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**Assisting parents of children with autism to make intervention decisions
by improving their health literacy about evidence.**

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Abstract

Parents of children newly diagnosed with Autism Spectrum Disorders (ASD) are faced with the daunting task of choosing from numerous autism interventions. At the time this research project began, little was understood about how parents made decisions for their child following the diagnosis. A few groups and organisations, in Australia and overseas, have designed and disseminated resources in various formats to help parents with decision making, but none had been evaluated in a clinical trial that tested the effectiveness of the resource in facilitating this process. Based on a review of the literature, and with consideration for the gap in research on this topic, a mixed methodology project was designed. The project incorporated five studies aiming to: 1) develop an understanding of the information that parents of children with ASD currently use to make intervention decisions, and their information preferences; 2) develop an understanding of parents' decision making processes; 3) evaluate the quality of information most commonly accessed by parents, particularly web-based information; 4) determine how best to help parents understand what interventions are available and how they are classified; and 5) develop and conduct a pilot evaluation of the effectiveness of a decision aid. Study 1 was a cross sectional survey of Autism Advisors, and parents across Australia who were accessing the Helping Children With Autism (HCWA) funding package. The study aimed to obtain a better understanding of how parents made decisions about autism interventions, and which resources they accessed to obtain intervention information. Participants were Autism Advisors (n=13) and parents (n=113) attending initial consultations with an Autism Advisor. After determining that parents frequently accessed the Internet for ASD intervention information, it was considered important to investigate the quality of information parents were likely to be finding. Study 2 analysed the quality of health information in a sample of autism-related websites using a valid and reliable health information evaluation tool called DISCERN. This study found that websites were of variable quality and frequently lacked references to research evidence. Study 3 involved conducting focus groups and individual interviews with parents (n = 23) whose children were aged under 18 years and diagnosed with an ASD.

The aim was to further investigate parents' decision making processes and further explore the various formats and sources of information used. This study revealed that parents engaged in both a pragmatic and emotional journey and gained confidence over time in relation to their decision making regarding interventions for their child. Study 4 involved developing a web-based decision aid informed by the results of the first three studies, and with consideration for the literature on shared decision making, health literacy and patient education. The resource aimed to assist parents to make better-informed decisions about autism interventions, with consideration of research evidence, and with the view to promoting shared decision making. Study 5 was a pilot randomised controlled trial (RCT), which aimed to determine the effectiveness of the decision aid. Participants were parents (n= 81) (all mothers) of children newly diagnosed with autism within 12 months prior to commencing the trial. The primary outcome was decisional conflict measured using the Decisional Conflict Scale (DCS). Secondary outcome measures were confidence about decision making and parenting sense of competence. Parents in the intervention group were provided with access to the web-based decision aid. Parents in the control group received usual care. Data were analysed for 71 participants, following the loss of 10 participants at follow-up. The baseline mean total Decisional Conflict scores for both groups fell within the low to moderate range of decisional conflict. Follow-up scores on this measure were lower for both groups, indicating decisional conflict reduced over time, although the difference between the groups at follow-up was not significant. There were also no significant differences between the groups at follow-up in any of the Decisional Conflict Scale (DCS) subscales, the Parenting Sense of Competency (PSOC) total or subscales, or the measure of confidence. There was a small increase in the mean score for confidence with making decisions about ASD interventions for both groups. This is consistent with existing research that suggests that as parents have the opportunity to search for information about autism, become more familiar with their child's condition, and adjust to the diagnosis, they also report feeling more confident with making decisions related to their child's intervention needs. Increased confidence with decision making however, may not necessarily mean that parents better understand the intervention options available, including risks and benefits,

likely outcomes, or available research evidence. Parents' information needs change over time, with more prescriptive or instructive information preferred immediately post-diagnosis. Further research is required to explore alternative methods of communicating research evidence to parents of children newly diagnosed with ASD.

Declaration by Author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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Publications During Candidature

Peer-reviewed papers

Grant, N., Rodger, S., & Hoffmann, T. (2015). Evaluation of autism-related health information on the web. *Journal of Applied Research in Intellectual Disabilities*. 28, 4, 276 – 282.

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Conference abstracts and oral presentations

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Contributions by others to the thesis

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**Statement of Parts of the Thesis Submitted to Qualify for the Award of
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Autism interventions, autism spectrum disorder, decision making, evidence-based practice, health literacy, parental self-efficacy, patient decision aid, patient education, shared decision making.

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List of Abbreviations Used in Thesis

ABA	Applied Behaviour Analysis
ABIQ	Autism Behavioural Intervention Queensland
AIT	Auditory Integration Training
ASD	Autism Spectrum Disorder
DCS	Decisional Conflict Scale
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders – 4th edition
DSM-5	Diagnostic and Statistical Manual of Mental Disorders – 5th edition
DSS	Department of Social Services
DTT	Discrete Trial Training
EBP	Evidence-Based Practice
EI	Early Intervention
FaHCSIA	Families, Housing, Community Services and Indigenous Affairs
FCT	Functional Communication Training
GADS	Gilliam Aspergers Disorder Scale
GARS-2	Gilliam Autism Rating Scale (2nd edition)
HWCA	Helping Children with Autism
IBI	Intensive Behavioural Intervention
ICD-10	International Classification of Diseases – 10th edition
LEAP	Learning Experiences - an Alternative Program for Preschoolers and Parents
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
PECS	Picture Exchange Communication System
PSOC	Parenting Sense of Competence Scale
RCT	Randomised Controlled Trial
RDI	Relationship Development Intervention
REALM	Rapid Estimate of Adult Literacy in Medicine
SCERTS	Social-Communication Emotional Regulation and Transactional Support
SDM	Shared Decision Making
TEACCH	Training and Education of Autistic and Related Communication Handicapped Children

Introduction

Imagine.

For many years, you and your husband had longed for a child. You waited for a while after marrying, because you both had well-established careers, and really wanted to be financially secure before starting your family. It took a couple of years, longer than you had hoped, but not long after your 36th birthday a baby boy, Daniel was born. You and your husband were thrilled. This was your first child, and the first grandchild for both sets of grandparents. How spoiled this baby would be!

As the months passed by after Daniel's arrival, you thought about how different your life was now. You were feeling quite worn out. A good night's sleep had become a distant memory. "You have got a cranky baby there", people told you. Daniel was very hard to settle at times and was a fussy feeder, but you persevered.

Before long, you had a busy toddler on your hands. You joined a mother's group for some company and to give your boy a chance to spend time with other kids. You worried that he was not very sociable. He was an only child and you wondered if he had been missing out on the chance to learn how to interact with others. You'd noticed that your beautiful boy hadn't started talking, and did not seem to care whether you were in the room or not. He didn't seem to giggle much, and when he did, it was high pitched and more of a screech. His grandparents called him 'quirky'. Just like his father, you mused.

You went to the mother's group every week. As the weeks went by, you watched Daniel and the other kids carefully. He was 18 months old then. The other kids often ran over to their mothers and pulled their hands. "Come ere!" they would urge. Your boy didn't do this, but he seemed very happy in the group. His favourite thing to do was to sit on the pillows in the corner and look at picture books. There was a blue pillow he liked to sit on in particular. It was

just like the one you had in the playroom at home. Each week he found the same toy or book. It was a little car or Thomas the Tank Engine book. When he spun the wheels of the car, they made a humming noise. Daniel liked to hum too. He hummed a lot. Maybe his words were not coming along as quickly as the other kids, because he's too busy humming and making car noises, you wondered.

When Daniel was around two years of age, your pondering, wondering, and musing turned to worry and near panic at times. Your precious boy, with his beautiful big blue eyes, was still not saying any words, not even the name of your dog, mumma, dada or even his favourite things. And by now his 'quirks' as his grandparents called them, had become more numerous. The humming was more constant, and was now accompanied by rocking. The rocking stopped Daniel from playing properly. He seemed too distracted. It made it more difficult for him to focus on many different things. You often thought to yourself, if you just stop rocking you could focus better. Or maybe you can pay more attention to the mum who is reading this week's story. Daniel, you need to be quieter. The other mums are staring at you and are upset at your noises that are disrupting the other kids!

By now, it was not just at the mother's group you had noticed that Daniel seemed different. At home, you were becoming increasingly frustrated as you tried to get through the day. Getting your wriggly toddler dressed seemed to take forever. His curly hair needed to be brushed, but no matter which comb or brush you used, he jumped away as though you had a handful of stinging wasps. Certain clothes caused him to scream when you put them on. Meal times were another story. You had found he would only eat three different white foods. "He's just fussy", your husband would say. "You just need to be tougher!" said your in-laws who were happy to provide a lot of advice.

You also noticed that Daniel only played with a few select toys, and when he did play, he didn't play like the other kids. He loved the wheels on cars, trucks and trains. Actually, he seemed to be overly fascinated with anything that spun

He had a favourite TV show, and this gave you some reassurance he was just like other kids. He could watch Play School over and over. Actually he cried when it ended, and was only consoled when you put it on again. Lucky you had all the episodes on DVD, you thought! He was such a fan, he tried to sing along with the songs in the bath, and in the car, seeming to hold the tune very well. You found it incredible that he could eventually sing 'Wheels on the Bus' verbatim, but now aged 2 ½ still only said five words.

Imagine.

You went back to work when Daniel turned three. By this time you had stopped going to mother's group. You hadn't been for 6 months now. You could no longer stand the looks from the other mums. The other kids ignored him. Actually they gave him a very wide birth. They seemed to notice his quirks too. And as the other children began to succeed at toilet training, and talking and reached other big milestones, you just became more upset that your baby boy was struggling so much. You now introduced Daniel to a new group. This time it was the child care centre. You decided to start him for three days per week. This was a big step for both of you. You hoped that 'kindy' would help him to catch up. He was still an only child, and you were quite sure he would be OK, if he just spent more time with other kids his own age, and with child care experts to help him.

After a few weeks at the centre, everything seemed to be going well. Your little man seemed to be settling in. He was great with the routine. Actually he was thriving with the routine. He loved familiarity so much, that one day you went a different way to the centre and he screamed at you, "No !" You laughed. Yep, he's quirky, just like his grandparents say!

One day at drop off, the Director came to you. She wanted to have a chat when you came back that afternoon. You worried all day about what the problem could be. You knew Daniel had some challenges but he followed directions most of the time, and was generally quiet and cooperative,

particularly if the day's routine remained unchanged. That afternoon, the Director told you that your darling boy was showing signs of developmental delay. That's OK, you knew that, you thought. Maybe she will tell you how to help him catch up. She then told you that she would like you to get him assessed for Autism Spectrum Disorder. You were taken aback. You didn't really know much about that, but it sounded serious. You had seen a lot of stories on the news about autism, and the kids in those stories seemed out of control. Your boy was not like that. You recalled watching Rain Man years ago. You got angry suddenly that this Director would liken your child to Rain Man. You took your baby home, and that night talked to your husband.

Your husband was equally offended that the Director would 'accuse' your child of having autism. He refused to talk further about it. But, that night you lay awake. You thought back over the past 3 years, and recalled how your Daniel seemed so different to the kids at your mother's group. And now he was different to the kids at his new centre. You got out of bed at 1pm, not able to shake the thought that the Director might be right. You sat at the computer and started 'Googling'. You typed into the search bar the word Autism. Up popped millions of results. It was mind boggling and overwhelming. Where to start? You clicked randomly at each link. Each page was filled with lots of information. Some of the government sites seemed to be more helpful, but you still could not make much sense of what you were reading. At that early hour, in the dim light, and with your muddled head, the words that stood out were difficulties, challenges, no cure, and life long, behaviour issues, lack of language, social difficulties, lack of friends. You came across the websites of experts who all seemed to offer different solutions. You read parent forums that were full of stories from parents who were struggling, crying for help. Their stories painted a bleak picture of their and their child's future. You read their descriptions of their child, and you thought no, that's not me. My child doesn't do that. And then you read another story, and you thought – yes, that's me. That's him.

The next day, you went to your GP. Your GP scribbled a referral to a paediatrician. You rang to make an appointment, and were told that the next available appointment was three months away. You took that appointment as you were not sure what else to do. While waiting for the appointment to come around, you jumped back on Google and started searching again and again – Autism Help, Autism Cure, Autism Treatment. Some treatments seemed to promise that they would cure autism and you wondered if you should give them a try. You were not sure about anything. You gave up. None of it seemed to make sense, and anyway, so many of these websites were American. You felt that you would not find what you needed there. The next three months were a blur.

