
- The NSW government Department of Education and Training Disability Advisor
- Diagnostic service
- Dietician
- Expo
- Friend or relative
- Funding list
- Initial source of information about this intervention
- Internet
- Internet>government websites
- Internet>online parent support or chat groups
- Internet> The Raising Children website
- Intervention staff member
- Media
- Medical
- Medical>General Practitioner
- Medical>Paediatrician
- Medical>Specialist
- Newsletters
- Occupational therapist
- The parent already had knowledge of this intervention, and did not need another information source
- Other parents

- Previously used intervention
- Research
- Schools
- Service Providers
- Speech therapist
- Support Group
- Traditional Chinese Medicine Master
- Teachers

Reasons for trusting sources:

- Gut feelings/intuition
- Local
- Other parent with first-hand experience of ASD interventions
- Perception of intentions
- Relationship
- Verification

CHAPTER 5: THE IMPORTANCE OF FACTORS IN INTERVENTION DECISIONS MADE BY AUSTRALIAN PARENT OF PRESCHOOL-AGE CHILDREN WITH ASD

Chapter Overview

Included in this chapter are two related papers. One is in press at the Journal of Developmental and Physical Disabilities (Carlon, Carter, and Stephenson, in press)¹ and one has been submitted for publication (Carlon, Carter, Stephenson, and Sweller, 2014)². Based on the findings of the reviews presented in Chapters 2 and 3 of this thesis, and of the qualitative study presented in Chapter 4, a survey was developed. The survey was designed to collect data regarding the weight of importance that parents placed on different declared factors in their decision-making and about possible underlying implicit factors that may be related to intervention choices. Declared decision-making factors were defined as those factors which parents indicated had directly impacted their decision-making. A copy of the survey is presented in the appendix of this chapter.

The study reported in Carlon, Carter, and Stephenson (in press) was one of the few in which parents were asked about the weight that they placed on different factors in their decisions, rather than simply identifying factors that had some impact on their decision-making. It was the first Australian study of this kind. The factors that were most frequently identified as considered by parents in the literature were not the same factors that were given the most weight in these parents' actual decisions. Based on data collected in the same study, Carlon, Carter, Stephenson, and Sweller (2014) present a regression analysis of potential implicit parent and child factors that may affect decision-making. This represented the first

¹ Publication Status:

Carlon, S., Carter, M., & Stephenson, J. (in press). Decision-making regarding early intervention by parents of children with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*.

² Publication Status:

Carlon, S., Carter, M., Stephenson, J., & Sweller, N. (2014). *Parent and child factors predicting early intervention choices of Australian parents of children with ASD*. Manuscript submitted for publication.

Australian study of this type. Few significant relationships between factors and the number or type of interventions used were found, and specific findings of previous research were not replicated, suggesting that a complex interplay between different factors is likely and that the influence of factors may be context specific.

Pages 227-247 of this thesis have been removed as they contain published material. Please refer to the following citation for details of the article contained in these pages.

Carlson, S., Carter, M., & Stephenson, J. (2015). Decision-Making Regarding Early Intervention by Parents of Children with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, 27(3), 285-305.

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Parent and Child Factors Predicting Early Intervention Choices of Australian Parents of
Children with ASD

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Abstract

Seventy-four parents of preschoolers with autism spectrum disorder (ASD) were surveyed regarding their use of early intervention. The possible relationships between implicit parent factors (education level, age, causal beliefs about ASD, complementary and alternative medicine use, and family income), and child factors (time since diagnosis, and perceived severity of ASD); and the number and type of interventions used were examined. Only a small number of significant relationships were found. This finding is consistent with previous research in the area and may be a reflection of the complexity of the interplay between many idiosyncratic factors that influence parental decision-making. Some specific findings of previous research were not replicated in the present study, indicating that factors affecting decision-making may not be consistent across samples. Nevertheless, future research including an expanded range of possible implicit factors with more diverse samples may provide a more accurate predictive model of parent decision-making.

Keywords: ASD, autism, decision-making, early intervention, parent

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Parent and Child Factors Predicting Early Intervention Choices of Australian Parents of Children with ASD

Parents of children with autism spectrum disorder (ASD) have many types of early intervention from which to select, including those that are supported by research evidence, those with limited research support, those for which the efficacy is currently unknown, and some that are ineffective and/or controversial (Metz, Mulick, & Butter, 2005; National Autism Center, 2009; Odom, Boyd, Hall, & Hume, 2010; Prior, Roberts, Rodger, Williams, & Sutherland, 2011). Furthermore, recent surveys including parent reports of interventions used indicate that parents are typically using multiple interventions (with varied levels of empirical support) concurrently (Carlon, Stephenson, & Carter, 2014; Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006). The factors that influence parents to commence using some interventions and reject others are therefore of interest.

Parents have declared in recent studies that their decision-making has been influenced by a range of factors. These included advice (e.g., from other parents of children with ASD, teachers, and therapists) and pragmatic considerations, such as availability, financial, and logistic considerations (Authors, 2014; Bowker, D'Angelo, Hicks, & Wells, 2011; Christon, Mackintosh, & Myers, 2010; Miller, Schreck, Mulick, & Butter, 2012; Wong & Smith, 2006). Additionally, parents have reported considering the perceived effectiveness of the proposed intervention and that of interventions they were already using with their children, their child's needs, and research evidence when making intervention decisions (Authors, 2014; Bowker et al., 2011; Hanson et al., 2007; Smith & Antolovich, 2000; Wong & Smith, 2006).

In addition to such declared decision-making factors, there is evidence to suggest that parent decision-making may be influenced by other implicit factors of which parents are not necessarily aware. A number of studies that have included preschool-age children within the sample have examined the relationship between implicit factors and ASD intervention decisions. Hebert and Koulouglioti (2010) conducted a review of 13 articles which explored

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parent's beliefs about the causes of ASD and the connection between parent's causal beliefs about autism and intervention choices. The belief that ASD was caused by vaccinations was found to be related to withholding or delaying vaccinations in three studies (Dale, Jahoda, & Knott, 2006; Harrington, Patrick, Edwards, & Brand, 2006; Harrington, Rosen, & Garnecho, 2006), and a belief in a specific cause of ASD (as opposed to an unknown cause) was reported to be related to increased complementary and alternative medicine (CAM) use (Harrington, Patrick, et al., 2006).

Dardennes et al. (2011) explored the relationships between different causal beliefs about ASD and interventions used by 78 parents of children (aged 2 – 44 years) with ASD in France. They reported significant associations between causal beliefs of food allergies and greater use of detoxification treatments, dietary interventions, and vitamins. These beliefs were also associated with lower rates of medication use. Causal beliefs relating to illness during pregnancy were positively associated with the use of medication. Parents who believed ASD was caused by traumatic experiences very early in life were less likely to use some behavioral interventions, and those who believed in brain abnormalities were less likely to use vitamins.

The parent's education level was another factor that Dardennes et al. (2011) examined. They found no significant relationships between the parent's education and the use of any of the interventions examined. However, Hall and Riccio (2012) and Wong and Smith (2006) both reported significant relationships between higher parent education levels and CAM use. In addition, Hanson et al. (2007) reported a positive association between maternal education levels and CAM use. Furthermore, Patten, Baranek, Watson, and Schultz (2013) reported that higher maternal and paternal education levels were associated with the use of gluten-free/casein-free diets and/or vitamins with their preschool-age children.

Family income may logically be associated with variations in intervention use but there have been mixed findings in this area. Irvin, McBee, Boyd, Hume, and Odom (2012)

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found that higher socio-economic status increased the probability of parents of preschool-age children using occupational therapy outside of the educational environment, as well as applied behavior analysis ABA. However, Patten et al. (2013) did not find any significant relationships between family income and the number of different services used, the use of sensory integration, or the use of alternative interventions. This indicates that family income may be associated with some early intervention decisions of parents but not with others.

Erba (2000) reported that mothers who themselves used “alternative” treatments for their personal healthcare were more likely to use CAM interventions and/or “alternative” educational and therapy-based interventions (such as auditory integration, facilitated communication, and sensory integration) with their children with ASD, than those who did not use “alternative” healthcare treatments. The possible relationship between one or both parents’ use of CAM interventions and the use of CAM interventions (alone) with their child with ASD is yet to be examined.

Child factors may also play an implicit role in the choice of interventions. The child’s age is one factor that has been reported to be associated with intervention use. Bowker et al. (2011) and Goin-Kochel et al. (2007) reported that parents utilized different types of interventions at different ages. Furthermore, Green et al. (2006) found that younger children were currently using significantly more interventions than older children. Green et al. (2006) also reported that more interventions were used when the child was described as having “severe autism” and fewer when the child was described as having Asperger’s syndrome. The apparent severity of the diagnosis was described in Green et al. (2006) as also influencing the type of interventions used. Other researchers have investigated the relationship between severity of ASD symptoms and CAM use. Christon et al. (2010) found that the total number of CAM interventions used increased with the apparent severity of ASD diagnosis. This was consistent with the findings of Hall and Riccio (2012), who reported that the severity of symptoms predicted the number of CAM interventions used, and the findings of Hanson et al.

(2007), who reported that CAM use was significantly associated with a more severe diagnosis. In contrast, Irvin et al. (2012) did not find any association between the severity of ASD and the use of alternative interventions (and neither the use of sensory integration nor the number of different services used). Similarly, Dardennes et al. (2011) did not report any associations between the number of observed ASD symptoms and the use of any of the examined interventions.

Although some implicit parent and child factors have been associated with the type and number of different interventions used, in many cases the results have been mixed. Furthermore, no studies have been conducted with an Australian sample (although some included a small number of Australian participants within mainly North American samples; e.g., Goin-Kochel, 2007; Green, 2006). Investigation of implicit factors that predict selection of early intervention by parents of children with ASD may assist in both understanding factors that affect decision-making and in providing guidance to parents in this process. The present study investigated the possible implicit underlying parent and child factors related to early intervention choices of Australian parents of preschool-age children with ASD. Specifically, through secondary analysis of data collected in Authors (2014), the following questions were addressed: (a) Do implicit parent factors (education level, age, causal beliefs about ASD, CAM use, or family income) or child factors (time since diagnosis, or perceived severity of ASD) predict the number of interventions used by parents?; and (b) Do implicit parent or child factors predict the type of interventions used by parents?

Method

This research was part of a larger study of the importance that parents place on different factors in decision-making (Authors, 2014). The description of the participants, instrument, distribution, and data collection was adapted from Authors (2014).

Participants

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The participants were parents of preschool-age children with ASD. The children were receiving autism-specific early intervention services from one of three providers in New South Wales (NSW): Autism Spectrum Australia (Aspect), Playgroup NSW, or Autism Behavioural Intervention (ABI) NSW. Surveys were distributed to 175 parents and 75 were returned (return rate = 42.9%). One participant who did not provide any data for the section of the survey regarding intervention use was excluded from the current analyses. Participant characteristics are shown in Table 1. All participants reported that their child had received a formal diagnosis of ASD (85.1% autistic disorder). The children were aged between 34 and 75 months ($M = 51.3$), and the time since diagnosis ranged from 2 – 36 months ($M = 16.4$).

Instrument

Three of the authors developed a paper survey containing five sections. The first section was designed to collect demographic information regarding the child and family. This included items regarding the child's diagnosis, the parent's rating of the severity of their child's ASD (mild, moderate, or severe), both parents' education levels (high school; technical and further education [TAFE], college or further training; undergraduate university; or postgraduate university), both parents' own use of CAM interventions, annual family income, and the primary intervention decision-maker in the household. Additionally, a list of causal beliefs about ASD was developed from those commonly reported in the literature (Dardennes et al., 2011; Furnham & Buck, 2003; Mercer, Creighton, Holden, & Lewis, 2006), and participants were asked to select those they thought may cause or contribute to the development of ASD. They were also invited to add beliefs not listed. The second section consisted of a checklist for parents to nominate sources of information used in making decisions about interventions.

In the third section, a list of interventions available in NSW was developed from the guidelines for funding in Australia through the Federal Government's "Helping Children with Autism (HCWA) Package" (Australian Government Department of Families, Housing,

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Community Services and Indigenous Affairs, 2012) and parent reports of interventions used in a recent study of preschool-age children with ASD in NSW (Carter et al., 2011). This list was presented and participants were asked to indicate whether they: (a) had not heard of the intervention; (b) considered using it but decided not to; (c) were currently using it; or (d) had used it in the past. Parents were also invited to add interventions to the list. The final two sections of the survey addressed the declared importance placed by parents on different factors in decision-making and are not relevant to the present analysis (see Authors, 2014 for further details).