The day of the paediatrician's appointment finally arrived. You took Daniel to the paediatrician and he looked at him. Barely. "You'll need a full assessment", he said. And within 20 minutes, you were handed a list of names and were dismissed. You felt cheated. You were supposed to get an answer right there and then! Now more waiting?!

Thankfully you were able to book in for an assessment with private therapists who undertook a speech and language assessment, completed an Autism Diagnostic Observation Schedule, and wrote a report for your paediatrician. You were able to get a follow up appointment with him quite quickly. This time things seemed to be moving faster, but you were hundreds of dollars out of pocket and still unsure what the future held. At the follow up appointment that was longer, the paediatrician confirmed that based on the ADOS assessment, his clinical observations, and his discussion with you, your child met the criteria for an Autism Spectrum Disorder diagnosis. You were numb. Then sad. Then numb again. When the paediatrician handed you another list of names of people to contact for intervention, and dismissed you again with not a lot of information provided about what to do next, you were angry.

In the car outside the paediatrician's office, you called your husband. He didn't say much. He did not know what to say. You then called the first name on the

list the paediatrician gave you. It seemed to be some kind of autism authority. You made an appointment to meet with them. You went home and started 'Googling' again. You also started joining autism parenting forums on Facebook. You recognised some of the stories there.

The meeting you made an appointment for turned out to be with an Autism Advisor. At this meeting, you had the opportunity to speak with a kind and patient person who seemed to know a great deal about autism. You started to feel like finally someone was making an effort to help you and your son. The advisor provided a huge pack of information about autism. She told you that there are lots of different treatment or intervention options, and gave you a long list of people who provided different services. She told you about a funding package that was available. That's a relief, you thought. She also told you about some workshops that the agency provided to help you navigate your new world, which was especially tailored for parents with newly diagnosed children with autism. You signed up for one of these workshops immediately.

On returning home, you threw the big information pack on the table along with your bag, and grabbed Daniel. He was now 3 ½. You looked into his big blue eyes, and gently brushed his curly hair away from his eyes. Which he hated of course. You told him you loved him, and that he was still your gorgeous boy. He looked away, started humming and took off in the direction of the TV. It was time for Playschool again. You looked back at the pack of information. In that thick folder, you must discover the help you need to get your child to use his voice, play with other kids, learn to use the toilet, stop rocking and humming constantly (look 'normal'), tolerate his hair being brushed, get a haircut without screaming, eat more than three foods, return a hug from his grandparents... After making a coffee, you sat down and started to sift through the paper. The wave hit you. The same feeling that you had when you first started to Google Autism many months ago. So many options. So much information. Too much information! What now, you thought, your head in your hands. What now?

How do you choose? What is best for Daniel? Where do you start? What will it cost?

In recent years, the number of children diagnosed with an Autism Spectrum Disorder (ASD) has steadily increased worldwide. In this thesis, the terms ASD and autism will be used interchangeably, as is common practice in the literature on this topic. Where there is reference to particular studies, the term used by the particular author/s will be used. In essence, Autism Spectrum Disorder (ASD) is the preferred diagnostic term used since the DSM-5 was released (APA, 2013) two years ago. Essentially ASD refers to a neurodevelopmental condition characterised by difficulty with social communication and atypically restricted, repetitive behaviour and fixed interests (Lai, Lombardo, & Baron-Cohen, 2014).

There has been much debate about whether the increase in diagnoses can be attributed to greater awareness of ASD signs and symptoms, better detection using screening, surveillance and other diagnostic methods (Centers for Disease Control and Prevention, 2014), the change to diagnostic criteria (American Psychiatric Association, 2013), or because of genetic and/ or environmental factors (Bent, Dissanayake, & Barbaro, 2015; Valentine, 2010; Williams, MacDermott, Ridley, Glasson, & Wray, 2008) or a range of these.

Parallel with the increasing numbers of children being diagnosed with ASD, there is also an increasing number of available autism interventions that focus on different characteristic behaviours, are based on a range of different approaches such as behaviours, development, and social pragmatics, and are delivered by a range of different health professionals and early childhood educators. Parents of children newly diagnosed with autism are faced with the overwhelming task of choosing from these early interventions. Many interventions have limited, if any, evidence supporting their efficacy (outcomes), which is not always given consideration by parents when they make decisions about interventions. Due to the complexity of decision making

required by parents during this overwhelming early stage post diagnosis, several authors and organisations (Autism Treatment Network, 2011; Mulligan, Steel, Macculloch, & Nicholas, 2010; US Agency for Healthcare Research and Quality ((AHRQ), 2011) have developed resources to help parents make the best intervention decisions for their child, however none of these have been clinically trialled to determine their effectiveness.

Before the decision making journey that parents undertake post-diagnosis can be investigated, and how parents can best be supported to make these decisions is determined, it is important to understand the most recent trends in autism diagnosis, etiology and intervention options available. It is also important to understand the methods by which intervention information is conveyed to parents, and the principles of decision making that are relevant in this context. These concepts will be discussed within the review of the literature (Chapter 1), along with the rationale for the research studies undertaken throughout the course of this thesis.

The scenario outlined in the first part of this chapter, is continuously being played out over and over again in Australia and other countries when autism is diagnosed. It is a rare parent who describes a “satisfactory’ experience of receiving a diagnosis and the provision of information about what is next, namely discussions about interventions and assistance with decision making (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Mulligan, Steel, Macculloch, & Nicholas, 2010; Osborne & Reed, 2008; Valentine, 2010). Hence, the primary aim of this research project is to assist parents of children with autism to make informed decisions about appropriate early interventions for their child. This will be achieved by:

1. Developing an understanding of the information that parents use to make intervention decisions;
2. Developing an understanding of parents’ decision making processes;
3. Evaluating the quality of web-based information commonly accessed by parents;

4. Developing a resource to help Australian parents understand what evidence-based interventions are available, and decide which may be most suited to them, and;
5. Evaluating the effectiveness of a decision aid about interventions for parents of children newly diagnosed with ASD.

The thesis utilises mixed methodologies, incorporating five separate studies with each informing the nature of the next study. The thesis is laid out as follows:

Chapter 2 (Study 1) utilises a cross sectional survey of Autism Advisors who are the first point of contact for most parents with a newly diagnosed child (n = 13) and their clients (parents of children newly diagnosed with ASD) (n = 113) to obtain a better understanding of how parents currently make decisions about autism interventions and by exploring what resources are provided by Advisors and sought independently by parents post-diagnosis.

Chapter 3 (Study 2) involves the analysis of the quality of a sample of autism-related websites, in particular information on intervention research evidence, using a valid and reliable health information evaluation tool called DISCERN. This chapter explores the quality of existing autism-related information on the Internet, and helps to inform the nature of the website content included in the web-based decision aid to be developed as part of Study 4.

Study 3 is described in **Chapter 4** which outlines, focus groups and individual interviews conducted with parents (n = 23) to further investigate how they make decisions about which interventions to pursue for their child upon receiving a diagnosis of ASD.

Little is understood about how decision making tools, that are more typically used in relation to medical interventions by GPs and other medical practitioners, can facilitate intervention choices that need to be made by parents of children with ASD. In **Chapter 5, Study 4** is described. This

involves a review and selection of patient education strategies, and the subsequent development of a web-based decision aid (hosted at www.autismdecisionaid.com.au). The responses obtained through the data collection process outlined in the first three studies, and with consideration of the extant literature on shared decision making, health literacy, autism treatment research evidence, and patient education will be discussed as they impact on the development of the decision aid. The aid aims to assist parents to make informed decisions about autism early interventions. Parents involved in earlier studies, reviewed the decision aid at various stages of its development and provided comment and feedback.

Parents of children newly diagnosed with autism experience an enormous amount of stress post-diagnosis, and report finding the process of sifting through information to find interventions that best meet their child's needs extremely overwhelming. There is a need for better support of parents in the period shortly after diagnosis to help them to make decisions based on high quality and accurate evidence-based health information.

In **Chapter 6** of this thesis, **Study 5** is explicated. This study involves a pilot randomised controlled trial (RCT). Parents (n = 81) of children newly diagnosed with autism (within the past 12 months) participated in the trial in which participants are randomly allocated to one of two groups - the intervention who access the decision aid and control group who continued gaining information as usual.

Parents in the intervention group are provided with access to the password protected web-based decision aid and asked to use it at their convenience. Parents in the control group access standard information from Autism Advisors and other professionals (usual care).

Finally, **Chapter 7** provides a discussion of the results of each of these studies and also outlines the clinical and research implications of the collective results of this project.

**Chapter 1 - Early Intervention for Children with Autism Spectrum Disorder (ASD) and Parent Decision Making:
A review of the literature**

1.1 Risks and Causes of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) (also used interchangeably with 'autism' by authors in the literature on this topic) is the term given to the group of neurodevelopmental disorders that are characterised by difficulty with social communication and atypically restricted, repetitive behaviour and fixed interests (Lai, Lombardo, & Baron-Cohen, 2014). ASD is a lifelong condition with no known cure (Coates, 2009; Prior, Roberts, et al., 2011), although early intervention can improve function and reduce the impact of adverse autism characteristics on daily living (Lai et al., 2014; Valentine, 2010).

Several risk factors for the onset of ASD have been identified in recent years, while none have been identified as a contributing factor in each and every ASD case (Lai et al., 2014). The risk of giving birth to a child who develops ASD is higher for parents who are older, and/ or live in a city where many jobs are in the field of information technology (Lai et al., 2014). Other understood risk factors include complications during pregnancy, and maternal exposure to chemicals (Lai et al., 2014), although the exact nature of this exposure is not well known. There is no established link between ASD and vaccinations (Lai et al., 2014).

Although there is no known specific cause of ASD (National Autism Centre, 2015), current research links autism to biological or neurological differences in the brain. According to Lai et al., (2014) genetics is a significant factor in the etiology of ASD, although no single gene has been directly linked to the disorder. It is considered that a range of genes (hundreds) are implicated in increasing the risk of ASD. Through the use of Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET) scans, researchers are able

to examine neurological factors that may contribute to the development of autism characteristics. These scans have revealed abnormalities in the structure of the brain, with significant cellular differences in the cerebellum of some children with ASD (National Autism Center, 2015).

1.2 Autism Prevalence in Australia and Worldwide

Around the world, autism prevalence rates are increasing (Case-Smith & Arbesman, 2008; Valentine, Rajkovic, Dinning, & Thompson, 2010; Williams et al., 2008). In the United States, the number has increased steadily from 1:100 children diagnosed with ASD in 2011 (Warren et al., 2011) to 1:88 in 2012, and more recently 1:68 (Centers for Disease Control and Prevention, 2014). These numbers and the methods used to determine them have been questioned, particularly as there is much variability in the data available for each US state (Mandell, 2014). In 2008 in Australia, although difficult to reliably establish (Williams, et al., 2008) it was thought that at least one out of every 160 children were diagnosed with autism (O'Reilly & Smith, 2008; Williams et al., 2008). Using data from the Australian Bureau of Statistics (ABS) from June 2010 to June 2012, Bent, Dissanayake, and Barbaro (2015) conducted a review of children registered for the Helping Children with Autism (HCWA) funding program. More information on the HCWA program appears later in this chapter. Bent et al. (2015) analysed the data of 15 074 children (all aged under seven years) and found that 0.74% of the population had been diagnosed with ASD.

For the Australian population, it appears that autism diagnoses are increasing as per the trend worldwide (Bent et. al., 2015; Valentine, 2010; Williams et al., 2008). ASD is almost five times more likely to occur in boys than in girls for unknown reasons (National Autism Center, 2015; Lai et. al., 2014; McCarthy, 2014).

1.3 Autism Diagnosis

Until May 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 2000) or the International Classification of Diseases (ICD-10) (World Health Organization, 1992) was

used to define diagnostic criteria for this condition. Within the group of Pervasive Developmental Disorders (more commonly called Autism Spectrum Disorders), the DSM-IV encompassed Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder (CDD), Asperger's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD – NOS) (First, 1994). Following the publication of the DSM-5 in 2013 (American Psychiatric Association, 2013), Asperger's Disorder and Childhood Disintegrative Disorder (CDD) were removed, and an alternative classification system put in place. The term Pervasive Development Disorder was also replaced entirely by Autism Spectrum Disorder, which had been more commonly used in recent literature (Szatmari, 2011). The new diagnostic manual also allows for the provision of a severity level of ASD symptoms. These include Level 1, Requiring Support; Level 2, Requiring Substantial Support; and Level 3, Requiring Very Substantial Support (American Psychiatric Association, 2013). The DSM-5 (American Psychiatric Association, 2013) defines the levels according to Figure 1-1.