Distribution and Data Collection

Approval for conducting the study (and for the use of an incentive prize draw) was obtained from the relevant ethics committees. Surveys were distributed to parents of preschool-age children with ASD using one of three autism-specific early intervention services in NSW. These were: (a) Building Blocks, a centre-based early intervention program delivered by Aspect (the largest provider of autism-specific early intervention services in NSW); (b) The Footprints “Stepping into Learning” program (commonly known as ABI), a home-based autism-specific early intervention program based on the principles of ABA, provided by ABI NSW, and funded in part by the NSW Government Department of Ageing, Disability and Home Care; and (c) PlayConnect Playgroups, ASD-specific playgroups delivered by Playgroup NSW as part of the Federal Government’s HCWA package. The Building Blocks and ABI services were selected because they were delivered by the two largest autism-specific early intervention service providers in NSW. The PlayConnect Playgroups were included because they were delivered by a community-based organization and offered the opportunity of potentially reaching a broad sample of families.

Where it was practical to do so, the first author visited the centre-based (group) services and provided the parents with a brief overview of the project before distributing the surveys. The early intervention staff later collected surveys from those parents who wished to

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participate and posted them back to the first author. For the home-based services and centre-based groups where it was not practical for the first author to attend, in addition to collecting the surveys, the early intervention staff also distributed them to the parents.

It was possible that families may have been using more than one of the three services. To avoid distributing the surveys to the same families more than once, parents were asked if they had received the survey from a different service provider. Surveys were only distributed to those who had not already received one. Participants were given the option to provide contact details for the incentive prize draw and/or to be informed of future research opportunities. Two return envelopes were provided to each parent with the survey so that those wishing to provide their contact details could submit their details and the anonymous survey separately.

Data Analysis

Initially, descriptive statistics were calculated and interventions were collapsed into seven overarching groups (as shown in Table 2). As shown in Table 3, the causal beliefs about ASD were collapsed into four categories: neurological/medical, psychological, environmental, and unknown. The neurological/medical category included genetics/hereditary, abnormality/chemical imbalance in the brain, and illness or complications during pregnancy, plus premature birth or complications during birth, and a different brain structure (the latter items being “other” causes added by participants). The psychological category included traumatic experiences early in life and the child’s upbringing. The environmental category included allergies to some foods, environmental triggers, and vaccinations, plus the use of antibiotics and vaccinations during pregnancy, and preservatives (again, the latter items being “other” causes added by parents). Unknown causes were a stand-alone category. Participants were required to select the severity of their child’s ASD (mild, moderate, or severe). In two cases participants indicated “mild to moderate” and in one case “moderate to severe”. In these cases the most conservative rating of severity (i.e., the least

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severe option) was used in the analyses. Pearson and Spearman correlation coefficients were calculated to test for correlations between: (a) the mother's education levels and father's education levels; (b) the mother's age and father's age; and (c) the child's age and time since diagnosis. Spearman correlation coefficients were used because the age ranges for the parents and their education levels were measured on ordinal scales.

The number of interventions currently used and the current use of each of the seven groups of interventions (intensive behavioral, autism-specific, CAM-based, therapy-based, generic, social skills training, and medication) were the dependent variables in the first round of regression analyses. The predictor variables used in the regression analyses included both categorical variables (mother and/or father's own use of CAM treatments, mother's education level, neurological/medical causal beliefs, psychological causal beliefs, environmental causal beliefs, and unknown causal beliefs) and continuous variables (time since diagnosis, perceived severity of ASD, mother's age, and family income). The dependent variable (number of interventions used) was continuous and normally distributed, so linear regression was used. In this initial round of analyses binary logistic regressions were also run using the predictor variables above and the current use of each of the groups of interventions (intensive behavioral, autism-specific, CAM-based, therapy-based, generic, social skills training, and medication) as the outcome variables, coded as either currently using or not currently using each intervention type.

A second round of targeted analyses, replicating the work of Dardeness et al. (2011) and Patten et al. (2013) was undertaken. Dardeness et al. (2011) included the current use of specific interventions (rather than groups of interventions) as the dependent variables in their analyses of causal beliefs about autism as predictors of intervention use. Therefore, logistic regressions using the same predictor variables as used in the first round of analyses were run with those interventions common to Dardeness et al. (2011) and the present study as the dependent variables. These were ABA, detoxification, dietary interventions,

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vitamins/minerals/supplements, and medications. Patten et al. (2013) used the current and/or past use of groups of interventions as the dependent variables in their analyses. Furthermore, they divided the CAM interventions into vitamin therapy and/or gluten-free/casein-free diets and other CAM. Therefore, logistic regressions were run using the same predictor variables as used in the first round of analyses, with the current and/or past use of the groups of interventions as used in the first round of analyses, plus the current and/or past use of dietary interventions and/or vitamins/minerals/supplements, as the dependent variables. A linear regression was also repeated using the same predictor variables and the number of interventions ever used (currently or in the past) as the dependent variable. All analyses were conducted using SPSS Version 20.0 (IBM Corp., 2011), and in each of the analyses the predictor variables were entered simultaneously rather than in a stepwise manner.

Results

Interventions Used

The interventions used currently and in the past are shown in Table 2. A mean of 7.3 interventions were reported to be used currently (range = 2 - 14 interventions) and 2.7 in the past (range = 0 - 10). The interventions most commonly used (as measured by current use and/or past use) were the therapy-based interventions, specifically speech therapy (66 parents currently, 6 in the past) and occupational therapy (57 currently, 11 in the past). These were followed by the generic interventions of preschool (55 currently, 3 in the past) and child care (39 currently, 15 in the past); and the autism-specific interventions of autism-specific early intervention (55 currently, 3 in the past) and autism-specific playgroups (32 currently, 21 in the past).

Predictors of Interventions Used

Pearson and Spearman correlation coefficients were calculated to test for correlations between the mother's education levels and father's education levels, and between the mother's age and father's age. Both relationships were significantly correlated, so only the

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mother's education level and mother's age were used in the regression analyses. Similarly, the child's age and time since diagnosis were also found to be significantly correlated. Although other researchers (e.g., Bowker et al., 2011; Goin-Kochel et al., 2007) have used the child's age when assessing child factors related to intervention use, the age range of the children in those studies was much wider. Given that the children's ages were restricted to six years and under in the present study, we believed that it was more appropriate to use the measure of time since diagnosis in our analyses.

Predictors of number of interventions used. Initially, the GLM procedure was used with the number of interventions currently used as the dependent variable. The overall corrected model was significant ($R^2 = .374$, $F(12,56) = 2.786$, $p = .005$). A significant positive association between the belief that the etiology of ASD was unknown and the number of interventions currently used ($B = 1.402$, $p = .025$) indicated that those with this belief currently used more interventions than those who only attributed ASD to specific causes. A significant negative association between family income and the number of interventions currently used ($B = -.948$, $p = .007$) indicated that those with a higher annual family income were currently using fewer interventions than those with a lower annual family income. Although there was no significant overall effect for mother's education, there was a significant difference between mothers with an undergraduate university degree as the highest level of education obtained compared to those with a postgraduate university degree. Those with an undergraduate university education used fewer interventions than those with a postgraduate university education ($B = -2.177$, $p = .013$). No other significant relationships were found.

The GLM procedure was repeated using the same independent variables and using the number of interventions ever used (currently or in the past) as the dependent variable. Again, the overall corrected model was significant ($R^2 = .309$, $F(12,56) = 2.084$, $p = .033$). Time since diagnosis was significantly positively associated with the number of interventions ever

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used ($B = .145, p = .005$). No parental CAM use was significantly negatively associated with the number of interventions ever used ($B = -2.047, p = .024$). Although no other significant relationships were found, family income did approach significance ($B = -.863, p = .059$).

Predictors of types of interventions used. The first round of logistic regressions did not reveal any significant relationships between the predictor variables and the current use of intensive behavioral interventions or CAM-based interventions. A test of the full model for the current use of social skills training against a constant model was statistically significant ($\chi^2(13, n = 69) = 22.59, p = .047$), indicating that at least one of the predictor variables was associated with the current use of social skills training. The model correctly classified 81.2% of cases. The results of the logistic regression are shown in Table 4. Time since diagnosis made a significant contribution to prediction. An increase in a month since their child's diagnosis increased the odds of a parent currently using social skills training by 1.1 times. There was no overall significant effect for mother's education, and the effect between undergraduate university education and postgraduate university education was non-significant after Bonferroni adjustment. Only one participant was not using an autism-specific intervention currently, only two were not using therapy-based interventions, only six were not using generic interventions, and only six were using medications, so logistic regression analyses for those groups of interventions were not meaningful.

In the second round of regression analyses for the current use of the interventions tested in replication of the Dardennes et al. (2011) study, no significant effects were found. When the current and past use of interventions were combined to replicate the analyses undertaken by Patten et al. (2013), all of the participants had used autism-specific interventions and therapy-based interventions, and all but one had used generic interventions. Therefore, the regression analyses were only repeated for the remaining groups of interventions, and for dietary interventions and/or vitamin/mineral/supplements. A test of the full model for the current or previous use of social skills training against a constant model was

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statistically significant ($\chi^2(13, n = 69) = 27.95, p = .009$), indicating that at least one of the predictor variables was associated with the current or previous use of social skills training. The model correctly classified 79.7% of cases. The results of the logistic regression are shown in Table 5. Time since diagnosis and the parent's perception of the severity of their child's ASD made a significant contribution to prediction. An increase in a month since their child's diagnosis increased the odds of a parent either using social skills training currently or having used it previously by 1.1 times. Conversely, one unit change in the parent's perception of the severity of their child's ASD (i.e., from mild to moderate, or moderate to severe), decreased the odds of a parent either using social skills training currently or having used it previously by 0.2 times. None of the other models for the current or previous use of interventions were found to be significant.

Discussion

In the present study relationships between implicit parent and child factors and the number and type of interventions employed by parents of preschoolers with ASD were examined. These will be discussed, along with implications for future research and practice, and comparisons with the previous research of Dardennes et al. (2011) and Patten et al. (2014), followed by limitations of the present study.

Implicit Factors in Decision-Making

The belief in an unknown etiology of ASD was significantly positively associated with the number of interventions currently used. It seems logical that parents who selected the uncertain option (even when other possible causes were also selected) might try a number of different interventions with their child rather than committing to a small number of interventions. Time since diagnosis was significantly positively correlated with the number of interventions ever used (currently or previously). Given that it is common for parents of children with ASD to try and then discontinue interventions (Carlson et al. 2014), it is not

surprising that those whose children had been diagnosed for a longer time would have tried more interventions than those who had been recently diagnosed.

It might be assumed that those with a higher family income level would more easily afford to employ a greater number of interventions. However, in the present study family income was significantly negatively associated with the number of interventions currently being used and the same relationship approached significance for lifetime use (currently or previously). A possible explanation for this result is that those with a higher income were accessing fewer interventions but using such interventions intensively. Siller, Reyes, Hotez, Hutman, and Sigman (2014) reported that preschool-age children in families with higher incomes received more intense individual services than those with lower family incomes. In contrast Irvin et al. (2012) did not find a significant relationship between socioeconomic status and the amount of time spent by the preschool-age children using interventions outside of the educational environment. Thus there is some evidence that families with higher incomes may be more likely to use fewer but more intensive interventions with their preschoolers with ASD, but further examination of this issue may be appropriate.

The number of interventions ever used was also significantly negatively associated with both parents having not personally used CAM within the past year. In a study investigating the relationship between CAM use in adults and personality traits, social support, and coping strategies it was found that those with the personality trait of an “openness to experience” were more likely to use CAM (Honda & Jacobson, 2005). It is possible that parents who chose not to use CAM themselves were less open to trying different approaches, both for themselves and their children, and that for this reason they tended to try fewer interventions than parents who used CAM.

Green et al. (2006) reported a relationship between the parent-reported type/severity of ASD (Asperger’s syndrome, mild autism, or severe autism) and the number of interventions currently being used. Specifically, more interventions were currently being used by those that

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reported their child as having “severe autism”. In the present study, however, parent-reported severity was not associated with the number of interventions used. The difference in the two findings could be reflective of underlying differences between the mainly North American sample (including only one third of the children younger than six years of age) in Green et al. (2006) and the Australian sample including children of preschool-age only in the present study. These possible differences could be investigated using more diverse samples from different geographic locations in the future.

The only type of intervention that was significantly associated with any of the examined implicit factors was social skills training. The odds of a parent currently using this intervention with their child and the odds of them having ever used it (currently or previously) both increased as the time since diagnosis increased. Goin-Kochel et al. (2007) found that older children were more likely to be using social skills training currently, or to have ever tried it, than younger children. Despite the limited age range in the present study, it appears that those who had been diagnosed for a longer time (and were older) were more likely to be using social skills training. This may perhaps reflect an increasing focus on core social skills as children age and social demands increase, making deficits more apparent. Increased severity of ASD as perceived by the parent decreased the odds of the parent having ever used social skills training. It is possible that parents who considered their child’s ASD to be more severe were more likely to focus on the use of interventions that targeted all of the core symptoms of ASD (including social skills), rather than undertake social skills training as a stand-alone intervention.

In the present study the current or lifetime (current or previous) use of CAM interventions were not significantly associated with any of the examined implicit factors. This was somewhat surprising given that in previous studies CAM use has been associated with higher parental education levels (e.g., Hall & Riccio, 2012; Hanson et al., 2007; Wong & Smith, 2006), and with increased severity of ASD as reported by the parent (e.g., Christon et

al., 2010; Hall & Riccio, 2012; Hanson et al., 2007). It should be noted that these previous studies were conducted with mainly North American samples and included children of a wider age range than those in the present study. Possible differences related to children's age and geography may be explored in the future.

Specific comparisons of the findings of the present study and the studies of Dardennes et al. (2011) and Patten et al. (2013) are presented as follows. Consistent with the findings of Dardennes et al. (2011), in the present study the implicit factors of the parent's education level and parent's age were not associated with the use of any particular type of intervention. However, in contrast to the findings of Dardennes et al. (2011), which indicated that some causal beliefs about ASD were associated with the use of particular interventions, in the present study causal beliefs about ASD were not found to be significantly associated with the use of any particular type of intervention. It appears somewhat counterintuitive that in the present study causal beliefs related to environmental etiology of ASD did not increase the odds of parents using CAM interventions or the individual interventions detoxification, dietary interventions, or vitamins/minerals/supplements, especially given that Dardennes et al. (2011) reported that beliefs related to food allergies were positively associated with the use of those individual interventions.

These apparently contradictory findings may be related to differences in the design of the two studies. In Dardennes et al. (2011) very specific beliefs were examined (e.g., food allergies) whereas in the present study beliefs were collapsed into categories (e.g., environmental) to allow for analysis. Additionally, the way in which beliefs were measured varied between the studies. In Dardennes et al. (2011) participants were required to indicate the extent to which they believed in different statements regarding the etiology of ASD on a 7-point Likert-type scale. In contrast, a broader approach was taken in the present study in which parents were asked to indicate which of the listed causal beliefs they agreed with and to add beliefs not listed. Given that many participants who indicated they held environmental

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causal beliefs also held beliefs in one or more of the other categories, possible subtle differences related to the influence of the strength of different beliefs may not have been identified in the present study. Alternatively, the differences in findings could be a result of differences between the two samples. The sample in Dardeness et al. (2011) were French parents and no restriction was placed on the age of the children ($M = 13.5$ years), whereas the sample in the present study were Australian parents of preschool-age children. Future researchers could investigate the influence of the strength of different causal beliefs with populations from different geographic locations and with children of varying ages using a more sensitive tool for the measurement of causal beliefs.

Patten et al. (2013) found that few of the examined implicit factors were significantly associated with the use of the interventions examined, which was consistent with the findings in the present study. Patten et al. (2013) did report, however, a significant positive association between higher parental education levels and the use of gluten-free/casein-free diets and/or vitamin therapy; a finding that was not replicated in the present study. Other research conducted in North America has also revealed relationships between higher parental education levels and the use of CAM interventions (e.g., Hanson et al., 2007; Wong & Smith, 2006), yet in the French study of Dardennes et al. (2011) no such relationships were found. It is possible that geographic differences may exist, which could be examined in future research.

In summary, in the present study relationships between a number of implicit parent and child factors and the number and type of interventions employed by parents of preschoolers with ASD were examined. Few significant predictors were found and there were inconsistencies with previous research in the area. It is possible that this was because the intervention decisions of the parents were influenced by implicit factors that were not examined, such as marital status (Hall & Riccio, 2012), or caregiver/parental stress (Irvin et al., 2012; Konstantareas, Homatidis, & Cesaroni, 1995). However, the finding of limited significantly predictive relationships was generally consistent with previous research in the

area (e.g., Dardennes et al., 2011; Hall & Riccio, 2012, Patten et al., 2013). It may therefore be more reflective of the complexity and idiosyncratic nature of the interplay between different factors (both implicit and those explicitly acknowledged by parents) in parent decision-making. Although understanding parental decision-making processes may be potentially important in providing guidance and support to families, available research provides an inconsistent picture. It may be appropriate to expand the range of predictors examined in future studies and possibly attempt to integrate consideration of both implicit and declared factors in decision-making into predictive models. While the influence of different implicit factors remains unclear, practitioners could support parents in their early intervention decision-making through focusing on explicit declared parental decision-making factors, such as advice and research evidence. Teachers and other professionals working in early intervention with children with ASD should keep up-to-date with research regarding the efficacy of interventions for ASD so that they can provide accurate and useful information to parents.

Limitations

Some limitations of the present study should be acknowledged. The participants were recruited through service providers of autism-specific intervention programs, including two of the largest autism-specific early intervention providers in the state of NSW. Therefore, almost all of the children were currently using autism-specific early intervention and all of them had used it in the past. Nevertheless, parents were using an average of approximately seven interventions that included a wide range of possible options. Additionally, therapy-based and generic early intervention use was highly represented in this sample and few parents were currently using medications, therefore meaningful analyses could not be completed for these intervention types. In the future researchers could include both participants who choose to use the most commonly used interventions for ASD, such as therapy-based interventions (Carlson et al., 2014), as well as those who decide not to employ these, to allow for examination of the

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possible implicit factors related to their use. Although the sample size in the present study ($n = 74$) was comparable with others in the area (e.g., Dardennes et al., 2011, $n = 78$; Patten et al., 2013, $n = 70$; Siller et al., 2014, $n = 70$), studies in the future with larger and more diverse samples would allow for the examination of possibly subtle differences in characteristics of those more likely not to use commonly employed interventions.

Conclusion

In the present study possible predictive relationships between implicit child and parent factors, and the number and type of interventions used by parents of preschool-age children with ASD were examined. Consistent with previous research few significant relationships were found. This may be reflective of a complex interplay between idiosyncratic implicit and explicitly declared factors in parental decision-making. Some specific findings of previous research could not be replicated in the present study. This indicates that factors influencing parental decision-making may not be consistent across samples from different geographic locations and/or including children of different ages. While reliable predictive models of parental decision-making do not yet exist, practitioners working in early intervention with children with ASD may support parents in their decision-making through providing accurate information about the efficacy of interventions. In the future a more accurate predictive model of parent decision-making may be developed through research with more diverse samples, including an expanded range of possible implicit factors and the examination of possible geographic differences.

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Table 1

Participant Characteristics (N=74)

Characteristic	Number of participants	% of total sample
Respondent		
Mother	63	85.1
Father	10	13.3
Other (foster mother)	1	1.3
Mother's Age		
<25 years	1	1.4
25-34 years	18	24.3
35-44 years	55	74.3
Father's Age		
25-34 years	11	14.9
35-44 years	49	66.2
>44 years	10	13.5
Unreported	4	5.4
Mother's Education		
High school or equivalent	12	16.2
TAFE, college, or further training	23	31.1
Undergraduate University degree	23	31.1
Postgraduate University degree	15	20.3
Unreported	1	1.4
Father's Education		
High school or equivalent	9	12.2
TAFE, college, or further training	26	35.1
Undergraduate University degree	22	29.7
Postgraduate University degree	12	16.2
Unreported	5	6.8
Annual family income		
<\$40,000	10	13.5
\$40,000-\$80,000	29	39.2
\$80,000-\$120,000	22	29.7
>\$120,000	13	17.6
Primary decision-maker regarding intervention use		
Mother	33	44.6
Father	2	2.7
Both parents together	39	52.7
Child's gender		
Male	68	91.9
Female	6	8.1
Child's diagnosis		
Autistic Disorder	63	85.1
Asperger's Disorder	2	2.7
PDD-NOS	8	10.8
Other (high functioning autism)	1	1.3
Additional diagnoses	8	10.8
Parent rating of severity of ASD		
Mild	28	37.8

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Moderate	35	47.3
Severe	7	9.5
Unreported	1	1.4
<i>Others</i>		
Mild-to-moderate	2	2.7
Moderate-to-severe	1	1.4

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Table 2

Interventions Used Currently and Ever Used (currently or in the past), by Category (N=74)

Intervention	Currently using n (%)	Ever used n (%)
Intensive behavioral interventions		
Applied behavior analysis (ABA)	17 (23.0)	19 (25.7)
Lovaas/Discrete Trial Training	0 (0)	1 (1.4)
Total number of parents using interventions in category	17 (23.0)	19 (25.7)
Autism-specific interventions		
Autism Behavioural Intervention (ABI)	24 (32.4)	33 (44.6)
Autism-specific early intervention program	55 (74.3)	58 (78.4)
Autism-specific playgroup	31 (41.9)	52 (70.3)
Floortime	11 (14.9)	23 (3.1)
More than Words: the Hanen Program for parents of children with ASD	13 (17.6)	27 (36.5)
Relationship Development Intervention (RDI)	2 (2.7)	2 (2.7)
<i>TalkAbility: The Hanen Program for parents of verbal children with ASD</i>	0 (0)	1 (1.4)
Total number of parents using interventions in category	72 (97.3)	74 (100)
CAM-based interventions		
Acupuncture	2 (2.7)	3 (4.1)
Chiropractic	4 (5.4)	7 (9.5)
Detoxification treatments (e.g., chelation)	4 (5.4)	5 (6.8)
Dietary restrictions	12 (16.2)	20 (27.0)
<i>Melatonin</i>	1 (1.4)	1 (1.4)
<i>Stem cell therapy</i>	1 (1.4)	1 (1.4)
Sound/auditory treatment (e.g., Tomatis, Berard)	5 (6.8)	5 (6.8)
Vitamin, mineral, or dietary supplements	30 (40.5)	39 (52.7)
Total number of parents using interventions in category	40 (54.1)	49 (66.2)

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Therapy-based interventions

<i>Multisensory therapy</i>	1 (1.4)	1(1.4)
Music therapy	9 (12.2)	19 (25.7)
Occupational therapy	57 (77.0)	68 (91.9)
Play therapy	19 (25.7)	28 (37.8)
Physiotherapy	3 (4.1)	10 (13.5)
Sensory integration	19 (25.7)	29 (39.2)
Speech therapy	66 (89.2)	72 (97.3)
Total number of parents using interventions in category	72 (97.3)	74 (100.0)

Generic interventions

Child care	39 (52.7)	54 (73.0)
<i>Cognitive training</i>	1 (1.4)	1 (1.4)
Generic (non autism-specific) early intervention	15 (20.3)	28 (37.8)
Generic (non autism-specific) playgroup	15 (20.3)	37 (50.0)
<i>Gymnastics</i>	1 (1.4)	1 (1.4)
Preschool	55 (74.3)	58 (78.4)
<i>Psychology</i>	1 (1.4)	1 (1.4)
<i>Swimming</i>	1 (1.4)	1 (1.4)
Total number of parents using interventions in category	68 (91.9)	73 (98.6)

Social skills training

Social skills training	16 (21.6)	20 (27.0)
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Medication

Medication (to treat the symptoms of ASD- not for other reasons)	7 (9.5)	9 (12.2)
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Note: Italicized interventions were volunteered by parents, not listed in the survey.

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Table 3

Causal Beliefs and Percentage of Participants Endorsing Each Belief, Shown by Category.

Causal Belief	% of Participants Endorsing
Neurological/medical beliefs	81.1
Genetics/hereditary	71.6
Abnormality/chemical imbalance in the brain	41.9
Illness/complications during pregnancy	20.3
Premature birth/complications during birth*	4.1
A different brain structure*	1.4
Psychological	9.5
Traumatic experiences early in life	9.5
Child's upbringing	1.4
Environmental	48.6
Allergies to some foods	16.2
Environmental triggers	35.1
Vaccinations	28.4
Use of antibiotics and vaccinations during pregnancy*	1.4
Preservatives*	1.4
Unknown causes	47.3

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Table 4

Logistic Regression Analysis of the Current Use of Social Skills Training

Predictor variable	<i>B</i>	<i>S.E.</i>	Wald	<i>df</i>	<i>p</i>	Exp(<i>B</i>)
Time since diagnosis	.104	.050	4.313	1	.038	1.109
Severity	-1.209	.659	3.365	1	.067	.299
Mother's age	-.313	.836	.140	1	.708	.731
Mother's education ^a			4.890	3	.180	
High school or equivalent	.059	1.293	.002	1	.964	1.060
TAFE, college, or further training	-.359	1.089	.109	1	.742	.699
Undergraduate university	-3.027	1.536	3.884	1	.049	.048
Family income	.757	.487	2.420	1	.120	.469
Parent's own use of CAM interventions ^b			1.899	2	.387	
Neither parent used CAM	-.677	1.211	.313	1	.576	.508
One parent used CAM	.503	1.234	.167	1	.683	1.654
Belief in neuromedical etiology of ASD	.793	.974	.663	1	.415	2.211
Belief in psychological etiology of ASD	.712	1.290	.305	1	.581	2.039
Belief in environmental etiology of ASD	-.968	.867	1.246	1	.264	.380
Belief in unknown etiology of ASD	-1.023	.824	1.542	1	.214	.359
Constant	2.490	3.156	.622	1	.430	12.064

^a Baseline measure is Postgraduate University education

^b Baseline measure is both parents used CAM

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Table 5

Logistic Regression Analysis of the Current or Previous Use of Social Skills Training

Predictor variable	<i>B</i>	<i>S.E.</i>	Wald	<i>df</i>	<i>p</i>	Exp(<i>B</i>)
Time since diagnosis	.135	.050	7.149	1	.007	1.144
Severity	-1.752	.737	5.649	1	.017	.173
Mother's age	-.646	.837	.595	1	.440	.524
Mother's education ^a			5.165	3	.160	
High school or equivalent	.676	1.283	.278	1	.598	1.967
TAFE, college, or further training	.119	1.085	.012	1	.912	1.127
Undergraduate university	-2.361	1.425	2.748	1	.097	.094
Family income	-.723	.497	2.113	1	.146	.486
Parent's own use of CAM interventions ^b			2.845	2	.241	
Neither parent used CAM	-1.850	1.385	1.782	1	.182	.157
One parent used CAM	-.592	1.349	.193	1	.660	.553
Belief in neuromedical etiology of ASD	1.555	1.057	2.167	1	.141	4.737
Belief in psychological etiology of ASD	1.639	1.274	1.655	1	.198	5.149
Belief in environmental etiology of ASD	-1.547	.959	2.601	1	.107	.213
Belief in unknown etiology of ASD	-.323	.804	.161	1	.688	.724
Constant	5.620	3.579	2.466	1	.116	275.980

^a Baseline measure is Postgraduate University education

^b Baseline measure is both parents used CAM

APPENDIX

Survey used in Carlon, Carter, & Stephenson (in press), and Carlon, Carter, Stephenson, & Sweller (2014).