While the aforementioned MRI and PET scans can reveal abnormalities in the brain structure of some children diagnosed with autism, this method is not the only, or most reliable way to diagnose the disorder. Additionally due to the cost of these scans and difficulty keeping young children still in scanners, these are rarely used clinically, and never routinely. There are no existing biomarkers that reliably confirm ASD, although some genetic determinants exist in a small percentage of cases (Lai et al, 2014). Diagnoses are made primarily based on observations of behaviour, and by obtaining a detailed parent history of the child's development, along with reports from early childhood teachers, other therapists and structured clinical observations (Valentine et al., 2008).

ASD screening tools, such as the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins, Fein, & Barton, 2009) are designed to determine the likelihood or possibility that a child has an Autism Spectrum Disorder. Other assessment tools, while not specifically screening for ASD, will (depending on the tool) seek to obtain more information about the child's function in areas most

Level 1:

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others.

Level 2:

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others.

Level 3:

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.

(American Psychiatric Association, 2013)

Figure 1-1: DSM-5 levels of severity

commonly affected by the disorder. For example, the Vineland Adaptive Behaviour Scale (VABS) (Sparrow, 2011) assesses motor adaptive and daily living functioning, while the Social Responsiveness Scale (SRS) (Constantino, 2005) focuses on the child's social interaction and communication.

In 2010, when this research project began, information regarding the screening and assessment tools considered appropriate for use with children undergoing ASD diagnosis in Australia were listed on the website of the Australian Federal Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) (2010). These tools are listed in Table 1-1. Therapists or health professionals who have experience working with children on the autism spectrum, and undergo the necessary training in the use of the tools, are able to use them.

Children are usually diagnosed with autism around three to four years of age although greater awareness of ASD, and improvement in diagnostic

procedures has led to an increase in diagnoses of children as young as 18 months (Lai et al., 2014; Valentine, 2010). In a more recent Australian study, Bent et al. (2015) analysed the data of 15 074 children with ASD accessing the HCWA package (all aged under seven years) and found that the average age of diagnosis for these children was 49 months (4 years, 1 month).

1.4 The Difficulty Faced by Parents in Choosing Intervention Options

There are hundreds of interventions that claim to assist children with autism (Green et al., 2006). The large number of possible interventions, some offering cures, adds to the confusion faced by parents in making decisions about which is right for their child. Autism interventions generally aim to either target specific skill areas, with consideration of what is developmentally appropriate; or work on decreasing challenging behaviours (NAS, 2015). Study results provide varied data due to the differences in how interventions are defined and categorised by various authors, however several studies demonstrate that parents trial on average five (5) to seven (7) different interventions at any one time (Bowker et al., 2010; Green, et al., 2006), with parents of children with more severe autism characteristics trialling an even greater number of interventions (Green et al., 2006).

Table 1-1: Assessment and Screening Tools used in Australia to Screen for, and Diagnose ASD

Autism screening and diagnostic tools	Tools for assessment of functional areas typically affected by ASD
Autism Behaviour Checklist (ABC) (Krug, 1980)	Pre-Linguistic Diagnostic Observation Schedule (PL-ADOS) (DiLavore, Lord, & Rutter, 1995)
Autism Detection in Early Childhood (ADEC) (Young, 2007)	Social Responsiveness Scale (SRS) (Constantino, 2005)
Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, Goode; et al.,1989)	Vineland Adaptive Behaviour Scales Second Edition (Vineland-II) (Sparrow, Cicchetti, Balla, 2005)
The Autism Diagnostic Interview Revised (ADI-R) (Le Couteur, Lord, & Rutter (2003)	Psycho Educational Profile-3 (PEP-3)
Australian Scale for Asperger's Syndrome	

– Revised (ASAS-R) (Attwood, 1998) (Schopler, Lansing, Reichler & Marcus, 2004)
Childhood Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, Daly, 1980).
Checklist for Autism in Toddlers (M-CHaT) (Robins, Fein, & Barton, 2009)
Gilliam Autism Rating Scale (GARS) (Gilliam, 1995)
Parent Interview for Autism (PIA) (Stone & Hogan, 1993)

(Adapted from the Department of Families Housing Community Services and Indigenous Affairs (FaHCSIA), 2010)

Autism interventions, particularly Early Intervention (EI) options aim to improve social and cognitive functioning, enhance adaptive and communication skills, and manage difficult behaviours (Valentine et al., 2010). Success of the intervention is dependent upon a multitude of factors, including the presence of coexisting or comorbid disorders (Sanders, 2008), severity of autism characteristics, appropriateness of treatment chosen, frequency and intensity of treatment, among others (Thompson, 2011b). While improvement of social and cognitive functioning and reduction in symptom severity is usually possible, as aforementioned, it is generally accepted that there is no cure for autism (Sanders, 2008).

1.5 Intervention Options Available in Australia

The Helping Children with Autism Package (HCWA) was an initiative of the former Australian Government Department of Families, Housing, Community Services, and Indigenous Affairs (FaHCSIA) to increase access to early intervention for children under the age of seven (7). Roll out of the funding scheme commenced in 2008, and is now administered by the federal government Department of Social Service (DSS). Funding is provided for access to Autism Advisors, who are based in every Australian State and Territory to provide information to parents on how to access the funding and select interventions for their child once an ASD diagnosis has been received. The HCWA funding scheme includes the development of the Raising Children Network website (<http://www.raisingchildren.net.au>) which provides information

on autism interventions and describes the research available to help parents make decisions which are evidence-based (Valentine, 2010).

In Australia, each state and territory has a key organisation (service provider) or peak body positioned as the main point of contact for parents of children with a diagnosis of autism. All of these agencies (at the time of writing), with the exception of Autism Northern Territory, are the point of contact for Autism Advisors. A new federal government scheme, the National Disability Insurance Scheme (NDIS) is being trialled around Australia, and is currently transitioning Helping Children with Autism (HCWA) recipients to this new scheme in one trial site. Prior to this, DSS had appointed Autism Advisors in each state to determine if a child diagnosed with an ASD is eligible for funding under the Helping Children with Autism program, and to provide information regarding services and support. Autism Advisors typically have training in a health or educational field and are provided with training specific to the role.

The DSS funding is to be used for services from broad intervention categories. These intervention categories include: Behavioural Interventions (application of learning theory and skill development); Developmental and Social Learning interventions (building relationships and development of social emotional capacities); Therapy-based interventions (communication and social development or sensory motor development); and Family-based interventions (working with families to develop skills in working with their children) as recommended in the Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice' 2012 (Roberts & Prior, 2012; Department of Families Housing Community Services and Indigenous Affairs (FaHCSIA), 2010). This guideline is further explained in Chapter 6. Approved interventions or services are outlined in Table 1-2 below. Services are provided by nominated service providers from an approved panel that meet specific requirements. A small amount of funding for services is also available from the Department of Health & Ageing (DoHA) and the Department of Education, Training & Workplace Relations (DEEWR).

Table 1-2: Evidence-based Interventions as Classified in the Early Intervention for Children with Autism Spectrum Disorders: "Guidelines for Good Practice".

Intervention category	Name of intervention
Family-based including parent training	Hanen 'More Than Words' Preschoolers with autism – manualised parent training program Triple P – Stepping Stones Adaptation
Therapy-based Interventions	Speech Generating Devices (SGD) and other Augmentative & Alternative Communication (AAC) Signing and Makaton PECS – Picture Exchange Communication System
Single element components addressing one aspect of autism	PALS Social Skills Program Toilet Time Music Therapy Alert Program for Self Regulation Social Stories
Therapies not specific to autism, but which may benefit children with autism	Circles of Support

(Adapted from Prior & Roberts, 2012)

1.6 Autism Interventions and Research Evidence

There have been many attempts by individuals and organisations (as detailed below) to determine which autism interventions are most effective, versus those that have no obvious effect, and those interventions that could possibly cause harm. The following section will expand on those organisations that have reviewed intervention research, and developed rating systems and specific methods to explore and comment on the research evidence related to early intervention.

Many countries have peak bodies that have developed clinical practice guidelines based on these reviews, Australia included. In Australia, Professors Jacqueline Roberts and Margot Prior, along with a selection of their colleagues

were commissioned to undertake a number of reviews of Early Intervention (EI) services for children diagnosed with autism for the Commonwealth Department of Health and Ageing (DoHA), Department of Social Services (DSS) and the National Disability Insurance Agency (NDIA). In their 2006 review, which informed the eligible services for HCWA funding, Roberts & Prior identified three (3) broad groups of ASD interventions – Biological, Psychodynamic and Educational. Educational interventions were further classified according to modality (for example, Behavioural, Combined, Family-based, and Developmental Therapies). The most widely used evidence-based interventions in Australia were identified as Applied Behaviour Analysis (ABA) (Behavioural), Treatment and Education of Autistic and Communication-related handicapped Children (TEACCH) (Combined), Hanen programs (Family-based), and Speech therapy (Developmental) (Roberts & Prior, 2006; Valentine, et al., 2010).

A second review was undertaken in 2011, again involving Professors Roberts and Prior, along with their colleagues Professors Sylvia Rodger and Katrina Williams. In this review, the authors employed the Scientific Rating Merit Scale (SRMS) (National Autism Center, 2009) (further details in paragraphs to follow) to determine the evidence base of interventions, based on research emergent since the previous review. The authors described their findings for each of the intervention areas. For this report, the intervention areas were classified as Comprehensive Interventions, Family-Based Interventions, Therapy-Based Interventions, and Other.

When rating the research on comprehensive interventions (behavioural, developmental and eclectic interventions), Roberts et al. (2011) found that as per the previous review, intensive behavioural interventions such as Applied Behaviour Analysis (ABA) and Early Intensive Behavioural Intervention (EIBI) have good evidence supporting their use, particularly in the areas of cognitive development, communication and adaptive behaviour. This was surmised from a review of clinical trials. The study authors warn however, that outcomes will vary depending on characteristics of the individual.

When reviewing recent studies featuring other types of comprehensive interventions, Roberts et al. (2011) found that intensive eclectic approaches (such as TEACCH, and Building Blocks) were also beneficial, and had positive effects on developmental age, adaptive skills, and language (Roberts et al., 2011). The authors reported that intervention intensity and parental involvement in comprehensive intervention delivery play a role in enhancing the intervention program outcomes.

In the 2011 review, some family based interventions, such as the Triple P Parenting Program – Stepping Stones Adaptation, were found to help improve parental self efficacy and reduce problem behaviours (Roberts et al., 2011). The authors referred to the Comparative Effectiveness Review ((Warren, 2011), which also supported the use of parent training, particularly for the purpose of improving communication skills and managing difficult behaviours (Roberts et al., 2011).

Therapy based interventions focus more on specific skill areas, typically facilitated by occupational therapists and/or speech and language pathologists, rather than addressing core autism characteristics (Roberts et al, 2011). The authors found that, as per the previous review, evidence supporting the use of Social Stories™ (Gray & Garand, 1993) and communication aids, such as Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) is of poor quality. Evidence supporting the use of sensory based strategies, such as the use of weighted vests and therapeutic listening or sound therapy is lacking (Roberts et al, 2011). This was also the case for other interventions such as music therapy and physiotherapy. While there is emerging research and some low level, positive studies do exist for Music Therapy in particular (Kim, Wigram, & Gold, 2009; See, 2012; Whipple, 2004), the literature to date does not adequately support the use of these therapies (Roberts et al., 2011). It is understood that the same authors have been commissioned by the Australian Government Department of Social Services (DSS) for the NDIA to conduct a

third review, which is currently underway (S. Rodger, personal communication, December 2015).