Survey of factors influencing the intervention decision-making process for
parents of preschool-age children with ASD.

*Please answer the following questions with regard to your **preschool-age child** with ASD. If you have more than one child with ASD please answer the questions for your oldest child who has not started school yet.*

Participation is voluntary and returning this survey indicates that you consent to participating.

When you have completed the survey please return it in the *envelope marked “SURVEY”* to your early intervention staff member. If you wish to enter the draw to win one of three \$100 Coles/Myer gift cards, and/or to provide your details to be contacted with information about the follow-up study then please also return the attached form with your details in the other envelope marked *“PRIZE DRAW/FOLLOW-UP”*.

Section 1: Your child and your family.

1. How old is your child? _____ years _____ months

2. What is your child's diagnosis? (*please tick*):

- a. Autistic Disorder ☐
- b. Asperger's Disorder ☐
- c. Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) ☐
- d. No official diagnosis, or other (please specify) _____ ☐

3. When was your child diagnosed? Month: _____ Year: _____

4. Do you consider your child's autism spectrum disorder (ASD) to be: (*please tick*)

- a. Mild ☐
- b. Moderate ☐
- c. Severe ☐

5. Do you have any other children?

Yes ☐ No ☐

If yes, a) How old are they? _____

b) Have any of your other children been diagnosed with ASD?

☐ Yes ☐ No

6. How old are you? (*please tick*)

- a. Under 25 ☐
- b. 25-34 ☐
- c. 35-44 ☐
- d. Over 45 ☐

7. How old is your child's other parent? (*please tick*)

- a. Under 25 ☐
- b. 25-34 ☐
- c. 35-44 ☐
- d. Over 45 ☐
- e. N/A ☐

8. Are you your child's (*please tick*):

- a. Mother ☐
- b. Father ☐
- c. Other guardian ☐ (please specify relationship) _____

9. What is the highest level of education you have received? (*please tick*):

- a. High school ☐
- b. TAFE, college or further training ☐
- c. An undergraduate university degree ☐
- d. A postgraduate university degree ☐

10. What is the highest level of education your child's other parent has received? (*please tick*):

- a. High school ☐
- b. TAFE, college or further training ☐
- c. An undergraduate university degree ☐
- d. A postgraduate university degree ☐
- e. N/A ☐

11. What is your postcode? _____

12. What is your yearly family income? *(please tick)*:

- a. Less than \$40,000 per year ☐
- b. \$40,000-\$80,000 per year ☐
- c. \$80,000-\$120,000 per year ☐
- d. Over \$120,000 per year ☐

13. In the past year have you used any complementary or alternative medicine (CAM) treatments **yourself** (for you own health/wellbeing)? (e.g. acupuncture, herbal therapies, homeopathy, naturopathy, chiropractics, biofeedback, hypnosis) *(Please tick)*

Yes ☐ No ☐

14. In the past year has **your child's other parent** used any complementary or alternative medicine (CAM) treatments **his/herself** (for his/her own health/wellbeing)? (e.g. acupuncture, herbal therapies, homeopathy, naturopathy, chiropractics, biofeedback, hypnosis) *(Please tick)*

Yes ☐ No ☐ N/A ☐

15. What do you think may cause or contribute to the development of ASD? *(please tick all that apply)*

- ☐ a. Genetics/hereditary
- ☐ b. Abnormality/chemical imbalance in the brain
- ☐ c. Traumatic experiences early in life
- ☐ d. Illness or complications during pregnancy
- ☐ e. The child's upbringing
- ☐ f. Allergies to some foods
- ☐ g. Environmental triggers
- ☐ h. Vaccinations
- ☐ i. Unknown causes
- ☐ j. Other (please specify)

16. Which of the following best describes how your family makes decisions about the interventions to use with your child with ASD? (*Please tick*)

- ☐ a. I primarily make the decisions about which interventions to use
- ☐ b. My child's other parent primarily makes the decisions about which interventions to use
- ☐ c. We make decisions about which interventions to use together (50/50)

Section 2: Sources of information about interventions available

1. Have you received information about any interventions available for children with ASD from any of the following? (please tick)

- | | |
|---|---|
| <input type="checkbox"/> Autism Advisor | <input type="checkbox"/> Autism Associations/Organisations |
| <input type="checkbox"/> Medical doctors | <input type="checkbox"/> Autism association websites |
| <input type="checkbox"/> Friends or relatives | <input type="checkbox"/> Websites of service providers |
| <input type="checkbox"/> Other parents | <input type="checkbox"/> Service providers |
| <input type="checkbox"/> Government websites | <input type="checkbox"/> The Raising Children website |
| <input type="checkbox"/> Books | <input type="checkbox"/> Print media/TV/radio/movies |
| <input type="checkbox"/> Newsletters | <input type="checkbox"/> Parent forums/blogs/online support groups |
| <input type="checkbox"/> Teachers/educators | <input type="checkbox"/> Parent training programs/conferences/workshops |
| <input type="checkbox"/> Research literature | <input type="checkbox"/> Social workers/counsellors |
| <input type="checkbox"/> Alternative medical staff (e.g. naturopaths, homeopaths, nutritionists, chiropractors) | |
| <input type="checkbox"/> Therapists (e.g. speech therapists, occupational therapists, physiotherapists) | |
| <input type="checkbox"/> Other (please specify) _____ | |

Section 3: Interventions considered, used currently, and used in the past.

Below is a list of interventions that you may or may not have considered using with your child.

1. For each intervention listed please indicate by circling the appropriate box whether you have considered using it, are currently using it, or have used it in the past (have discontinued using it); **as an intervention for your child's ASD, not for other reasons** (e.g. other medical diagnoses, general health and development).

For example: If you considered using Applied Behaviour Analysis but decided not to use it, you would circle "Considered but decided not to use"

Applied Behaviour Analysis (ABA)	Have not heard of this.	<u>Considered but decided not to use.</u>	Currently using	Used in the past
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You may also add interventions not listed.

An Autism-specific early intervention program	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
A generic (non autism-specific) early intervention program	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Applied Behaviour Analysis (ABA)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Autism Behavioural Intervention (ABI)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Speech therapy	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Occupational therapy	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Sensory integration	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Dietary restrictions (e.g. Gluten-free diet)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Detoxification treatments (e.g. chelation)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Preschool	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Child care	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Autism-specific playgroup	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Playgroup (non autism-specific)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Vitamin, mineral, or dietary supplements	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Acupuncture	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Physiotherapy	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Play therapy	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Music therapy	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
More than Words: the Hanen Program	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Social skills training	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past

Lovaas/Discrete Trial Training	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Floortime	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Sound/auditory treatment (eg Tomatis, Berard)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Relationship Development Intervention (RDI)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Chiropractics	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
Medication (to treat the symptoms of ASD- not for other reasons)	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
<i>Other(s):</i>				
	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past
	Have not heard of this.	Considered but decided not to use.	Currently using	Used in the past

*In the following two sections you will be asked to think about interventions (excluding medications or drugs prescribed by a medical doctor) that you have either considered using or have used to treat your child's ASD. You will be asked to think about (1) the **most important** intervention that you are **currently** using with your child, and (2) an intervention that you **considered using but decided not to use**.*

Please think about what influenced you to make the decisions that you have made.

Section 4: An intervention you are currently using with your child.

*Please think about the **one intervention or treatment** (not a medication or drug prescribed by a medical doctor) that you are **currently** using with your child that you consider the **most important**. Think of the factors that you considered when you were trying to decide whether or not to use this intervention.*

1. The intervention is _____
2. When did you begin using this intervention with your child?
Month: _____ Year: _____
3. On the scale below please indicate how important (from very unimportant to very important) the following were in your decision to use the intervention: (please circle). You may also add other considerations not listed.

Advice from medical doctors	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from other parents	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from therapists	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from friends or relatives	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from teachers/educators	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Research evidence	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

The information provided about the intervention from the service provider	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the intervention was ASD-specific	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The cost of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Government funding available to help pay for the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention appeared professional	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My own intuition or “gut feelings”	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention were experienced	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The feeling that I may need to try anything that might help	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The location or accessibility of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The specific needs of my child (e.g. communication skills, social skills)	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The lack of availability of alternative interventions	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My child’s age	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The compatibility of this intervention with other interventions we are using.	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My hope that it would work for my child	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My hope for a cure for my child’s ASD	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

I thought my child would enjoy it	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
It was convenient time-wise and “fit” my child’s and/or our family’s schedule	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I thought it would have a positive impact on our family	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Most people thought that this was an effective intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
<i>Other(s) (Please specify)</i>	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

Section 5: An intervention that you decided not to use with your child.

*Please think about **one intervention** or treatment (not a medication or drug prescribed by a medical doctor) that you **considered using but decided not to use** with your child. Think of the factors that you considered when you were trying to decide whether or not to use this intervention.*

1. The intervention is _____
2. On the scale below please indicate how important (from very unimportant to very important) the following were in your decision **not** to use the intervention: (please circle). You may also add other considerations not listed.

Advice from medical doctors	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from other parents	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

Advice from therapists	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from friends or relatives	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from teachers/educators	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Research evidence	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The information provided about the intervention from the service provider	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the intervention was ASD-specific	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The cost of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Government funding available to help pay for the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The effectiveness of other interventions that I was already using with my child	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention appeared professional	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My own intuition or “gut feelings”	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention were experienced	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of alternative interventions	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The location or accessibility of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The specific needs of my child (e.g. communication skills, social skills)	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

The compatibility of this intervention with other interventions we were using.	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Fears about side effects or adverse effects	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My child's age	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I did not think my child would enjoy it	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
It was not convenient time-wise and did not "fit" my child's and/or our family's schedule	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I thought it would have a negative impact on our family	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Most people thought that this was not an effective intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Other(s) <i>(Please specify)</i>	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

Thank you for your participation. ☺

Please return this survey to your early intervention staff member in the envelope marked "SURVEY".

CHAPTER 6: AN INTERVENTION PROVIDING PARENTS WITH INFORMATION ABOUT THE EFFICACY OF INTERVENTIONS FOR ASD

Chapter Overview

This chapter includes a paper that has been submitted for publication in a peer reviewed journal (Carlon, Carter, and Stephenson, 2014)¹. The findings of Chapters 2-5 of this thesis indicated that many parents placed a greater weight on factors other than research evidence in their decision-making, and that research evidence appears to be only mid-ranked in terms of importance. The paper provides details of a pilot study of a parent education package that was designed to provide parents with guidelines for choosing interventions and guided access to two websites with reliable information about the efficacy for different interventions for ASD. This study was originally designed as a randomised control trial, but despite distributing recruitment notices via autism associations and service providers in all seven Australian states and territories, only 14 parents consented to participate, so a pre-test post-test design was employed. The 12 parents that completed the trial provided positive feedback regarding the DVD-based package and an increased confidence in their ability to make decisions. The package, including guided access to websites providing reliable information about the research efficacy of interventions, did not, however, appear to influence the factors that parents considered important in decision-making, their understanding of the level of research support for interventions, nor their desire to use different interventions. These findings raise questions regarding whether such websites are influencing parental views and/or behaviours.

The pre-test and post-test interview schedules used in this study are presented in Appendices 1 and 2 of this chapter. Details of the rating procedure used to summarise the

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ratings of interventions provided on the two websites used in the DVD-based intervention package is provided in Appendix 3.