The United Kingdom-based organisation Research Autism began a review in 2010, and rated early interventions for ASD based on a system they developed to evaluate quality of evidence available (<http://www.researchautism.net>, 2010). The ratings are based on how many scientific studies support the intervention, and the quality of those studies. The available research is either considered Grade A, B, C or D. The website also uses a tick and cross system, which aims to represent which interventions have positive and negative effects, determined by the research evidence available. A maximum of three (3) ticks or crosses is awarded to each intervention. Where no evidence is available, or inconsistent results are obtained, a question mark or zero (0) is used. Table 1-3 outlines the criteria for the rating scale used to grade individual studies, and Table 1-4 details the rating scale used to grade individual interventions. Research Autism, at the time of publishing the 2010 study, had not evaluated the evidence available for all known ASD interventions.

The results of Research Autism's evaluation are presented in list format on their website

(http://www.researchautism.net:autism_treatments_therapies_interventions.ikml) with interventions and corresponding scores arranged in columns alphabetically. Links are provided to allow consumers to obtain more information about the intervention (See Figure 1-2 for a screenshot of how information is presented). Those interventions scoring the highest number of ticks include Early Intensive Behavioural Intervention (EIBI), and Picture Exchange Communication System (PECS).

Table 1-3: Rating Scale Used by Research Autism (2010) to Grade Individual Studies

Grade	Description
Grade A	Methodologically rigorous studies with adequate statistical power
Grade B	Well conducted controlled trials. This includes: Non-randomised control group study, where there is adequate statistical power and where the study is conducted by researchers independent of the intervention. Randomised control trial which does not meet the criteria for Grade A e.g. where there is inadequate statistical power.
Grade C	Case series study, where there is a sufficient number of participants, where there is robust statistical analysis e.g. regression analysis. Staggered or ABA multiple baseline study where there is a sufficient number of participants. Randomised control trial or control group study, crossover/reversal/withdrawal study which does not meet the criteria for Grade B
Grade D	Studies which do not meet the criteria for other grades e.g. case series where there is insufficient number of participants, or where there is no robust statistical analysis. Such studies and trials to be published in English-speaking peer-reviewed journals.

<http://www.researchautism.net/autism-interventions/other-aspects-autism-interventions/process-for-evaluating-studies/our-ratings-system> (accessed on 18 May 2015).

Table 1-4: Rating Scale Used by Research Autism (2010) to Grade Individual Interventions.

Symbol	Description
	Very strong, positive evidence. ≥2 Grade A studies or 1 Grade A study and ≥3 Grade B studies. Majority of studies showing significant positive effects.
	Strong, positive evidence. 1 Grade A study or ≥3 Grade B studies. The majority of these studies show significant positive effects.
	Limited, positive evidence. 1 Grade B study or ≥3 Grade C studies. Majority of studies showing significant positive effects.
	Insufficient/Mixed evidence. Some Grade B/C studies but findings inconsistent or Grade D or < 3 Grade C studies only.
	No evidence. We have been unable to identify any studies of this intervention being used to help people with autism spectrum disorders published in peer-reviewed journals.
	Some negative evidence 1 Grade B study or ≥3 Grade C studies. Majority of studies showing significant negative effects.
	Strong negative evidence. 1 Grade A study or ≥3 Grade B studies. Majority of studies showing significant negative effects.
	Very strong negative evidence. ≥2 Grade A studies or 1 Grade A study and ≥3 Grade B studies. Majority of studies showing significant negative effects.

NA

Not Applicable It is not possible to provide a rank for this intervention. This is usually because the intervention described, such as speech and language therapy, incorporates a wide range of other interventions, methods and techniques.



Evidence of harmful effects.

Objective evidence indicating significant adverse/harmful effects.

<http://www.researchautism.net/autism-interventions/other-aspects-autism-interventions/process-for-evaluating-studies/our-ratings-system> (accessed on 18 May 2015).

ABA and Autism	NA	Advocacy, Self Advocacy and Autism	NA	Animal Therapies and Autism	NA
				Anticonvulsants and Autism	NA
Antidepressants and Autism	NA	Antipsychotics and Autism	NA	Applied Behaviour Analysis and Autism	NA
Aripiprazole and Autism		Assistance Dogs and Autism	U	Auditory Integration Training and Autism	
Chelation and Autism		Cognitive Behavioural Therapy and Autism		Coloured Filters and Autism	
Dietary Supplements and Autism	NA	Dimethylglycine and Autism		DIR Method and Autism	
Discrete Trial Training and Autism		Dolphin Therapy and Autism		Dore Programme and Autism	0
Early Intensive Behavioural Intervention (UCLA YAP Model) and Autism		Equine-Assisted Activities and Therapies		Dramatherapy and Autism	U
		Feingold Diet and Autism	0	Facilitated Communication and Autism	
Holding Therapy and Autism		Hyperbaric Therapy and Autism	U	Gluten-Free, Casein-Free Diet and Autism	
Incidental Teaching and Autism		LEAP and Autism		Immune Globulins and Autism	
Methylphenidate and Autism		Milieu Training and Autism		Lightwave Stimulation and Autism	0
				Melatonin and Autism	
				Multi-Vitamin and Mineral Supplements	

(<http://researchautism.net/autism-interventions/our-evaluations-interventions>, accessed 28 July 2010).

Figure 1-2: Screenshot of autism interventions as presented on the research autism website (2010)

The Academy of Medicine, Singapore (Bee, 2010) developed a clinical guideline based on what the working group considered to be the best available intervention evidence. The guidelines cautioned against use of a number of complementary alternative therapies due to insufficient, conflicting or

inconclusive evidence. These unsupported interventions included Amino acid supplementation, Animal assisted therapy, Behavioural optometry, Expressive psychotherapy, Gluten-free and/ or casein-free diet, Sound therapies (Samonas Sound Therapy and the Listening Program), Massage and other sensory-based interventions, Music Therapy, and Omega-3 fatty acid (O3FA) supplementation (Bee, 2010).

Additionally, the Academy of Medicine Singapore (Bee, 2010) claimed that a number of complementary alternative methods might actually be harmful or cause adverse effects in pre-school children with ASD. These include Acupuncture, Antibiotics and Anti-yeast medication, Ascorbic Acid (Vitamin C) supplementation, Auditory Integration Therapy, Chelation Therapy, Chiropractic, Cranio-sacral therapy, Digestive enzymes, Facilitated Communication, Folate supplementation, Holding therapy, Hyperbaric oxygen therapy, Intravenous immunoglobulin therapy, Patterning with masking, Secretin therapy, Vitamin B6- Magnesium supplementation, Weighted vests, and Zinc Supplementation (Bee, 2010).

Intervention options that focussed on early intervention were recommended, with specific support for Early Intensive Behavioural Intervention (EIBI), Structured Teaching, Hanen “More Than Words”, Developmental, Individual-Difference, Relationship-based (DIR)/ Floortime and Relationship Development Intervention (RDI) models (Bee, 2010).

The New Zealand Ministries of Health and Education, in their Autism Spectrum Guidelines (2008), also failed to support Auditory Integration Therapy, Holding Therapy, and Vitamin B6-Mg supplementation, and also stated that based on the lack of evidence available, six (6) interventions are “unlikely to be useful” (Ministries of Health and Education, 2008). These include Dimethylglycine, Gluten and Casein Free (GCF) diet, Omega-3/ long chain polyunsaturated fatty acids, Options Therapy, Sensory Integration Therapies, and Irlen Lenses (Ministries of Health and Education, 2008).

The recommendations in the New Zealand Autism Spectrum Disorder Guidelines (Ministries of Health and Education, 2008) are based on a grading system conceived by the New Zealand Guidelines Group. Interventions are assigned a grade of A, B, C or I. Grade A is given where 'good' evidence is available. 'B' is given where 'fair' evidence is available, and 'C' is awarded if an intervention is supported by Expert Opinion only. 'I' represents those interventions where evidence is unavailable or insufficient. Behaviour management interventions received the highest score using this method. The Scottish Intercollegiate Guidelines Network Clinical Guidelines (Scottish Intercollegiate Guidelines Network [SIGN], 2007) evaluated evidence and assigned a rating according to quality of research. High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias have been given the highest rating of 1 ++, with Expert Opinion being rated the lowest at 4. Recommendations were also graded according to the strength of the evidence, in addition to consistency of results and/ or applicability to the target population. These were rated A, B, C, or D, with A being not recommended, and D being highly recommended. Interventions recommended based on this analysis included Parent Mediated Interventions, Communication Interventions, and Behavioural/ Psychological Interventions (SIGN, 2007). The Lovaas Program, Auditory Integration Training, Facilitated Communication, and Secretin were not recommended (SIGN, 2007).

The National Autism Centre in Massachusetts commissioned the National Standards Report, which was originally published as Phase 1 in 2009, and Phase 2 in 2015 (National Autism Center, 2009, revised 2015). Phase 2 began in 2011 in acknowledgement of the rapidly increasing amount of autism intervention research being conducted, and to include the new evidence into the revised report.

For Phase 1, a specific measurement tool was developed for the purpose of this report. The Scientific Merit Rating Scale (SMRS) and Strength of Evidence Classification System sought to objectively evaluate the methods used for studies of specific educational and behavioural interventions, and to decide

whether these methods could determine efficacy of autism treatments (National Autism Center, 2009). A score was awarded to each intervention based on whether the evidence was Established, Emerging, Unestablished or Ineffective/ Harmful.

Based on their research, The National Autism Center (US) (2009) identified 11 autism interventions as being Established Treatments in Phase 1 of their report. These interventions are outlined in Table 1-5 below. The Phase 1 study by the National Autism Center (2009) reportedly failed to identify any ineffective or harmful treatments based on their criteria used to assess the evidence.

During Phase 2, a review of intervention categorization was undertaken, based on feedback received from the previous report. Interventions formerly classified as Behavioural Package and Antecedent Package, were now to be known collectively as Behavioural Interventions ((National Autism Center, 2015). The Centre also made the decision to use the term 'intervention' rather than 'treatment' in their most recent report. The Phase 2 study identified 14 Established Interventions (See Table 1-5), 18 Emerging Interventions, and 13 Unestablished Interventions. It is important to note that the National Autism Centre evaluated evidence for interventions targeting individuals under 22 years of age. Not all the interventions listed are Early Interventions.

The US-based Vanderbilt Evidence-based Practice Centre (Warren et al., 2011) conducted a systematic review of 159 studies of autism interventions for children, and rated the quality of the evidence, based on the Evidence-based Practice Center's Methods Guide for Effectiveness and Comparative Effectiveness Reviews. Of the studies reviewed, 13 were considered good quality, 56 were fair quality, and the remaining 90 studies were considered poor. Based on this review, they determined that there was clear support for Early Intensive Behavioural Intervention (EIBI), Developmental Intervention (Including UCLA/ Lovaas Model, and Early Start Denver Model), Cognitive

Table 1-5: Comparison of Established Autism Interventions as Described in the National Autism Center's National Standards Project Phases 1 and 2

Phase 1 (2009)	Phase 2 (2015)
Antecedent Package	Behavioral Interventions
Behavioural Package	Cognitive Behavioral Intervention Package
Comprehensive Behavioural Treatment for Young Children	Comprehensive Behavioral Treatment for Young Children
Joint Attention Intervention	Language Training (Production)
Modeling	Modeling
Naturalistic Teaching Strategies	Natural Teaching Strategies
Peer Training Package	Parent Training
Pivotal Response Treatment	Peer Training Package
Schedules	Pivotal Response Training
Self-Management	Schedules
Story-based Intervention Package	Scripting
	Self-Management
	Social Skills Package
	Story-based Intervention

Behavioural Therapy (CBT) and The Treatment and Education of Autistic and Communication-related Handicapped Children (TEACCH).

Based on this review of the various guidelines and reviews of research evidence in this section of the chapter, it is apparent that there continues to be limited evidence available for a substantial number of autism interventions that are available. There have been many attempts to classify and evaluate the efficacy of autism interventions, however there continues to be inconsistent approaches to gathering, appraising and interpreting the evidence, and therefore differing and sometimes contradictory recommendations regarding autism interventions. This can be partially attributed to the number of independent health disciplines involved in studying autism treatments (Mesibov & Shea, 2010), and the differing approaches to determining efficacy of interventions (Reichow, Volkmar, & Cicchetti, 2008).

Mesibov & Shea (2010) suggest that because of the heterogeneous nature of autism, RCTs and systematic reviews may not be the best method of describing the efficacy of autism interventions. Cardon & Azuma (2011) concurred that the heterogeneous population makes it difficult to study using experimental group designs. Selecting early intervention options for children based on available evidence alone is therefore difficult, and the differing values and circumstances of the individuals involved in the decision to be made, must also be taken into consideration. It is imperative that intervention decisions are made with not only consideration for the evidence, but also in consultation with individuals and their families, to determine which evidence-based interventions are a 'good fit' for the family. Shared decision making is a process that assists patients and clinicians to engage in discussions about the best intervention options for their situation. Shared decision making is discussed in the next section.