Pilot study of a parent education package for early intervention decision-making for autism
spectrum disorder

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Abstract

A pilot study of the effectiveness of a DVD-based parent education package was conducted with 12 parents of preschool-aged children with autism spectrum disorder (ASD). The DVD-based package provided guided access to reliable websites that included information about the efficacy of interventions for ASD (Raising Children Network, 2006-2014; Research Autism, 2006-2014). It also included a section which provided guidelines for choosing interventions, including 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. Participants regarded the DVD-based package providing guided access to reliable websites as useful and reported an increased level of confidence in making intervention decisions after using the package. However, the DVD-based package providing guided access to reliable websites did not appear to influence the factors that parents considered important in decision-making, their understanding of the level of research support for interventions, nor their desire to use different interventions. Implications for future research and attempts to disseminate information to parents are discussed.

Keywords

ASD, autism, decision-making, evidence-based practice, intervention, parent training

Pilot study of a parent education package for early intervention decision-making for autism spectrum disorder

Introduction

In recent years numerous review studies examining the efficacy of interventions available for children with autism spectrum disorder (ASD) have been published (e.g., National Autism Center, 2009; Prior et al., 2011). For a variety of reasons, however, ineffective and controversial interventions for ASD continue to be employed (Matson et al., 2013). These interventions are typically used by parents concurrently with other interventions that have empirical support, and/or with interventions for which the efficacy is currently unknown (Carlon et al., 2014; Goin-Kochel et al., 2007; Green et al., 2006).

There has been extensive research undertaken regarding how people make decisions (Beach & Lipshitz, 1993; Klein, 2008; Robinson & Donald, 2015). Classical decision-making models focused on the decision-maker undertaking a rational analysis of the possible benefits of a fixed set of alternatives, but researchers in recent years have acknowledged that the way that people actually make decisions is not necessarily through a rational or predictable process (Beach & Lipshitz, 1993; Robinson & Donald, 2015). As a result, research has been undertaken in naturalistic environments (Klein, 2008; Meso et al., 2002). It should be noted that this research, and the resulting decision-making models, have focussed on the decision-making of experts (e.g. military and medical personnel; Klein, 2008) or shared decision-making undertaken by experts and patients in the context of medical decisions (Stacey et al., 2010). Although a model of decision-making that parents may employ when making decisions about interventions to use with their children has not been developed, a number of factors that may influence such decision-making have been identified in recent studies (Carlon et al., 2013). Factors such as cost, availability, recommendations from others and the level of research evidence supporting different interventions have been reported to influence parent decision-making (Carlon et al., 2013).

Government bodies and other organisations have used the internet to disseminate information about the efficacy of different interventions to parents (e.g., Raising Children Network, 2006-2014; Research Autism, 2006-2014). Due to the nature of the internet, this information has been provided alongside many other websites offering unfiltered information about ASD and possible interventions. After recent reviews of autism-related websites, Reichow et al. (2012) recommended that parents use caution when accessing information from any website, and that they should only use it to supplement rather than replace information received from professionals. Nevertheless, parents of children with ASD frequently use the internet to access information about ASD and interventions for ASD (Green, 2007; Mackintosh et al., 2006; Sabo & Lorenzen, 2008).

Although information regarding the level of research support for interventions is provided in public forums, including the internet, there is evidence to suggest that research is not a strong consideration for many parents in their decision-making regarding interventions to use with their children. Parents employ interventions without empirical support (Carlton et al., 2014; Goin-Kochel et al., 2007; Green et al., 2006), which indicates that they may not place a high level of importance on research evidence in their decision-making. Furthermore, when parents of pre-schoolers with ASD were asked to rate the importance of different factors in decision-making, other factors such as the parents' intuition, staff attributes and whether or not the intervention was ASD specific were given more weight than research evidence (Authors, 2014). It is not clear whether parents place less importance on research evidence because they are dismissive of the evidence, unaware of the concept of evidence-based practice, or unaware of the level of research support for different interventions for ASD. In a recent evaluation of the Australian Federal Government's Helping Children with Autism (HCWA) package, parents were asked about their use of the "Raising Children Network" website which provides information to parents of children with ASD, including the level of research support for interventions. Only 42% of the 4,437 families registered for HCWA

funding surveyed had used this website, and 63% of those who did not use it were unaware of it (ARTD Consultants, 2012). This indicates that parents may not be accessing information about the efficacy of different interventions even when it is made publicly available, and raises the question of whether being made aware of this information would influence their decision-making. In addition, there does not appear to be any research examining the impact of such reliable sources of information about the evidence base for interventions on the preferences or decision-making of parents.

The present small scale pilot study aimed to investigate whether a DVD resource package designed to provide parents with guidelines to follow when considering interventions, along with guidelines for accessing reliable information online, would change their views and/or behaviours related to intervention decision-making. Specifically, the following research questions were addressed: 1. Would the parents regard the DVD as a useful resource? 2. Would the parents become more confident in making decisions about interventions to use with their children with ASD after using the package? 3. Would the parents' ratings of the importance of different factors in decision-making change after using the package? 4. Would the parents' understanding of the level of research evidence supporting different interventions become more reflective of the information provided on the websites after using the package? 5. Would the parents' desire to use different interventions (with/without empirical support) change after using the package?

Method

Participants

Participants were parents of preschool age children with ASD, who either had previously expressed interest in participating in research regarding intervention decision-making with the researchers, or had responded to recruitment notices distributed via autism associations and service providers in Australia. Fourteen parents began the trial, however, two did not complete the post-test interviews. The participants were eight mothers and four fathers

covering five of the eight states and territories in Australia. Seven parents stated that they were the primary intervention decision-maker for the family and five that they shared this role equally with their child's other parent. 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. The children were nine boys and three girls. At the time of recruitment their ages ranged from 21 to 66 months ($M = 51.8$), and the time since diagnosis ranged from 2 to 32 months ($M = 15.2$). 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)). Seven parents considered their child's ASD to be mild and five considered it moderate. Parent completion of the Childhood Autism Rating Scale, second edition (CARS 2; Schopler et al., 2010) indicated that three children had minimal-to-no symptoms of ASD, five had mild-to-moderate symptoms, and four had severe symptoms.

DVD-based package

A DVD was developed by the authors. It contained two sections. The first section provided guidelines (adapted from the Raising Children Network (2009)) for choosing interventions. 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 directions for how to access two websites, including navigation, a summary of the type of information provided, and an explanation of ratings scales and symbols used. The websites were selected by the authors because they provided generally accurate information about the evidence support for different interventions for children with ASD (Raising Children Network, 2006-2014; Research Autism, 2006-2014). Two external experts in the area of autism, both with extensive

international publication profiles, also examined the websites, and they confirmed that the sites provided a reasonably balanced and accurate view of the available research.

To facilitate the comparison of the research ratings supplied on the two websites and the ratings provided by participants, the ratings on the two websites were evaluated by the authors to give a “summary research rating”. Interventions were rated as having either: (a) no, or negative research evidence; (b) weak research evidence; (c) moderate research evidence; (d) strong research evidence; (e) not rated; or (f) unable to be rated. Detail of the rating procedure is available from the authors on request.

Instruments

The authors developed pre-test and post-test questionnaires. The first section of the pre-test questionnaire included items regarding demographic information about the participant and their family. The second section included items regarding decision-making, including the primary intervention decision-maker in the household; how confident the participant felt in making decisions about interventions (on a 5-point Likert-type scale from (1) not at all confident to (5) very confident); and 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; adapted from Authors, 2014).

The final section of the pre-test questionnaire listed interventions for preschool-age children with ASD that were available in Australia and was developed from several sources (Carter et al., 2011; Prior et al., 2011; Raising Children Network, 2006-2014; Research Autism, 2006-2014). 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”).

The post-test questionnaire included items related to whether the parents completed all parts of the DVD-based training package, and their impressions of the usefulness of the DVD and websites. In addition, it included the repetition of items from sections two and three of the pre-test questionnaire.

Procedure

Ethics approvals were obtained from all of the relevant ethics committees. Participants of a previous survey project who had expressed interest in participating in future research regarding intervention decision-making were sent recruitment notices for the present study (via email or post). Additionally, electronic and/or hardcopy recruitment notices were distributed to parents of pre-schoolers with autism via early intervention providers and autism-specific early learning and care centres in the five states or territories. Furthermore, all state and territory-based autism associations in Australia were contacted and recruitment notices were distributed (via email, on autism association websites, and/or autism association Facebook pages). Twenty-two parents expressed interest in participating and were sent an information and consent form. Sixteen parents returned the consent form 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 fourteen participants were sent a copy of the pre-test questionnaire and the CARS 2 (Schopler et al., 2010). They completed these over the phone with the first author and were sent the DVD package. The post-test questionnaire was administered over the phone to participants approximately 3 months later. Two participants chose not to participate in the post-test interview.

Results

Usefulness of the package

The participants provided feedback regarding the DVD package overall, for the guidelines for choosing interventions, and for each of the websites. All of the parents reported

that they had watched the DVD. They all indicated that they would recommend the DVD package to other parents of children with ASD, and half of the 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 indicated 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 parents indicated that it was very likely that they would visit it before commencing an intervention, and three that it was somewhat likely. All 10 parents who had visited the website indicated that they would recommend it 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 and/or they would only recommend this website to certain people, because they believed the Raising Children Network website was more accessible to parents.

Parent confidence

The mean score increased from 3.8 in the pre-test to 4.7 in the post-test. A 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

As shown in Table 1 there was very little change in the importance placed on different factors. Those factors with the greatest change in the mean were hope for a cure (-0.91), advice from friends/relatives (-0.50), and the hope that it would work (-0.41). 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

Table 2 shows a summary of the participant ratings of the desire to use and understanding of the level of research support for the interventions asked about in the survey, at pre-test and post-test, as well as summary of change in the final columns. The interventions are presented in the first column, grouped by the study research rating. Those interventions for which six or more parents either had a strong desire to use or were currently using at pre-test are shaded grey.

A general trend was for a pre-test to post-test decrease in the number of parents stating that they had not heard of interventions and in the number of parents that were unsure about the level of research support for interventions.

It seems reasonable to expect that parents would be more likely to seek information about the interventions that they were either currently using, or had a strong desire to use at pre-test. The parents' accuracy regarding the level of research support for the interventions (compared to the ratings supplied on the websites, illustrated through the "summary research rating"), however, did not improve when we examined only interventions that six or more of the participants were using or had a strong desire to use at pre-test. For example, social stories, which had a study rating of moderate support (3), had a mean score of 3.6 for research support with four participants unsure, which increased to 3.9 at post-test, with two participants changing their response from unsure to providing a rating. Similarly, three more participants provided a rating for visual schedules/picture schedules/visual strategies/visual supports at post-test, but the accuracy of the rating for this intervention with weak research support (study rating = 2) improved only slightly, with the mean score changing from 3.9 at pre-test to 3.8 at post-test. There was very little change in the high mean research ratings given to occupational therapy and speech therapy at pre-test, and none of the participants changed their rating to "unsure" even though these interventions were not rated on the Raising Children Network (2006-2014) website and were given the rating of "not applicable" on the

Research Autism (2006-2014) website because they incorporated a wide range of possible techniques, methods, and interventions.

It was of interest to determine if the research ratings provided by participants were related to their desire to use interventions rather than the actual level of research support for the interventions. Spearman correlation coefficients were therefore calculated in order to examine the relationships between the pre-test desire to use interventions and pre-test research ratings, and the post-test desire to use interventions and post-test research ratings, for each participant. One participant did not have any variance in the ratings supplied for the four interventions rated at pre-test (this participant rated all of these interventions as highly effective), therefore the pre-test correlation coefficient for this participant could not be calculated. For the remaining participants, ratings were supplied at pre-test for both the desire to use interventions and research support for these interventions for a mean of 16.2 interventions (range = 9 - 24, $SD = 4.51$). The mean of the correlation coefficients was .47 (range = -.03 to .93, $SD = 0.29$), representing a moderate positive relationship. Ratings for both the desire to use interventions and research support for interventions at post-test were supplied for a mean of 18.8 interventions (range = 10 - 27, $SD = 5.57$). The mean of the correlation coefficients was .27 (range = -.44 to .77, $SD = 0.38$), representing a small-to-moderate positive relationship.

Discussion

This pilot study provided an investigation of the effect of a DVD-based package providing guided access to reliable websites for parents of preschool-age children with ASD. The parents' views of the DVD-based package, level of confidence in making decisions, ratings of the importance of factors in decision-making, understanding of the level of research support for interventions, and desire to use interventions will be discussed seriatim, including implications for future research. This will be followed by discussion of limitations of the present study and implications for future research.