1.7 Shared Decision Making (SDM) in the Context of ASD Intervention Decision Making

Shared decision making (SDM) is the collaboration between the individual seeking information for, and making decisions about their health, and the expert and experienced health practitioner (Charles, Gafni, & Whelan, 1997; Elwyn, Lloyd, May, van der Weijden, Stiggelbout, Edwards, Frosch, Rapley, Barr, Walsh, Grande, Montori, & Epstein, 2014). SDM principles seek to empower the individual (or parent) to make decisions, based on the provision of quality health information (Charles et al., 1997; Coulter & Ellins, 2007) and their own personal preferences (Godolphin et al., 2001). For SDM to be effective, sufficient time within consultations is required to allow for a full discussion of client preferences, concerns, and any other information relevant to the individual's health condition (Thistlethwaite, 2006).

Shared decision making in the context of autism intervention decision making has not been extensively considered in the literature. Perhaps this is because of its origins in medical treatment decision making, for example deciding between cancer treatment options (Whelan, Levine, Willan, et al., 2004),

however it is highly appropriate and much needed. Some parents feel that they were given insufficient information from paediatricians at the time of their child's diagnosis (Osborne & Reed, 2008). With the limited time health practitioners have to spend with their clients (Kertoy, 2011; McMullan, 2005), they may not be able to adequately impart the information that is required for parents to make informed decisions (Godolphin, Towle, & McKendry, 2001, Hawk & Evans, 2013). Furthermore, some observations in the literature suggest that there are practitioners who avoid providing too much information for fear of overwhelming their clients with information (Valentine et al., 2010). This is concerning, as parents typically do not have access to research journal articles, and therefore there is an increased likelihood that they rely upon their practitioners to provide them with the information they need. Ishikawa and Kiuchi (2010) agreed that too much information can be confusing, however they also support the provision of information, and discussion with patients in order to empower them to make better treatment choices. Finding a balance between parents' need for information, the type and amount of information required, their educational background and interests, and the length of consultations continues to be challenging for many practitioners.

There is an increasing trend for individuals to more actively pursue information related to their own health care (McMullan, 2005), and an expectation from health care professionals that individuals will make decisions related to their own intervention options (Ishikawa & Kiuchi, 2010). This is also the case for parents making decisions about autism treatments for their child. Sanders (2008) urged practitioners to be mindful of the fact that while they may be experts in their particular fields of practice, parents are experts on their child and family, and their observations and judgments are valid and need to be heard and taken into account.

Research evidence is readily available to guide health practitioners, and to a lesser extent the general public, however parents continue to pursue treatment options with no proven effectiveness (Green et al., 2006). It is therefore important to consider how parents are making intervention decisions for their

children with ASD, and what sources of information they are accessing to obtain information about the options available. Resources that aim to encourage and facilitate an increased understanding of autism intervention options and their evidence (particularly with regards to their potential to help or harm) may assist parents to make informed decisions for their child.

Previous research on how parents make decisions about autism interventions for their child is very limited (Bowker, et al., 2010; Lipstein, Brinkman, & Britto, 2012; Green, et al., 2006). Lipstein et al. (2012) conducted a review of parent decision making research. They found a total of 55 research papers that used qualitative or mixed-method designs, with on average 54 participants in each study. None of these papers focused specifically on children with Autism Spectrum Disorder and decision making about interventions.

The goals of informed consent and shared decision making are undermined when there is lack of information transparency in any field of health where parents are required to make health decisions, and can leave parents vulnerable to political and commercial manipulation (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2008). Within healthcare and early education settings, parents are expected to be involved in setting goals for interventions and choose the most appropriate Early Intervention option for their child with ASD. This requires an in depth understanding of the intervention options available. Shared decision making is considered best practice in the healthcare literature to help individuals with the decision making process (Elwyn, Tilburt, & Montori, 2013; Hoffmann, Legare, Simmons et al., 2014), however there is limited indication of SDM being used in the context of ASD intervention decision making.

1.8 Where Parents Look for Information about Autism Interventions

We have established that there is an ever increasing amount of research focusing on the efficacy of autism interventions, that this information is not freely or readily available to parents, and that parents have not been optimally supported to understand and consider research evidence when making

decisions about autism interventions for their child. For these reasons, and others to be explored in later paragraphs, research evidence is not the most important factor that parents consider when choosing autism interventions (Bowker, D'Angelo, & Hicks et al., 2011; Carlon, et al., 2013; Green, Pituch, & Ichon, et al., 2006).

Following diagnosis, parents search for information on autism interventions from a range of sources (Mackintosh, Myers, & Goin-Kochel, 2005; Valentine, et al., 2010). Studies that have used parent interviews and questionnaires suggest that parents obtain information from approximately seven different sources including other parents, friends or family members, professionals, print materials, workshops/ meetings and the Internet (Mackintosh, Myers, & Goin-Kochel, 2005; Valentine et al., 2010).

1.8.1 Intervention decision making and the Internet. A number of studies have reported that parents use the Internet to gather information on a range of health treatment options (Batchelor & Ohya, 2009; Fleischmann, 2005; McMullan, 2005; Sabo & Lorenzen, 2008; Schwarz, 2011). The most frequently accessed source of information for autism interventions reported by Mackintosh, Myers et al. (2005) was books (88%), closely followed by Internet sites (86%). In a more recent Australian study conducted by Valentine et al. (2010), parents reported the Internet to be their primary source of information. By 2009, 72% of Australian homes had access to the Internet demonstrating that it is widely available (Australian Bureau of Statistics, 2009). As well as increase in Internet use, there has been a concurrent increase in the use of social media to obtain health information, although there is still much to learn about how social media sites such as Facebook and Twitter are used by consumers to obtain health information.

Chiarella et al. (2009) proposed that an Internet resource would be useful to help parents find information about autism interventions. Unfortunately information currently provided on Internet sites is often of poor quality, incorrect, out-dated or misleading, hence parents often receive questionable

information on which to base intervention decisions (Coates, 2009; Chiarella, 2009; Sabo & Lorenzen, 2008; Schwarz, 2011). This is particularly concerning, as parents tend to trust links that appear on the websites of peak bodies and service providers (Valentine et al., 2010). In her editorial entitled “Grappling with the grey evidence” for the *Journal of Developmental Medicine & Child Neurology* (2010), Anne O’Hare, from The University of Edinburgh, UK noted that parents frequently access information about evidence from various media including the Internet, and do so “in good faith”. This adds to the responsibility of website content providers to ensure the accuracy of information provided, and further reinforces the need for the opportunity for patients to discuss health information obtained from the Internet with their practitioners.

One benefit of web-based content is that information can be constantly amended and updated (Mulligan, Steel, Macculloch, & Nicholas, 2010). Another advantage of the Internet is the presence of forums that allow parents of children with autism to communicate with one another (Jordan, 2010), feel less isolated (Fleischmann, 2005), and discuss aspects of autism. This can include voicing their opinions of treatment options and treatment providers, although anecdotal reports of an intervention’s effectiveness, and the perceived value parents place on other parents opinions, may contribute to parents selecting interventions that are not evidence-based (Valentine et al., 2010).

Reviews of autism-related websites reveal variable quality in terms of the content and reporting of evidence (Reichow, 2010; Reichow, 2011). Even if some information obtained on the Internet is of high quality, some parents do not have access to this type of technology due to geographical location, cost of hardware and connection costs, and other factors. Hence, it is important that information on autism interventions is provided in a range of formats (Blackburn & Read, 2005), to account for possible lack of access to technology, to accommodate individual learning needs, and to ensure that parents have every opportunity to completely understand and consider all

aspects of autism interventions, in particular the risks and benefits of different treatment options (Valentine et al., 2010).

Despite the growing number of research articles published on autism interventions, and documented evidence for particular interventions, there appear to be few resources available to parents to help them understand the literature and make intervention decisions based on the available research. Most parents do not possess the skills to interpret research findings (Valentine et al., 2010) although some have expressed interest in obtaining more information about their child's care (Kertoy, 2011), and learning how to decipher which interventions are best for their child (Valentine et al., 2010).

Practitioners as well as parents are finding it difficult to determine what type of early intervention strategies are best for individual children (Thompson, 2011b). There are few resources for health practitioners to help them facilitate parents' understanding of research. In his book, *How to Talk to Parents About Autism* (2008), Dr Roy Sanders mentions the importance of evidence-based medicine, but does not explain to the reader why or how to convey the importance of this approach to their client/s. Organisations such as The Ohio Centre for Autism and Low Incidence (OCALI), aim to provide education about autism interventions to parents – in this instance via a series of learning modules (www.autismInternetmodules.org), however autism interventions are classified in such a way that the skill areas targeted, or the age groups these interventions are best tailored for, are not easy to identify.

The conflicting terminology for different types of interventions, and the categories to which they belong can be confusing, particularly for parents who are already feeling overwhelmed and confused following the diagnosis of their child's autism (Chiarella, 2009; Sanders, 2008). The experts agree that there will always be ongoing debate about how interventions are classified (National Autism Center, 2015). On websites aimed at supporting parents who have children diagnosed with ASD, interventions are often described according to broad categories, which may not help parents understand what specific skills

the intervention is aiming to address. Parents are generally not provided with the necessary information to help them understand the terminology used by health and educational professionals. Often the material they are provided with is full of jargon and accompanied by information that is irrelevant, conflicting or confusing (Freeman, 1997; Osborne, 2008; Valentine, et al., 2010).

1.8.2 Intervention decision making and books. In addition to the Internet, resources to assist parents discover and research interventions are found in a variety of media, such as in print (brochures, leaflets, books), and in audio-visual format (for example DVD). Researchers from The Hospital for Sick Children in Toronto, Canada, evaluated a book that had been published for parents of children newly diagnosed with autism (Mulligan et al., 2010) to help them understand general information about autism, as well as what interventions were available to them. Mulligan et al. (2010) reported that a bound, hard-covered copy of the book was preferable to a PDF version in this study, although it was convenient to be able to access online resources, and print relevant information from the electronic copy when the hardcopy was not unavailable.

1.8.3 Intervention decision making and workshops. Another source of information for parents are workshops, for example the Early Days workshops, which are part of the HCWA funding package (an Australian federal government initiative) are offered to all parents in Australia post autism diagnosis. The Early Days workshops are offered as a face-to-face series of workshops, as well as via online modules for those who are unable to attend in person (http://raisingchildren.net.au/articles/early_days_autism_workshops.html). These workshops cover topics such as autism characteristics and possible impact on daily function, service provider options, and how to choose early intervention therapies. Workshops provide the opportunity for parents to ask questions and make contact with others who may also have a child newly diagnosed with ASD (Valentine et al., 2010). A formal workshop setting, with opportunities for families to interact informally with each other is conducive to parents forming relationships and gaining contacts for ongoing mutual support.

Connecting parents and fostering supportive relationships can be a positive outcome in this type of setting. Parents report benefitting from contact with other parents of children with autism (Sanders, 2008). Information is provided verbally, and usually reinforced through provision of handouts, which will help parents to process and later review information obtained. Due to geographical location, time constraints, other commitments or financial reasons, workshop attendance may not be possible for all parents who may benefit.

1.8.4 Intervention decision making and written information kits.

Information kits are available from a number of organisations including the 100 Days Kit from Autism Speaks (<http://www.autismspeaks.org/>), and Life Journey Through Autism from The Organization for Autism Research (OAR) (<http://researchautism.org>). These can be printed from a PDF or ordered directly from the organisation. These kits contain information on what to expect when a child is diagnosed with autism, what supports can be accessed, and what intervention options are available. One challenge with this format is that when information is printed, the source is not always clear, and the date of publication may be difficult to find. Information may quickly become out-dated.

Rudy (2008) was critical of the content of the Autism Speaks 100 Day Kit, stating that the information pertaining to services within the document was very biased toward the organisation (a not for profit organisation which provides funding to provide ASD services), and not necessarily tailored to the needs of parents. Other criticisms of information packages exist. In a study by Valentine et al. (2010), one parent commented that information provided in a package given to her by a health practitioner was “information overload”. Parents prefer information that is individualised, and relevant to their child’s particular needs (Valentine et al., 2010). This is difficult to achieve however, due to the heterogeneous nature of the disorder, and the inability to provide a “one size fits all” solution to challenges faced by families affected by ASD (Cardon & Azuma, 2011; Mesibov & Shea, 2010; Valentine, et al., 2010).

1.9 Health Literacy and Decision Making

Definitions of the concept of health literacy vary across the literature, however health literacy generally refers to an individual's capacity to acquire and use health-related information to make decisions about health care (Baker, 2006; Levasseur & Carrier, 2011; Pleasant & Kuruvilla, 2008). Cultural and conceptual knowledge, oral literacy, print literacy, and numeracy are all types of health literacy (Baker, 2006; Ishikawa & Kiuchi, 2010; Rootman & Ronson, 2005; Singleton & Krause, 2009). Poor health literacy can affect an individual's ability to understand and utilise health education material (Murphy, Davis, Long, Jackson, & Decker, 1993), including website content (Hawk & Evans, 2013; Sabo & Lorenzen, 2008). Low health literacy can affect parents' ability to understand and interpret information provided (Baker, 2006), which may impact on decision making. Good health literacy skills are necessary when considering intervention options (Singleton & Krause, 2009).

Where Internet sites are used for the provision of information on intervention options, health literacy should also be considered. The content included should be relevant to local users and be personalised as much as possible (Mulligan et al., 2010; Valentine et al., 2010). For individuals searching the Internet for health-related information, learning to assess web-page credibility may result in improved health literacy, and better decision making in terms of selecting the most appropriate health interventions (Chiarella, 2009; Schwarz, 2011).

Despite an increased focus on the importance of health literacy and its role in decision making over time (Mancuso, 2009), there continues to be a lack of information available on what health professionals understand of health literacy and how this knowledge is integrated into every day clinical practice (Ishikawa & Kiuchi, 2010; Levasseur & Carrier, 2011). Levasseur & Carrier (2011) suggested that health practitioners should be informed about health literacy, adapt their practice accordingly, make information accessible and take action to accommodate their patients' health literacy. A thoughtfully delivered educational resource aimed at parents of children with autism may help to improve their health literacy (Levasseur & Carrier, 2011), assist them to better

understand autism and autism treatments, and to make better informed decisions about which interventions to choose for their child (Valentine, 2010). While this has been suggested since 2010, no such resource was found in the literature prior to the commencement of this PhD thesis.

1.10 Parent Factors Affecting ASD Intervention Decision Making

Despite the increased awareness and support of evidence-based practice within health care, there remain a number of additional factors affecting how parents make decisions about which autism interventions to pursue. Green et al. (2006) interviewed parents of children with ASD to obtain an understanding of which interventions they chose for their child, and found that the effectiveness of autism interventions was not always a determining factor for parents when choosing interventions. Rather they found that parents were mainly influenced by the cost of treatment, access to/ and availability of therapists, and geographical proximity to services. These findings were consistent with those of Valentine et al. (2010).

By prioritising factors such as these over the evidence about intervention effectiveness, parents can inadvertently engage their children in interventions which are ineffective, possibly harmful, and/ or lacking in evidence supporting their efficacy (Sanders, 2008). For example, one particularly prominent and much discussed autism treatment is Applied Behaviour Analysis (ABA). ABA has strong evidence supporting it (Roberts et al., 2011), however this option is particularly time-consuming for the child and family members with a recommendation of at least 20 hours intensity per week, and it is expensive (Valentine et al., 2010). Hence it may not be viable for parents with limited funds or access to skilled service providers. They may therefore choose an alternative option that is readily available in their local area, but may have less or no effect.

Valentine (2010) described the parents' position as being "paradoxical", in that they are forced to choose treatment options, despite not all options being available in their locality. Waitlists have been found to be a particularly

common barrier to children accessing services in many parts of Australia (Valentine, 2010). Age and severity of autism characteristics, parents' beliefs and values (Green et al., 2006), and parents' emotional functioning following diagnosis (Sanders, 2008) can also impact on how parents make decisions about interventions for their child.

1.11 Conclusion

With the rapid increase in the amount of information becoming available for parents of children with autism, there is a growing risk of obtaining information that is incorrect or lacking in evidence (Reid & Fitch, 2011). Conversely, parents can become overwhelmed and confused with the sheer amount of information available, which may result in anxiety about the choices they are facing (Mackintosh, et al., 2005; Pietro, Whitely, & Illes, 2011). Mesibov & Shea (2010) suggested that one of the benefits of adopting an evidence-based approach to selecting autism interventions is a divergence from "fad" and possibly harmful or ineffective treatments.

Valentine, Rajkovic et al. (2010) interviewed 49 parents and ASD service providers across four Australian states, and asked about what parents and carers of children with ASD perceived as the most effective post-diagnosis support. Based on these interviews, Valentine et al (2010) concluded that the best way of providing information to parents is in-person, and by a healthcare practitioner. One challenge of this recommendation is that principles of evidence-based practice and SDM dictate that health practitioners keep up to date with research evidence (Glasziou & Haynes, 2005). There are currently no resources for practitioners working with families post-ASD diagnosis, that facilitates a SDM approach to decision making. There is therefore a significant gap in the support available for parents who are confronted with the task of choosing an autism intervention for their child.

Valentine et al. (2010) proposed that "one of the most important roles that parents play is in choosing treatments for their children" (p. 54). There are already a significant number of resources available to help parents identify

intervention options, such as websites, print material and DVDs, but few resources are available to help them understand and interpret autism research evidence or to enhance their health literacy. Scant literature exists on how parents of children with autism use these information materials to influence their intervention decisions. More research is needed to understand how individuals access health information (Levasseur et al., 2011), and subsequently make decisions about which interventions they will choose for their child immediately after diagnosis (Green et al., 2006).

This literature review has revealed that many parents rely on the Internet for information on autism interventions. While several studies have been undertaken (Reichow et al, 2011; Stephenson et al, 2012) to investigate the quality of intervention information on autism-related websites, there remains no published empirical studies that have specifically evaluated the quality of these sites using a tool that is purpose-designed to evaluate the quality of written health information. Further research is required to more adequately analyse the quality of autism-related websites, in particular intervention information and its presentation (such as benefits, harms, uncertainty, and supporting evidence). A better understanding of this information would also aid the development of appropriate educational resources for parents post autism diagnosis.

To date there has also been no clinical trials of specifically designed autism intervention decision making resources to determine their impact on parental decision making confidence or parental efficacy. Such an understanding would assist researchers, health professionals and policy developers to better support parents during this challenging time.

Based on this review of the literature, the following research questions were developed, which will be addressed via a number of studies, each informing the nature of the next. The research questions are:

1. What information do parents use to make decisions about interventions they pursue for their child with ASD? (Study 1)

2. What is the quality of the web-based information that parents access?
(Study 2)
3. What decision making processes do parents use when making
intervention decisions? (Study 3)
4. Does an interactive, web-based decision aid impact on how parents
make decisions, by reducing decisional conflict and increasing decision
making self-efficacy? (Studies 4 and 5)

Chapter 2 - Study 1: Information Provision to Parents post ASD Diagnosis

2.1 Introduction

Studies on parent decision making suggest that parents obtain information from a number of different sources including other parents, friends or family members, professionals, print materials, workshops/ meetings and the Internet (Mackintosh et al., 2005; Valentine, 2010). A study in the United States found that sources most frequently accessed by parents were books (88%), followed by Internet sites (86%) (Mackintosh et al., 2005). In a more recent Australian study (Valentine et al., 2010), parents reported the Internet to be their primary source of information. While some studies have explored what information is available to parents who seek information about autism on the Internet (Ademiluyi, Rees, & Sheard, 2003; Blackburn & Read, 2005; Charman, 1999; Coates, 2009; Green et al., 2006; Reichow et al., 2011; Reichow, Halpern, & Volkmar, 2010; Sabo & Lorenzen, 2008; Stephenson, Carter, & Kemp, 2012), none have explored how parents subsequently use this information to make decisions about autism intervention options.

In Australia, since the advent of the Helping Children with Autism Package (HCWA), Autism Advisors have usually been the first point of contact for parents when they have received a diagnosis of autism for their child. The HCWA funding package provides families with access to therapy services to a maximum of \$12,000 over two years. Families are able to use up to \$6,000 per financial year on therapy services until their child turns seven. They are also able to access a portion of these funds for therapy resources, such as aids and equipment that are deemed to support the achievement of therapy goals.

Autism Advisors are employed by various non-governmental organisations (such as state based autism peak bodies) with funding from the Australian Government Department of Social Services (DSS) (previously the Australian Government Department of Families, Community Services, Housing and Indigenous Affairs (FaHCSIA) and are responsible for determining the eligibility of families for funding and providing information to parents about available

services and intervention options when their child is newly diagnosed with an Autism Spectrum Disorder (ASD). To fulfil this role, Autism Advisors must be qualified in one or more of the areas of Community Development, Social Work, Psychology, Behavioural, Health, Social Science or related disciplines, and have experience working with families who have a child diagnosed with autism.

As Autism Advisors connect with parents very soon after they receive an autism diagnosis for their child, they are an appropriate conduit for information from parents, particularly with regards to what sources of information parents have accessed to date and prefer at that time. Autism Advisors typically interview parents in person or via the telephone when they have first received an autism diagnosis. During this interview, parents are given a Letter of Introduction, which they can then present to potential service providers as proof of eligibility for DSS funded services. During the initial interview, parents are usually given a package of information that includes relevant fact sheets and brochures, which may include, but not be limited to, information provided by service providers, or information explaining referral pathways or various financial support services.

The information provided by the Advisors varies from state to state, and is at the discretion of the Advisory team, although there are specific guidelines provided by DSS regarding which services are able to be accessed with the funding. Figure 2-1 provides a screenshot series from the Early Intervention for Autism Spectrum Disorders 'Guidelines for Good Practice' (Prior & Roberts, 2012, p 12 – 14) of the approved autism interventions deemed to have sufficient evidence to support their use, and therefore able to be provided by approved HCWA service providers at the time of the study.

HCWA Early Interventions Table	
<p>The following table indicates the eligibility of interventions for funding under the Helping Children with Autism (HCWA) Package.</p> <p>This table is based on the list provided in Table 6 in the 2011 Review*.</p>	
Key	<p>ER = Eligible based on established research evidence</p> <p>EE = Eligible based on emerging or best practice evidence</p> <p>EO = Eligible only where used in partnership with other eligible therapy/ies</p> <p>NE = Not Eligible - Insufficient or no established, emerging or best practice evidence</p>
<u>Comprehensive Programs, Including ABA, EIBI, Combined Approaches and Developmental Approaches</u>	
ER	Applied behavioural analysis (ABA) or early intensive behavioural intervention (EIBI)*
EE	Early Start Denver Model (ESDM)*
EE	TEACCH -Treatment and education of autistic and related communication handicapped children*
EE	LEAP - Learning Experiences – An Alternative Program for Pre-schoolers and Parents.
EE	PACT - Pre-school Autism Communication Trial.
EE	Building Blocks -centred based and home-based.
EE	SCERTS - Social-Communication, Emotional Regulation and Transactional Support*.
EE	DIR/Floortime Approach*
EE	Developmental Social-Pragmatic (DSP) model*
EE	RDI - Relationships Development Intervention*.
EE	The P.L.A.Y. Project® - Play and Language for Autistic youngsters.
NE	Miller Method
<u>Service Based Treatments Specific to Autism</u>	
EE	SERVAM - Sensory considerations, Environmental management, Routines and planned change, Visual supports, Autism friendly communication, Motivation.
EE	Play Links
EE	Autism Specific Long Day Care - Supported placement in inclusive long-day care setting. Regular IEPs, IFSPs, regular therapy sessions and consultations.
<u>Family Based Including Parent Training</u>	
EE	Hanan 'More than Words'*
NE	Hanan 'It takes two to talk'
EE	Pre-schoolers with Autism - Manualised parent training program.
EE	Triple P – Stepping Stones adaptation
EE	Other parent training programs - Any training provided for parents/carers by approved service providers must adhere to the key elements of effective early intervention, must be autism specific, individualised and have a maximum of six parents in a group.
<u>Therapy Based</u>	
EE	Speech Generating Devices (SGD) and other Augmentative & Alternative Communication (AAC)*
EE	PECS – Picture Exchange Communication System*.
EE	Signing/Other AAC*
EE	Alert Program for self-regulation
EO	Social Stories*
EO	Pragmatic Language Groups
EO	Aquatic OT Programs – Autism specific.
NE	Cognitive Behaviour Therapy
NE	Phonological Awareness/Literacy Groups
NE	Sensory Integration Therapy/Sensory Diet/Multi-sensory Environment
NE	Auditory Integration Therapy*
NE	Fast ForWord Program
NE	PROMPT (PROMPTS for Restructuring Oral Muscular Phonetic Target).
<u>Single Element Components Addressing One Aspect of ASD</u>	
EO	Sleepwise© - Positive Sleeping Practices for Young Children with Developmental Delay.
EO	PALS Social Skills Program - Playing and Learning to Socialise
EO	Toilet Time© - Toilet Training for Young Children with Developmental Delay.
EO	Music therapy (when autism specific)*.
NE	SoSAFE! (not relevant to early intervention age-group).
NE	“Social Eyes”
<u>Not Specific to Autism</u>	
EO	Circles of Support - inclusion program encourage other children to help the child participate in activities.
NE	“Super-nanny” - whole family support provided by a mental health nurse in the home.
NE	Narrative therapy
NE	Physiotherapy / motor skills NOTE: with exceptions made for children with Rett Syndrome.
<u>Teacher/ Centre Support</u>	
NE	Teacher training – NOTE: exceptions may be made when individualised or small group training is required to assist the transition of a child to pre-school or school.
<p>*From Prior, M., Roberts, J. M.A., Rodger, S., Williams, K.& Sutherland, R.(2011), <i>A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders.</i> Department of Families, Housing, Community Services and Indigenous Affairs, Australia.</p> <p>Published on www.fahcsia.gov.au/autism</p>	