Overall, the parents' views of the DVD package were positive, with all of the parents stating that they would recommend the DVD to other parents of pre-schoolers with ASD. Half of the parents added that they believed it would be particularly helpful to parents of newly diagnosed children. Parents have reported becoming overwhelmed with the information received after their child's diagnosis (Mulligan et al., 2012; Valentine, 2010), and the training DVD may provide some structure to parents in terms of how to assess the information received about interventions during this time. Most of the parents also stated that they would personally use, and would recommend use of, the websites to other parents of pre-schoolers with ASD. Some qualitative responses indicated that the Raising Children Network (2006-2014) website appeared to be more accessible and user-friendly compared to the Research Autism (2006-2014) website. Reichow et al. (2012), Sabo (2008), and Sabo and Lorenzen (2008) reported that the high reading level of information presented on many autism related websites may act as a barrier to parents of children with ASD accessing relevant information, which may be reflected in the parents' impressions of the Research Autism (2006-2014) website in the present study.

The parents' ratings of confidence in making decisions increased substantially from pre-test to post-test, although this increase was not statistically significant given the limited sample. There was also little change in the level of importance placed by parents on different factors in decision-making. It was predicted that the intervention may have increased the level of importance placed by parents on research evidence and decreased the level of importance placed on factors such as advice from others and emotional factors such as hope and intuition. The hope for a cure and advice from friends or relatives were the only factors with a change of 0.5 or more in the mean score. They both decreased in importance from pre-test to post-test which may be a reflection of the influence of the guidelines for choosing interventions provided in the DVD. Conversely, the mean scores for both research evidence and intuition/gut feelings remained at a high level of 4.75 from pre-test to post-test. It appears

counter intuitive that parents who placed a high level of importance on research evidence would also place the same high level of importance on intuition. This finding, however, is consistent with previous parent reports of the importance of factors in decision-making (Authors, 2014).

In the present study, the parents were more likely to provide a rating of the level of research support for interventions at post-test which was consistent with their reported increased confidence. However, the ratings provided were not necessarily consistent with the ratings supplied on the websites, indicating that the DVD-based package providing guided access to the websites did not appear to have an effect on the parents' understanding of the level of research support for interventions in most cases. It should be noted that the DVD-based package used in the current study provided parents with general advice, modelled on that provided in the Raising Children Network (2009) website, as well as guided instruction on use of two reliable websites. Thus, parents were provided with considerably more guidance than those who may just access the websites independently. Noting this, and acknowledging that only tentative conclusions should be drawn from this pilot study, this finding does raise the question as to whether websites such as the Raising Children Network (2006-2014), which provide information about the empirical support for different interventions, do actually have an impact on parent's views about the efficacy of different interventions. Given the current preliminary findings, the impact of such websites on parents' views and decision-making, both in the short-term and longitudinally, could be assessed systematically with a much larger sample in the future.

The ratings of research evidence appeared to be related to the parent's current use or desire to use the intervention (rather than the level of research support for the intervention). This relationship was confirmed by correlations between desire to use an intervention and parent research ratings. The relationship between the desire to use and research ratings was not as strong at post-test, may have been due to parents discontinuing the use of interventions

that they still believed to have strong research evidence. Some parents reported, for example, that they had discontinued the use of occupational therapy and autism-specific early intervention during the time between the pre-test and post-test because their children had commenced school, but still rated these interventions as having strong research support.

Although it may have been expected that being informed about evidence-based practice and being provided with information about the efficacy of interventions (via the websites) would have influenced the participant's level of desire to use interventions, this did not appear to be the case. There did not appear to be a relationship between the ratings of desire to use interventions at post-test and the ratings of research support for interventions provided on the websites.

A tendency to ignore information that may conflict with a person's original opinion on a given topic and to seek confirming information, has been described as selective exposure (Hart et al., 2009), and is part of a psychological phenomenon known as confirmation bias (Nickerson, 1998). Nickerson (1998) has noted that "if one were to attempt to identify a single problematic aspect of human reasoning that deserves attention above all others, the confirmation bias would have to be among the candidates for consideration" (p. 175). Thus, participants in the present study may have given greater weight to information that confirmed their decisions regarding intervention use and disregarded conflicting information. Parents in the current study were all currently using interventions and it is possible that their reasoning was motivated, tending to rationalise and justify past decisions. This would explain the limited correspondence between their views on research evidence and the information on the websites. Furthermore, the difficulty in recruiting participants for the study might reflect a lack of interest in seeking further information once decisions have been made regarding interventions.

While the current study was not designed to test decision-making theory or models, it should be noted that despite there being a number of theories of how decisions are made

(Klein, 2008; Robinson & Donald, 2015), the extent to which they are relevant to parent decision-making regarding the use of interventions for their children is unclear. Much of the research in naturalistic environments uses expert decision-makers (Klein, 2008; Meso et al., 2002). Nevertheless, experts tend to use pattern matching to identify when they have made similar decisions in the past (Klein, 2008; Meso et al., 2002). Parents may attempt a similar process but do not necessarily have adequate background, as past similar decisions, such as medical decisions, would have been made in consultation with a doctor acting as an expert advisor. Furthermore, parents are unlikely to have the skills to evaluate situations in the same way that experts do when making decisions. Therefore, future research regarding parent decision-making could focus not only on individual or groups of factors in decision-making, such as exposure to information about the efficacy of interventions, but could also investigate the decision-making process itself in more detail to provide a model of this type of parental decision-making.

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 being conducted. Further, the sample was well educated and probably highly motivated. The reader should therefore use requisite caution in interpreting the current research.

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. It is also possible that the DVD-based package may have different impacts on parents who had not yet committed to a specific intervention and this could be a direction for future research. Additionally, data regarding the frequency and duration of the viewing of the websites during the intervention was not collected from

participants. Whether longer and/or more frequent exposure to the websites would have a greater impact on parental beliefs or decisions may be explored in future research.

Conclusion

Parents in the present study had increased confidence in making decisions after using the DVD-based package. However, the DVD-based package providing guided access to reliable websites did not appear to influence the factors that parents considered important in decision-making, their understanding of the level of research support for interventions, nor their desire to use different interventions. This research raises questions regarding the difference between the decision-making process for those who have already made decisions to employ interventions and those with children who are newly diagnosed and who have not yet formed opinions on interventions. This may be explored in future research along with the role of websites such as Raising Children Network (2006-2014) in providing information about the efficacy of interventions to parents, and the detailed examination of the decision-making process undertaken by parents.

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*Note: The Research Autism website has been restructured and the *Treatments and therapies for autism currently under scientific evaluation by Research Autism* page (used in the present study) has been removed. The same information is now available at:

Research Autism (2014) Our evaluations of autism interventions, treatments and therapies
Available at: <http://www.researchautism.net/autism-interventions/our-evaluations-interventions> (accessed 27 October 2014).

Table 1. Participant ratings of importance of factors in decision-making at pre-test and post-test.

Decision-Making Factor	Pre-test Importance Rating		Post-test Importance Rating		Change in mean
	Mean (SD)	Range	Mean (SD)	Range	
Advice from medical doctors	4.50 (0.67)	3-5	4.67 (0.49)	4-5	+ 0.17
Advice from other parents	4.00 (0.60)	3-5	4.08 (0.67)	3-5	+ 0.08
Advice from therapists	4.92 (0.29)	4-5	4.58 (0.51)	4-5	- 0.34
Advice from friends/relatives	3.00 (1.13)	1-5	2.50 (1.24)	1-4	- 0.50
Advice from teachers/educators	4.33 (0.89)	3-5	4.42 (0.51)	4-5	+ 0.09
Research evidence	4.75 (0.45)	4-5	4.75 (0.45)	4-5	0
Information from an Autism Advisor	4.67 (0.65)	3-5	4.75 (0.62)	3-5	+ 0.08
Information from the service provider	4.25 (0.75)	3-5	4.00 (0.85)	2-5	- 0.25
Whether the intervention is autism-specific	3.75 (1.14)	2-5	3.92 (1.44)	1-5	+ 0.17
Cost	3.83 (1.27)	1-5	4.17 (1.11)	1-5	+ 0.34
Funding	4.50 (0.80)	3-5	4.67 (0.49)	4-5	+ 0.17
Whether the staff appeared professional	5.00 (0.00)	5-5	4.83 (0.39)	4-5	- 0.17
Intuition/gut feelings	4.75 (0.45)	4-5	4.75 (0.45)	4-5	0
Whether the staff were experienced	4.75 (0.45)	4-5	4.92 (0.29)	4-5	+ 0.17
Availability	4.67 (0.49)	4-5	4.50 (0.52)	4-5	- 0.17
Feeling I may need to try anything that might help	3.92 (1.24)	1-5	3.75 (1.29)	1-5	- 0.17
Location	4.00 (0.60)	3-5	4.25 (0.87)	2-5	+ 0.25
Child's individual needs	5.00 (0.00)	5-5	5.00 (0.00)	5-5	0
Availability of alternative interventions	4.25 (0.75)	3-5	4.17 (0.39)	4-5	- 0.08
Child's age	4.42 (0.67)	3-5	4.08 (1.31)	1-5	- 0.34
Side effects/adverse effects	4.92 (0.29)	4-5	4.92 (0.29)	4-5	0
Compatibility with other interventions	4.25 (0.87)	3-5	3.92 (1.31)	1-5	- 0.33
Effectiveness of other interventions	4.67 (0.49)	4-5	5.00 (0.00)	5-5	+ 0.33
The hope it would work	4.58 (1.16)	1-5	4.17 (1.40)	1-5	- 0.41
Hope for a cure	3.33 (1.83)	1-5	2.42 (1.78)	1-5	- 0.91
Whether I thought my child would enjoy it	4.50 (0.52)	4-5	4.25 (0.45)	4-5	- 0.25

Whether it was convenient time wise/fit the schedule	4.08 (1.00)	2-5	4.00 (1.04)	2-5	- 0.08
Family impact	4.75 (0.45)	4-5	4.92 (0.29)	4-5	+ 0.17
Whether or not most people think it is an effective intervention	3.42 (1.38)	1-5	3.25 (1.36)	1-5	- 0.17

Table 2. Participant ratings of desire to use and level of research support for interventions at pre-test and post-test.

Intervention	Pre-test				Post-test				Change			
	Desire rating		Research rating		Desire rating		Research rating		Mean desire	No. unaware	Mean research rating	No. unsure
	Mean (SD)	No. unaware	Mean (SD)	No. unsure	Mean (SD)	No. unaware	Mean (SD)	No. unsure				
With strong research support												
Applied behaviour analysis (ABA)	3.0 (1.2)	1	4.0 (0.0)	1	2.7 (1.3)	0	3.8 (0.4)	0	- 0.3	- 1	- 0.2	- 1
Positive behavioural support	3.2 (0.8)	6	4.0 (0.0)	7	2.2 (1.1)	3	3.6 (0.8)	5	- 1.0	- 3	- 0.4	- 2
Lovaas	2.0 (1.0)	9	3.3 (0.6)	9	1.4 (0.5)	5	3.6 (0.5)	7	- 0.6	- 4	+ 0.3	- 2
Functional Communication Training	2.0 (1.4)	10	4.0 (0.0)	10	2.5 (1.3)	8	3.3 (0.6)	9	+ 0.5	- 2	- 0.7	- 1
Pivotal response	2.5 (0.7)	10	4.0 (0.0)	10	2.0 (1.0)	9	4.0 (0.0)	10	- 0.5	- 1	0	0
With moderate research support												
Picture Exchange Communication System (PECS)	2.7 (1.1)	1	3.9 (0.3)	1	2.4 (1.2)	0	3.9 (0.3)	1	- 0.3	- 1	0	0
Social stories	3.2 (0.8)	2	3.6 (0.5)	4	3.0 (1.0)	1	3.9 (0.3)	2	- 0.2	- 1	+ 0.3	- 2
Music therapy	2.3 (0.6)	1	2.4 (1.0)	5	2.3 (1.0)	0	2.8 (0.8)	2	0	- 1	+ 0.4	- 3
Incidental teaching	n/a	12	n/a	12	2.5 (0.7)	10	3.0 (1.4)	10	n/a	- 2	n/a	- 2
With weak research support												
Gluten free/casein free diet	2.3 (1.1)	1	2.5 (1.1)	1	2.0 (1.2)	0	2.7 (1.0)	1	- 0.3	- 1	+ 0.2	0
Signing	2.1 (1.2)	2	3.5 (0.8)	4	2.2 (1.5)	1	3.5 (0.8)	2	+ 0.1	- 1	0	- 2
Visuals	3.2 (0.9)	2	3.9 (0.4)	4	3.3 (1.0)	0	3.8 (0.4)	1	+ 0.1	- 2	- 0.1	- 3
DIR/Floortime	2.6 (1.2)	3	3.4 (0.5)	5	2.2 (1.1)	0	3.2 (0.8)	3	- 0.4	- 3	- 0.2	- 2