(Roberts & Prior, 2012, <http://www.casg.org.au/casg/documents/casg-info-hotline/G/Guidelines%20for%20Good%20Practice%202012.pdf>, accessed 1/6/15).

Figure 2-1: Approved Interventions Under the DSS Guidelines

Since completion of this study, and drafting of the results, the National Disability Insurance Scheme (NDIS) has taken on administration of the HCWA funding package in some states. At the time the study was conducted however, the Autism Advisors were the main point of contact for parents and were considered an appropriate conduit for information that would assist to answer the research questions that focus on how parents obtain and use ASD intervention information.

The study outlined in this chapter is one of several studies that address the first and second research questions posed in this thesis; (a) what information parents use to make decisions about interventions for their children when newly diagnosed with autism, and (b) the decision making processes parents use in making intervention decisions. The study design aimed to obtain a better understanding of the information parents received when accessing an Autism Advisor following an ASD diagnosis for their child. Autism Advisors, often the first point of contact for these parents, were the participants in this study.

2.2 Methodology

2.2.1 Participants. The participants for this study were Autism Advisors employed by various state based organisations with funding from the Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and were recruited via email invitation. All Advisors whose email addresses were available via an industry contact list (n = 56) provided by the department were emailed and invited to participate. A total of 12 (21.4 %) Autism Advisors elected to participate between August 2011 and February 2012. These Advisors were from Queensland (3), The Australian Capital Territory (ACT) (1), Victoria (4), and South Australia (4). The states of NSW and WA were not represented.

2.2.2 Instruments. The instruments used for data collection in this study were a purpose-designed data collection form and a web-based survey. Autism Advisors were emailed a Participant Information Sheet (Appendix B),

along with an attachment that contained instructions (Appendix C) and a data collection form (Appendix D). The data collection form contained the following questions: Have you accessed the Internet to obtain information regarding autism interventions? If you did, what terms or words did you use to search for information? What search engine (e.g. Google, Yahoo, Bing) did you use to conduct your search? What websites did you visit? The data collection form was used by the Autism Advisors to capture the responses given by parents during the interview. It was assumed that by providing the Advisors with this form, it would be easier for responses to be entered into the electronic survey at a later date.

The Autism Advisor survey was developed and hosted on Zoomerang™, a website designed for building and hosting web-based surveys. The survey had two parts (refer to Table 2-1 below). Part A requested information about the Advisors, their experience and their current habits with regards to sharing information with parents about service providers, websites and intervention evidence. Part B was completed after the Advisor had completed 10 interviews with a parent/s or carer/s, and included the abovementioned questions listed on the data collection form.

The survey questions developed by the researcher and PhD Advisory team and based on the literature to date were chosen to obtain the best quality information about what information parents were receiving about autism interventions and evidence at the point of initial interview. The questions also sought to capture information that would enable comparison between the information gathering processes of this sample of parents (n = 113) and the studies reported in the literature.

Table 2-1: Autism Advisor Survey Questions and Information Collected

Survey Part	Question
Part A	Demographics Gender of autism Advisor Australian state or territory where Advisor located

Professional background of Advisor

Approximate number of years working with children an ASD

Questions regarding contact with parents of children newly diagnosed with autism

How many new families with a child or children diagnosed with ASD would you see in a month on average?

What information is provided to parents during your initial meeting?

Parent concerns: From your experience with parents of a child newly diagnosed with autism, what do parents generally report to be most concerned about?

Resources: What do you believe is the best medium (e.g. paper-based, audio visual, web-based, workshops) for providing information to parents/ carers about autism interventions to assist them make relevant decisions for their child/family?

Parents' use of websites

In your estimation, what percentage of parents access the Internet to obtain information about autism interventions, once their child has been diagnosed with autism?

Which websites are you aware of that parent's access prior to the initial consultation with your organization, to obtain information about interventions?

If you provide information on specific websites for parents/ carers to visit to obtain more information on autism interventions, list the URLs.

Autism interventions and research

When discussing autism interventions, do you advise parents to consider the research evidence available regarding intervention outcomes and effectiveness?

Please rate your confidence with describing the evidence behind information on interventions provided.

Do you provide any information to parents to help them understand research evidence?

Part B Of the 10 parents/ carers you asked, how many had accessed the Internet to obtain information regarding autism interventions?

Keywords/ search terms: With regards to those parents/ carers who did access the Internet to find out information about autism interventions, what keywords or search terms did they recall using?

Search engines: what search engine was most commonly used (e.g. Google, Yahoo, bing etc.) by parents/ carers to find information about autism interventions?

Websites accessed: For those parents/ carers who did access the Internet to obtain information about autism interventions, which websites did they visit?

Ethical clearance was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland (Clearance Number 2011000783) prior to commencement of this study.

2.3 Procedure

On 26 August 2011, the survey was distributed electronically to 56 Autism Advisors across all states and territories within Australia. The Advisors were asked to answer a series of questions and to interview the next 10 consecutive parents or carers who contacted them by phone or in person using the data collection form described above. Parents were asked by the Autism Advisors about their use of the Internet, which keywords they used to search for information about autism interventions/information for their child, and which websites they had accessed in their search for information, as per the questions detailed in Table 3-1 above. No demographic data were collected for these families to maintain participant confidentiality and to minimise participant burden to both the Advisor and parents being interviewed.

During the period of time the survey was active, reminders were sent to the Advisors, and for a final time in January 2012. The Australian Government Department of Families, Community Services, Housing, and Indigenous Affairs (FaHCSIA) was also contacted during this time to advise relevant staff of the intention to involve Autism Advisors in the study. A discussion with representatives from FaHCSIA's Autism team via telephone in November 2011 resulted in inclusion of a statement of FaHCSIA's support of the project, and information about the study in the Autism Advisor eNewsletter delivered the following month to all Advisors in each state.

The survey was closed on 29 February 2012 after further correspondence with Autism Advisor Team Leaders across several states revealed that it was unlikely any more responses would be returned due to time/ workload constraints, or failure to obtain permission from senior staff to participate. A total of 12 responses were received. These 12 Advisors interviewed a total of

113 parents of children newly diagnosed with autism. One Advisor interviewed three parents, and the remaining 11 Advisors interviewed 10 parents each.

2.4 Data Analysis

Data from the survey were captured using the Zoomerang™ software program. Quantitative data were analysed descriptively and responses to open ended questions were analysed qualitatively using standard content analysis techniques.

2.4.1 Rigor. A range of techniques, as described by Patton (2002) were employed to enhance the quality and credibility of the study. Rigor in case selection involved purposeful sampling and selecting cases (i.e. the Autism Advisors and their clients) that aligned with the purpose of the study and could generate data relevant to the questions the study aimed to address (Patton, 1999). Purposeful sampling also helps to mitigate researcher bias (Patton, 1999). All Autism Advisors (total population) in Australia were approached, with 12 self-selecting to be involved in the project.

Trustworthiness and credibility of the researchers involved in qualitative studies is important (Patton 1999). The primary researcher conducted this study as part of a higher research degree, and this study was one of two that aimed to investigate how parents of children newly diagnosed with autism make intervention decisions. Patton (1999) suggests that full disclosure of researcher information lends credibility to qualitative reports. The research team all possess occupational therapy qualifications and have clinical and/ or research experience in the field of paediatrics and treatment decision making. The primary researcher is also a clinician providing occupational therapy services to children in receipt of the Helping Children With Autism Funding package, and therefore has an in-depth understanding of parents' information needs.

Triangulation refers to the practice of using a number of sources to provide a thorough understanding of the information obtained from research (Patton,

2002). Analyst triangulation was used in this study, which involved another researcher (one of the PhD Advisory team members) viewing and commenting on the survey responses. Triangulation of qualitative data sources was factored into the study design. The responses to the questions asked of the autism Advisors in Part A can be compared against the responses provided by the parents in the interview in Part B. Differences in the two sets of responses may indicate inconsistency or inaccuracy of information provided by either the Advisor or the parent participants. Patton (1999) postulates that differences in data sources does not necessarily invalidate the data. It provides an opportunity to further explore the potential reasons for the differences between responses.

2.5 Results

2.5.1 Autism Advisors: Characteristics and role requirements. Of the 12 Autism Advisors who responded, 11 interviewed ten parents of children with autism as requested. One Advisor provided responses from three interviews only. She stated that she did not see parents frequently and to interview an additional seven parents and record their responses would not be possible in what would be considered to be a reasonable timeframe. All Autism Advisors were female.

Seven of the Advisors had approximately three to five years experience working with children with ASD, three had between six and 10 years, and two Advisors had more than 11 years experience working with children with ASD. The Advisors were from a variety of health disciplines, including psychology (n = 2), early childhood education (n = 2), and other fields (n = 8). Those who responded 'other', indicated that they had qualifications relevant to social science (n = 2), education (not early childhood) (n=1), disability services (n = 3) and special needs education (n = 2). Advisors reported that they typically interviewed and provided information to between 6 and 50 newly diagnosed families each month. One Advisor saw between 6 and 15 per month, three Advisors saw between 31 and 50 new families each month, and eight Advisors saw between 16 and 30 families each month on average.

2.5.2 Autism Advisors: Information provided to families post-diagnosis. In Part A of the survey, Autism Advisors were asked to describe what information they currently provided to parents during their initial meeting. All reported that they provided contact information for approved panel providers. These are health professionals who have been approved by FaHCSIA to provide therapy services for children diagnosed with autism. Parents can authorise these providers to claim their fees from their allocated FaHCSIA funding.

Nine Advisors stated they provided fact sheets on autism diagnosis and interventions. Eleven of the Advisors provided information about specific FaHCSIA 'approved' early intervention services, in the form of brochures and leaflets about these services. Five provided text/ books or a specific handbook on autism interventions, namely the Australian Autism Handbook (O'Reilly & Smith, 2008). Ten Advisors also provided information about organisations and resources that were not FaHCSIA approved. All but one Advisor reported that they provided a list of websites containing information on autism interventions.

2.5.3 Autism information on the Internet. Prior to collecting data from parents, Advisors were asked what percentage of parents they believed might have accessed the Internet for information on ASD intervention options. One Advisor stated less than 10 percent. Seven estimated that around 75% of parents would access the Internet. Two Advisors estimated around 50% would access the Internet, and another two thought 95%. Of the 113 parents/ carers who were interviewed by the Advisors, 92 (81.4%) had accessed the Internet to obtain information about autism interventions. This is in stark contrast to the percentages that were provided by the majority of Advisors (in estimation), suggesting they underestimated actual Internet use by parents. As mentioned above, 11 Advisors provided a list of websites to parents to enable them to access additional information. In this study, eleven of the Advisors directed clients to the Raising Children Network website (www.raisingchildren.net). This website is an initiative of the Parenting

Resource Centre, and is a collaboration between some of Australia’s leading early childhood agencies, including the Murdoch Children’s Research Institute, and Centre for Community Child Health, Royal Children’s Hospital. The Raising Children website is funded by the Australian Government Department of Social Services (DSS) with support from a range of content and media sponsors. The URLs of other websites the Advisors mentioned specifically to parents are listed in Table 2-2 below.