Relationship Development Intervention (RDI)	2.2 (1.3)	7	2.3 (1.0)	8	1.6 (1.1)	4	2.7 (0.5)	5	- 0.8	- 3	+ 0.4	- 3
TEACCH	1.3 (0.6)	9	3.0 (0.0)	10	1.3 (0.5)	6	2.7 (1.5)	9	0	- 3	- 0.3	- 1
Developmental social pragmatic model	1.5 (0.7)	10	3.0 (n/a)	11	1.4 (0.5)	7	3.0 (0.0)	10	- 0.1	- 3	0	- 1
Early Start Denver	2.0 (0.8)	8	4.0 (n/a)	11	1.7 (0.8)	6	4.0 (0.0)	8	- 0.3	- 2	0	- 3
Milieu training	n/a	12	n/a	12	2.0 (n/a)	11	n/a	12	n/a	- 1	n/a	0
With no, or negative research support												
Sensory integration	2.2 (1.2)	1	2.9 (1.0)	2	2.3 (1.2)	1	2.9 (0.7)	2	+ 0.1	0	0	0
Auditory integration	1.8 (1.2)	4	2.6 (0.5)	7	1.4 (0.7)	2	2.8 (0.5)	8	- 0.4	- 2	+ 0.2	+ 1
Facilitated Communication	1.0 (n/a)	11	4.0 (n/a)	11	1.4 (0.5)	5	2.5 (1.0)	6	+ 0.4	- 6	- 1.5	- 5
Learning Experiences- An Alternative Program for Preschoolers and their Parents (LEAP)	2.0 (1.0)	9	2.0 (n/a)	11	1.5 (1.0)	8	4.0 (n/a)	11	- 0.5	- 1	+ 2.0	0
Unable to be rated												
Occupational therapy	3.3 (0.8)	0	3.8 (0.4)	0	2.9 (0.9)	0	3.9 (0.3)	0	- 0.4	0	+ 0.1	0
Speech therapy	3.4 (0.7)	0	4.0 (0.0)	0	3.3 (1.0)	0	3.9 (0.3)	0	- 0.1	0	- 0.1	0
Physiotherapy	1.8 (1.0)	0	3.6 (1.1)	4	1.4 (1.0)	2	2.8 (1.0)	4	- 0.4	+ 2	- 0.8	0
Not rated on the websites												
Speech Generating Devices	2.5 (1.3)	0	3.8 (0.5)	0	2.3 (1.3)	1	3.6 (0.5)	3	- 0.2	+ 1	- 0.2	+ 3
More Than Words: The Hanen Program	2.8 (1.0)	1	3.6 (0.5)	4	2.3 (1.2)	0	3.6 (0.5)	3	- 0.5	- 1	0	- 1
Omega 3 fatty acid supplements	2.9 (1.6)	4	2.9 (1.4)	4	2.5 (1.0)	1	3.0 (1.2)	2	- 0.4	- 3	+ 0.1	- 2
Building Blocks	2.9 (1.0)	4	3.6 (0.8)	5	2.3 (1.1)	3	3.6 (0.7)	4	- 0.6	- 1	0	- 1

Giant Steps	2.5 (1.3)	8	3.7 (0.6)	9	1.5 (1.2)	6	3.7 (0.6)	9	- 1.0	- 2	0	0
Triple Parenting Program- Stepping Stones Adaptation	1.7 (0.8)	6	2.5 (0.7)	10	1.4 (0.8)	5	3.7 (0.6)	9	- 0.3	- 1	+ 1.2	- 1
The P.L.A.Y project	2.5 (0.7)	10	3.0 (n/a)	11	2.0 (1.0)	9	3.5 (0.7)	10	- 0.5	- 1	+ 0.5	- 1
Social-Communication, Emotional Regulation and Transactional Support (SCERTS)	2.5 (0.7)	10	3.0 (n.a)	11	2.2 (1.0)	6	3.0 (0.8)	8	- 0.3	- 4	0	- 3
Alert program for self-regulation	2.0 (n/a)	11	n/a	12	1.8 (1.2)	6	2.0 (1.4)	10	- 0.2	- 5	n/a	- 2
Pre-school Autism Communication Trial (PACT)	n/a	12	n/a	12	1.5 (0.7)	10	3.5 (0.7)	10	n/a	- 2	n/a	- 2
Preschoolers with Autism Manualised Training Program	2.0 (n/a)	11	n/a	12	2.5 (0.7)	10	3.0 (0.0)	10	+ 0.5	- 1	n/a	- 2

* *Note: Grey shading indicates that six or more participants were either using the intervention or had a strong desire to use the intervention at pre-test*

APPENDIX 1

Pre-test interview schedule used in Carlon, Carter, and Stephenson (2014).

Section one- Your child and your family.

1. How old is your child? _____ years _____ months
2. What is your child's gender? Male ☐ Female ☐
3. What is your child's diagnosis?
 - a. Autistic Disorder
 - b. Asperger's Disorder
 - c. Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS)
 - d. Autism spectrum disorder
 - e. No official diagnosis, or other (please specify) _____
4. When was your child diagnosed? Month: _____ Year: _____ N/A ☐
5. Do you consider your child's autism spectrum disorder (ASD) to be:
 - a. Mild b. Moderate c. Severe
6. Do you have any other children?
If yes, a) How old are they? _____
b) Have any of your other children been diagnosed with ASD?
7. How old are you?
 - a. Under 25 b. 25-34 c. 35-44 d. Over 45
8. How old is your child's other parent?
 - a. Under 25 b. 25-34 c. 35-44 d. Over 45
9. Are you your child's:
 - a. Mother ☐ b. Father ☐
 - c. Other guardian ☐ (please specify relationship) _____

10. What is the highest level of education you have received?

- | | |
|---------------------------------------|--------------------------------------|
| a. High school | b. TAFE, college or further training |
| c. An undergraduate university degree | d. A postgraduate university degree |

11. What is the highest level of education your child's other parent has received?:

- | | |
|---------------------------------------|--------------------------------------|
| a. High school | b. TAFE, college or further training |
| c. An undergraduate university degree | d. A postgraduate university degree |

12. What is your postcode?

13. This is an optional question - you do not have to answer this question if you prefer. What is your yearly family income?

- | | |
|-----------------------------------|-------------------------------|
| a. Less than \$40,000 per year | b. \$40,000-\$80,000 per year |
| b. c. \$80,000-\$120,000 per year | d. Over \$120,000 per year |

14. What do you think may cause or contribute to the development of ASD? You may indicate as many as you think apply.

- | | |
|--|--|
| a. Genetics/hereditary | b. Abnormality/chemical imbalance in the brain |
| c. Traumatic experiences early in life | d. Illness or complications during pregnancy |
| e. The child's upbringing | f. Allergies to some foods |
| g. Environmental triggers | h. Vaccinations |
| i. Unknown causes | j. Other (please specify) - |
-

Section 2- Decision-making

15. Which of the following best describes how your family makes decisions about the interventions to use with your child with ASD?

- a. I primarily make the decisions about which interventions to use

- b. My child's other parent primarily makes the decisions about which interventions to use
- c. We make decisions about which interventions to use together (50/50)

16. How confident do you feel in making decisions about interventions to use with your child?

Not at all confident	Somewhat <u>un</u> confident	Neutral	Somewhat confident	Very confident
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17. On the scale from very unimportant to very important please indicate how important you consider the following to be when deciding which interventions to use with your child.

Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
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For example: If advice from other parents is somewhat important to your decision-making, you would indicate "Somewhat important"

Advice from other parents	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	<u>Somewhat Important</u>	Very Important
Advice from medical doctors	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from other parents	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from therapists	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from friends or relatives	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from teachers/educators	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

Research evidence	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The information provided about the intervention by an Autism Advisor	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The information provided about the intervention from the service provider	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the intervention is ASD-specific	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The cost of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Government funding available to help pay for the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention appeared professional	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My own intuition or “gut feelings”	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention were experienced	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The feeling that I may need to try anything that might help	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The location or accessibility of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The specific needs of my child (e.g. communication skills, social skills, sensory issues)	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of alternative interventions	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

My child's age	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Side effects or adverse effects	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The compatibility of this intervention with other interventions we are using	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The effectiveness of other interventions we are currently using	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My hope that it would work for my child	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My hope for a cure for my child's ASD	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I thought my child would enjoy it	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
It was convenient time-wise and "fit" my child's and/or our family's schedule	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I thought it would have a positive impact on our family	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Most people thought that this was an effective intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
<i>Other(s) (Please specify)</i>	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

Section 3- Interventions- Desire to use and level of research support.

17. For the following interventions please indicate your desire to use it (if the services were available in your area and cost was not an issue). Please indicate whether you:

Have not heard of this	Have no desire to use this	Have some desire to use this	Have a strong desire to use this	Are currently using this
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Also indicate your understanding of the level of research support for the intervention. Please indicate if you believe it has:

No evidence, or negative evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
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For example: If you do not desire to use Applied Behaviour Analysis, and you think that there is no research evidence supporting ABA or that there is research evidence showing that it does not help children with ASD, you would indicate “No desire to use this” and “No, or negative, evidence”.

Applied Behaviour Analysis (ABA)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
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Intervention	Desire to use this intervention					Level of research support for this intervention				
Applied Behaviour Analysis (ABA)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Alert Program for self-regulation	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Auditory integration training	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Building Blocks (Centre or home-based)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Developmental social-pragmatic model	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
DIR/Floortime/Individual Difference Relationship based/Greenspan model	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Early start Denver model	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Facilitated communication	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Functional communication training	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Giant Steps	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Gluten-free and/or Casein-free diet	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Incidental teaching	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

LEAP	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Lovaas program/UCLA Young Autism Project/UCLA model/Early Intensive Behavioural Intervention (EIBI)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Milieu Training	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
More than Words: The Hanen Program	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Music therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Occupational therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Omega 3 fatty acid supplements	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
PACT - Pre-school Autism Communication Trial	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Physiotherapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Picture Exchange Communication System (PECS)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Pivotal Response Training/Pivotal Response Intervention/Natural Language Paradigm (NLP)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Positive behavioural support	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

The P.L.A.Y. Project® - Play and Language for Autistic Youngsters	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Pre-schoolers with Autism - Manualised parent training program	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Relationship Development Intervention (RDI)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
SCERTS	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Sensory integration training/sensory integrative therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Sign language/manual signing/keyword sign	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Social stories/social scripts	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Speech and/or speech and language therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Speech-generating devices (SGDs)/Communication devices/electronic AAC systems/electronic augmentative and alternative communication/Voice Output Communication Aids (VOCAs)/Ipads	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
TEACHH	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Triple P – Stepping Stones adaptation	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

Visual schedules/Picture schedules/Visual strategies/Visual supports	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
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Are there any other interventions that you are using, or would like to add?

1. Have you ever looked for information about interventions for ASD on the Raising Children Network Website (www.raisingchildren.net.au)?

Yes

No

Unsure

If yes, how many hours have you spent looking at this website?

2. Have you ever looked for information about interventions for ASD on the Research Autism Website (www.researchautism.net)?

Yes

No

Unsure

If yes, how many hours have you spent looking at this website?

APPENDIX 2

Post-test interview schedule used in Carlon, Carter, and Stephenson (2014).

Post-test questionnaire for intervention group (Group A).

1. Did you receive the resource package?

2. Did you start using any new interventions with your child after receiving the package?

If yes, what intervention(s) have you started using? -

If yes, why did you start using the new intervention(s)?

3. Did you stop using any interventions with your child after receiving the package?

If yes, what intervention(s) have you stopped using? -

If yes, why did you stop using the intervention(s)

The DVD contained two parts: 1) the guidelines for choosing interventions; and 2) information about websites providing reliable information about interventions.
--

The next two questions are about Part 1 of the DVD- the guidelines for choosing interventions.

4. Did you have a chance to watch the guidelines for choosing interventions?

5. How likely is it that you would consult these guidelines before commencing an intervention in the future?

- a. Very likely b. Somewhat likely c. Somewhat unlikely
d. Very unlikely e. Unsure

Why?

After the guidelines you were provided with information on two websites. The next six questions refer to Part 2 DVD- the websites providing reliable information about interventions.

6. Did you have a chance to look at the Raising Children Network website?

7. How likely is it that you would visit the Raising Children Network website before commencing an intervention?

- a. Very likely b. Somewhat likely c. Somewhat unlikely
d. Very unlikely e. Unsure

Why?

8. Would you recommend this website to other parents of preschool-age children with ASD? Why or why not?

9. Did you have a chance to look at the Research Autism website?

10. How likely is it that you would visit the Research Autism website before commencing an intervention?

- a. Very likely b. Somewhat likely c. Somewhat unlikely
d. Very unlikely e. Unsure

Why?

11. Would you recommend this website to other parents of preschool-age children with ASD? Why or why not?

The following questions are about your impressions of the DVD package overall.

12. What did you like about the DVD?

13. Would you recommend the DVD to other parents of preschool-age children with ASD? Why or why not?

14. What do you think should be changed or added to make it useful to other parents?

15. How confident do you feel in making decisions about interventions to use with your child?

Not at all confident	Somewhat <u>un</u> confident	Neutral	Somewhat confident	Very confident
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16. On the scale from very unimportant to very important please indicate how important you consider the following to be when deciding which interventions to use with your child.

Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
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For example: If advice from other parents is somewhat important to your decision-making, you would indicate "Somewhat important"

Advice from medical doctors	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from other parents	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from therapists	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from friends or relatives	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Advice from teachers/educators	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

Research evidence	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The information provided about the intervention by an Autism Advisor	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The information provided about the intervention from the service provider	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the intervention is ASD-specific	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The cost of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Government funding available to help pay for the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention appeared professional	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My own intuition or “gut feelings”	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Whether the person/people carrying out the intervention were experienced	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The feeling that I may need to try anything that might help	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The location or accessibility of the intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The specific needs of my child (e.g. communication skills, social skills, sensory issues)	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The availability of alternative interventions	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

My child's age	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Side effects or adverse effects	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The compatibility of this intervention with other interventions we are using	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
The effectiveness of other interventions we are currently using	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My hope that it would work for my child	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
My hope for a cure for my child's ASD	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I thought my child would enjoy it	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
It was convenient time-wise and "fit" my child's and/or our family's schedule	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
I thought it would have a positive impact on our family	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
Most people thought that this was an effective intervention	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
<i>Other(s) (Please specify)</i>	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important
	Very <u>un</u> important	Somewhat <u>un</u> important	Neither important nor unimportant	Somewhat Important	Very Important

16. For the following interventions please indicate your desire to use it (if the services were available in your area and cost was not an issue). Please indicate whether you:

Have not heard of this	Have no desire to use this	Have some desire to use this	Have a strong desire to use this	Are currently using this
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Also indicate your understanding of the level of research support for the intervention. Please indicate if you believe it has:

No evidence, or negative evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
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For example: If you do not desire to use Applied Behaviour Analysis, and you think that there is no research evidence supporting ABA or that there is research evidence showing that it does not help children with ASD, you would indicate “No desire to use this” and “No, or negative, evidence”.

Applied Behaviour Analysis (ABA)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
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Intervention	Desire to use this intervention					Level of research support for this intervention				
Applied Behaviour Analysis (ABA)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Alert Program for self-regulation	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Auditory integration training	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Building Blocks (Centre or home-based)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Developmental social-pragmatic model	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
DIR/Floortime/Individual Difference Relationship based/Greenspan model	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

Early start Denver model	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Facilitated communication	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Functional communication training	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Giant Steps	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Gluten-free and/or Casein-free diet	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Incidental teaching	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
LEAP (Learning Experiences and Alternate Program for Preschoolers and their Parents)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

Lovaas program/UCLA Young Autism Project/UCLA model/Early Intensive Behavioural Intervention (EIBI)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Milieu Training	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
More than Words: The Hanen Program	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Music therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Occupational therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Omega 3 fatty acid supplements	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
PACT - Pre-school Autism Communication Trial	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

Physiotherapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Picture Exchange Communication System (PECS)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Pivotal Response Training/Pivotal Response Intervention/Natural Language Paradigm (NLP)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Positive behavioural support	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
The P.L.A.Y. Project® - Play and Language for Autistic Youngsters	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Pre-schoolers with Autism - Manualised parent training program	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Relationship Development Intervention (RDI)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

SCERTS (Social Communication, Emotional Regulation and Transactional Support model)	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Sensory integration training/sensory integrative therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Sign language/manual signing/keyword sign	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Social stories/social scripts	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Speech and/or speech and language therapy	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Speech-generating devices (SGDs)/Communication devices/electronic AAC systems/electronic augmentative and alternative communication/Voice Output Communication Aids (VOCAs)/Ipad	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

TEACCH	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Triple P – Stepping Stones adaptation	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure
Visual schedules/Picture schedules/Visual strategies/Visual supports	Have not heard of this	No desire to use	Some desire to use	Strong desire to use	Currently using	No, or negative, evidence	Weak research evidence	Moderate research evidence	Strong research evidence	Unsure

Are there any other interventions that you are using, or would like to add?

APPENDIX 3

Procedure used by authors in Carlon, Carter, and Stephenson (2014) to summarise research ratings supplied on the two websites used in the study.

To facilitate the comparison of the research ratings supplied on the two websites and the ratings provided by participants, the ratings on the two websites were consolidated to give a “summary research rating”. The ratings for the interventions given on each of the websites and used in the study are shown in Table 1. If the intervention received a rating of either established, very strong positive evidence, or strong positive evidence without a contradictory lower rating, it was rated as having *strong research evidence*. If one of the preceding ratings was given but it was contradicted on the other website it was rated as having *moderate research evidence*. If an intervention was rated as promising or having limited positive evidence on the websites it was rated as having *weak research evidence*. Those interventions that were rated as having either strong or very strong negative evidence, insufficient or mixed evidence, yet to be determined, or ineffective/harmful were rated as having *no, or negative evidence*. If an intervention received one of the preceding ratings on one website but it was contradicted with a higher rating on the other website it was rated as having *weak research evidence* (as it was predicted that parents may interpret the mixed findings across the websites as representing weak evidence). Interventions that were not listed on either website, or that were identified as unrateable or ungraded were rated as *not rated*, and those that received a not applicable rating (because they were broad interventions, e.g. speech therapy, and could therefore not be assessed) were rated as *unable to be rated*.

Table 1

Research Ratings Provided on Websites and “Summary Research Rating” Used in the Study

Intervention	Raising Children Network Rating	Research Autism Rating	Summary Research Rating*
Applied Behaviour Analysis (ABA)	Established	Not Applicable	4
Alert program for self-regulation	Not rated
Auditory integration training	Yet to be determined	Strong negative evidence	1
Building Blocks (centre or home-based)	Not rated
Developmental social-pragmatic model	Promising	2
DIR/Floortime/Individual Difference Relationship based/Greenspan model	Promising	Insufficient/mixed evidence	2
Early Start Denver model	Promising	2
Facilitated communication	Ineffective/harmful	Very strong negative evidence	1
Functional communication training	Established	Ungraded	4
Giant Steps	Not rated
Gluten-free and/or Casein-free diet	Unrateable	Limited positive evidence	2
Incidental teaching	Established	Limited positive evidence	3
LEAP- Learning Experiences – An Alternative Program for Preschoolers and Parents	Insufficient/mixed evidence	1
Lovass program/UCLA Young Autism Project/UCLA model/EIBI	Unrateable	Very strong positive evidence	4
Milieu training	Limited positive evidence	2
More than Words: The Hanen Program	Unrateable	Not rated
Music Therapy	Promising	Strong positive evidence	3
Occupational therapy	Not Applicable	Unable to be rated
Omega 3 fatty acid supplements	Ungraded	Not rated
PACT- Pre-school Autism Communication Trial	Not rated
Physiotherapy	Not Applicable	Unable to be rated
Picture Exchange Communication System (PECS)	Promising	Very strong positive evidence	3
Pivotal Response Training/Pivotal Response Intervention/Natural Language Paradigm	Established	Strong positive evidence	4
Positive behavioural support	Established	4

The P.L.A.Y Project- Play and Language for Autistic Youngsters	Not rated
Pre-schoolers with Autism- manualised parent training program	Unrateable	Not rated
Relationship Development Intervention (RDI)	Promising	Insufficient/mixed evidence	2
SCERTS - Social-Communication, Emotional Regulation and Transactional Support	Unrateable	Unrated	Not rated
Sensory integration training/sensory integrative therapy	Yet to be determined	Insufficient/mixed evidence	1
Sign language/manual signing/keyword sign	Promising	Unrated	2
Social stories/social scripts	Established	Limited positive evidence	3
Speech and/or speech and language therapy	Not Applicable	Unable to be rated
Speech generating devices (SDGs), Communication devices/electronic AAC systems/electronic augmentative and alternative communication/Voice Output Communication Aids (VOCAs)/iPads	Unrateable	Ungraded	Not rated
TEACCH	Promising	Limited positive evidence	2
Triple P- Stepping Stones Adaptation	Not rated
Visual schedules/Picture schedules/Visual strategies/Visual supports	Unrateable	Limited positive evidence	2

*Note: 1 = no or negative evidence; 2 = weak research evidence; 3 = moderate research evidence; 4 = Strong research evidence

CHAPTER 7: CONCLUSION

Chapter Overview

In this chapter a summary of the research contained in this thesis is presented, followed by a summary of the research questions addressed and the major conclusions that can be drawn from this research. The major contribution of this research to the field of special education is identified.

Summary of Research

The main purpose of the research reported in this thesis was to explore how parents of Australian children with ASD make decisions regarding intervention use. In Chapter 1 the purpose of the research was presented, along with a brief presentation of literature that provided a background and rationale for the research, and an overview of the research. In Chapter 2 the first systematic review of parent reports of interventions used with children with ASD was presented, along with one of the few surveys collecting these data from Australian parents. The range of interventions used and implications for future research were identified.

The first review of decision-making factors declared by parents of children with ASD as related to their intervention decision-making was presented in Chapter 3. A range of factors were identified, but very limited data were available regarding the weight that parents placed on different factors in their decision-making. Chapter 4 contained two papers detailing an exploratory qualitative study which was informed by the findings of the pilot survey study and two review studies. This research added to the very small Australian research base regarding sources of information used by parents in, and factors related to, intervention decision-making for ASD. In the first paper, how parents decided which sources are more reliable and trustworthy was identified. Issues relating to the usefulness of the information provided by sources (including uniquely Australian sources) were also discussed. In the second paper a range of factors influencing commencement, rejection, and discontinuation

decisions of parents were identified. Parents in this study nominated a “final criteria” for the vast majority of their commencement and rejection decisions. This was one of the few studies in which data regarding the weight of importance placed by parents on different factors in their decision-making were presented.

Drawing on the findings of the qualitative study and two review papers, a survey was developed to investigate the importance placed by parents on different factors in decision-making. The findings from this survey were provided in the two papers in Chapter 5. The first paper was one of the few that included reports from parents on the weight that they placed on the importance of different factors in intervention decision-making, and the only Australian study of this type. Factors that had frequently been reported as being considered by parents in previous research, such as advice or recommendations from others, were not those that were identified as the most important in the actual decisions of the parents in the study. This highlighted the importance of considering the weight that parents place on different factors in their decision-making, rather than how frequently they consider factors.

The second paper in Chapter 5 provided analysis of the possible relationships between implicit underlying parent and child factors and the number and type of interventions used with their children. This was the first study of this type with an entirely Australian sample. Few significant relationships were found, which was consistent with international research in the area. Some specific findings of researchers in other countries were not replicated in this study, indicating that factors affecting decision-making may differ across samples.

A paper detailing the pilot study of a parent education DVD including guided access to websites with reliable information about the efficacy of interventions for ASD was presented in Chapter 6. The 12 participants who completed the trial reported an increased confidence in making decisions. The DVD-based package did not appear to influence the factors parents considered important in decision-making, the accuracy of their ratings of research support for interventions (compared to the ratings provided on the websites), nor

their desire to use different interventions. Given that parents in this study were provided with considerably more guidance to access the information on the websites than parents who would normally access these websites independently, these findings raise questions regarding whether such websites are assisting parents to make better informed decisions.

Research Questions Addressed

The first research question related to the number and types of different interventions used by parents of children with ASD. This question was addressed in the review study of intervention use and the survey study of Australian parents presented in Chapter 2. The second question related to how parents find out about different types of interventions, this was addressed in the review study presented in Chapter 3 and the qualitative study presented in Chapter 4. The main factors that play a role in parental decision-making (research question 3) were identified in the review study in Chapter 3 and qualitative study in Chapter 4. The weight of importance that parents placed on these different factors in their decision-making was addressed in Chapter 5. Additionally, in Chapter 5 the exploration of relationships between parent and child characteristics and intervention choices (research question 5) was undertaken. The fifth research question, regarding whether the provision of information about empirically supported treatments would influence parent's opinions about interventions and/or their intervention choices was addressed in the trial of the education package presented in Chapter 6.

Conclusions

The major conclusions that can be drawn from the research presented in this thesis are:

1. There is general consistency in the reported use of interventions across studies using a variety of methodologies with different populations. In addition, consistent with

overseas research, Australian parents appear to be using multiple interventions (with varying levels of research support) simultaneously.

2. Recommendations or advice has been identified most frequently as a factor across studies examining factors declared by parents related to intervention decision-making.
3. Factors that are frequently considered in decision-making may not necessarily carry the most weight in parents' final decisions to use and/or reject interventions.
4. Parents appear to place a high level of importance on both professional and personal attributes of staff when making intervention decisions, and a lesser degree of importance on research efficacy.
5. Websites designed to disseminate information about the efficacy of interventions to parents and assist them in making informed decisions may not be influencing parents' views, and further research is required in this area.

Summary

This chapter provided a summary of the research presented in this thesis and the major conclusions drawn from this research. The unique contribution of this research to the field of special education was identified. The research adds to the very small Australian research base related to the intervention decision-making of parents of preschool-age children with ASD.

APPENDIX

Ethics final approval correspondence and amendment approval correspondence.

Appendix (pp. 352-366) removed from Open Access version as they may contain sensitive/confidential content.