Table 2-2: Autism Advisor recommended websites and number of times mentioned in survey responses

Type of website	Website URL*
State based autism agencies	www.autismvictoria.org.au (Victoria) www.autismqld.com.au (2**) (Queensland) www.autism.org.au (Western Australia) www.autismsa.org.au (3) (South Australia)
International autism organisations	www.autism.org.uk (UK) www.nas.org.uk (2) (UK) www.researchautism.net (UK) www.nlm.nih.gov/medlineplus/autism.html (US) www.autism-society.org (2) (US) http://health.nih.gov/ (US)
Australian parenting website	www.raisingchildren.net.au (11)
Australian government website	www.health.gov.au (2) www.fahcsia.gov.au www.med.monash.edu.au (2) www.earlydays.net.au (3)
Service provider website	www.playconnect.com.au www.mytime.net.au www.aeiou.org.au (3) www.autismtraining.com.au (6) www.autismpartnership.com.au www.autismhelp.info (2) www.tonyattwood.com.au
Intervention specific information	www.rdicconnect.com www.thegraycenter.org www.connectandrelateforautism.com.au www.abainternational.org.au www.pecsaustralia.com.au www.fastforwardaustralia.com.au

Autism information including	www.bookinhand.com.au
diagnosis, prognosis and	www.autism-resources.com (2)
support	www.healing-arts.org/children/
	www.aspergers.com
	www.aspires-relationships.com/index.html
	www.templegrandin.com/
	www.cnn.com/
	www.donnawilliams.net

* Some of these websites may no longer be active.

** The number in the brackets indicates number of times mentioned by Autism Advisors in the survey if more than once.

In addition to reporting on the websites provided to parents, the Advisors were asked to record the websites that parents reported accessing for information. Seven Autism Advisors listed Raising Children Network (www.raisingchildren.net.au) among the sites parents reported that they frequently visited. The websites of government-funded agencies such as FaHCSIA (www.fahcsia.gov.au), Autism Victoria (Amaze) (www.autismvictoria.org.au), Autism South Australia (www.autismsa.org.au), and Autism Queensland (www.autismqld.com.au) were also accessed by parents according to eight of the Advisors. Some parents could not recall specifically which sites they had visited, and others mentioned that they had 'Googled' rather than directly visited specific sites.

2.5.4 Autism Advisors: Understanding and explanation of research evidence. When asked about whether or not they advised parents to consider research evidence when making decisions about interventions, 11 Advisors responded, and all indicated that they did so. Advisors were also asked to indicate how confident they felt with describing the evidence underpinning a range of early interventions. Eleven Autism Advisors reported to be either 'Somewhat Confident' (n = 6) or 'Very Confident' (n = 5). Only one Advisor selected 'Neither' (indicating they could not claim to be confident or not confident).

Eight Advisors responded that they provided information to parents to help them understand the research evidence underpinning interventions. When discussing research evidence, and what information was provided to parents about research evidence, it was often in response to parents asking questions about the effectiveness of different treatments, or after mentioning interventions they were considering trialling. For example, one Advisor responded that when parents stated that they believed that vaccines cause autism, she would respond that there is no research evidence to support this belief. Another Advisor stated that she would only discuss evidence if the parent seemed “able to take it on at the time” (Advisor 3), based on a judgment call made after initial discussions with the parents. They also indicated that it was typically their experience that parents “rely on their current therapists to advise” on these matters. The trust that parents have in their Advisors in the context of decision making is further discussed in Chapter 5.

2.5.5 Preferred format for information delivery. Autism Advisors were asked to comment on what they thought the best format was for the provision of information to parents at this stage immediately after an ASD diagnosis. One participant responded,

“I do believe that a combination of tools is best. Families have reported benefits from paper based information, websites such as the Raising Children Network, parent forums, workshops and DVDs about families experiences of ASD (a DVD produced by Aspect NSW)”. (Autism Advisor 9).

This was typical of the other Advisors’ responses, with a variety of formats being recommended. Another Advisor responded,

“Families need access to information in a range of formats, written, workshops, websites, face to face. Information needs to be in plain English and in different languages”. (Autism Advisor 4).

The needs of the parents and family were also important according to the Advisors. One Autism Advisor stated that the parents and family were often

grieving post-diagnosis, which affects the way they are likely to process information, and that the timing of information provision is important.

2.5.6 Parents' concerns post autism diagnosis. The Autism Advisors were asked to consider what parents generally reported that they were most concerned about at this information gathering stage post diagnosis. The response options included cost of interventions, amount of time spent pursuing interventions, access to specific interventions due to either geographic location or travel, access to specific interventions due to therapist availability or waitlists, amount or type of evidence supporting the use of interventions available, confidence/ ability to decide what interventions are most appropriate for their child and family, or other. The responses for this question were collected prior to parent interview and Advisors were able to select any number of options based on their own opinion and experiences. Ten Advisors indicated that parents worry about the cost of interventions. Nine Advisors reported that parents were concerned about their confidence to decide what is best. Eight Advisors indicated that access to specific interventions due to therapist availability was a concern. Access to specific interventions due to geographic location or travel constraints was reported to be a parental concern by seven Advisors. One Advisor reported that parents were concerned about the amount of time required to pursue interventions. No Advisors commented on parental concerns about the amount or type of evidence supporting the use of available interventions.

2.6 Discussion

Consistent with the findings of this study, the literature suggests that parents typically search for autism information from many different sources. As many as seven have been reported in some studies (Mackintosh et al., 2005), however the Internet is one of the most frequently utilised (Batchelor & Ohya, 2009; Fleischmann, 2005; McMullan, 2005; Sabo & Lorenzen, 2008; Schwarz, 2011; Reid & Fitch, 2011; Valentine, Rajkovic, Dinning, & Thompson, 2010). The most frequently accessed source of information for parents in the study by Mackintosh et al. (2005) was books preferred by 88%

of their participants, which was closely followed by Internet sites (86%). In an Australian study conducted by Valentine et al. (2010) of 49 ASD parents, Advisors and service providers across Australia reported the Internet to be parents' primary source of information. The results of the survey question posed to parents about their Internet use (average 81.42%) is consistent with the literature on this topic.

An increasing number of people in Australia have Internet access. In 2009, around 72% of Australian homes were able to access the Internet (Australian Bureau of Statistics (ABS), 2009). By the time this study was completed, this number had increased to 83% (Australian Bureau of Statistics (ABS) 2014). This number is expected to increase yet again with the anticipated introduction of the National Broadband Network (NBN) across the country, with one third of Australia's homes and businesses scheduled to be connected by end 2015 (Australian Government Department of Broadband, 2012).

Information provided on Internet sites can be of poor quality, incorrect, out-dated or misleading, and parents are at risk of receiving questionable information on which to base intervention decisions (Chiarella, 2009; Sabo & Lorenzen, 2008; Schwarz, 2011). Parents tend to trust that links that appear on the websites of peak bodies and service providers are of good quality (Valentine et al., 2010). This trust also extends to the health professionals providing information to them about autism interventions (Grant, Rodger, & Hoffmann, 2015 (Chapter 5)). For this reason, it is imperative that website URLs that are provided to parents consist of good quality content. This also raises the question about how to assist parents to determine whether websites are of high quality and whether the information is trustworthy.

Grant, Rodger and Hoffmann (2015a) evaluated autism websites using a tool designed to assess the quality of patient education materials. This study will be fully described in Chapter 4 of this thesis. The study resulted in a list of websites mostly likely to be accessed by Australian parents searching for

autism information, ranked according to how best they fit the specific criteria for good quality health information. Of the 36 websites that appear in Table 3-2, four are among the 20 websites evaluated by Grant et al. (2014). The Raising Children Network website (www.raisingchildren.net) was rated as one of the best websites in terms of quality, second only to the Wikipedia articles on Autism Spectrum Disorders. It is reassuring that both the Advisors and parents have reported this website as being one of the most frequently accessed in the present study. The other websites evaluated by Grant et al. (2014) that appear in Table 3-2 include the websites belonging to Autism Queensland (www.autismqld.com.au), www.aspergers.com, and www.nih.gov.

There is an increasing amount of autism intervention information freely available for parents on the Internet. Concurrently there is also an increasing amount of research focusing on the efficacy of these autism interventions, as outlined in the Literature Review (See Chapter 1). This information however, is not freely or readily available to parents as it appears in journals with restricted access to subscribers, and reportedly is not the most important factor considered by parents when choosing autism interventions (Bowker et al., 2010). It is reassuring to note that the Advisors claimed to discuss research evidence with some of their clients, however it is unknown how well this information was conveyed by the Advisors, and how the information was interpreted and used by parents. The Advisors in this study reported to be either somewhat confident ($n = 6$), very confident ($n = 5$), or neither ($n = 1$), which leads to further questions about the efficacy of information transfer, and the ability of these professionals to adequately impart good quality information about autism research and evidence and the time required to do so in an initial interview. This study did not explore how much the Autism Advisors themselves understood about research evidence, or whether or not they possessed the skills and time required to impart this information in such a way that the recipients could understand. This issue should be explored in future research.

In the present study, Autism Advisors proposed that autism information is best provided in a range of formats, which is supported by what is understood of parent preferences, and their use of information sources (Batchelor & Ohya, 2009; Grant et al., 2015; Mackintosh et al. 2005; Valentine et al., 2010). It is important therefore, that any educational resources or information aimed at assisting parents with decision making about ASD interventions, be made available in a variety of formats.

There are no studies that describe how parents generally make decisions about autism intervention options for their children. While this study supports what is already known about the tendency of parents accessing the Internet for information, there is still much to be learned about what decision making processes parents of children newly diagnosed with autism undertake. This is further explored in Chapter 4, where a more thorough review of parent decision making post diagnosis has been undertaken, using more rigorous qualitative research strategies.

2.6.1 Limitations of the study. The study was conducted via an electronic survey for efficient and timely gathering of responses from participants across Australia. This data collection method has limitations however, which include limited opportunity for clarification of points or extended responses to queries (Van Selm & Jankowski (2006). To mitigate this, survey questions were thoughtfully structured to obtain the most useful and relevant information to answer the research questions for this study.

Parent demographic data were not captured, which was a design decision, intended to reduce the time required for Autism Advisors to participate in the study, and because the focus of the study was to capture Autism Advisor characteristics and practices, rather than parent demographic information. Assumptions can be made about the parent participants' details. The state in which some reside is most likely the state in which interviews took place, the parents had a child with an autism diagnosis, aged under seven years of age, and diagnosed within the past 12 months. Not all states and territories were

represented in the study. The distribution of participants between the states was uneven, therefore it is difficult to generalise these findings.

Fifty-six Autism Advisors were invited to be involved in the study, however only 11 chose to participate. The sample size was small, representing only 19.6% of Advisors. This information has helped however, to provide a view of the landscape in which Study 5, Chapter 6 took place, and along with the existing literature on intervention decision making, contributed to the decision to develop a web-based educational resource for parents to help them make better informed intervention decisions.

2.6.2 Implications for future research. This study used information obtained from Autism Advisors working within the Federal Government Department of Families, Housing, Community Services, and Indigenous Affairs (FaHCSIA) to obtain information about parents' use of the Internet to obtain information about autism interventions. The study did not investigate the Advisors' understanding of research evidence or their expertise in conveying this information effectively to their clients. As an important point of contact of parents of children newly diagnosed with autism, it would be useful to obtain this information for the benefit of those involved in training the Advisors for their role. This information would also be useful for researchers or clinicians involved in developing materials for parents to access post-diagnosis, so that any gaps in information provision can be addressed.

2.7 Conclusion

Many parents of children with autism turn to the Internet for information on autism interventions. From previous studies undertaken, it is evident that more research is required to understand how parents use information to make decisions about intervention options for their child with ASD.

As the primary point of contact for many parents post-ASD diagnosis, the Autism Advisors in each Australian state and territory may benefit from additional training to allow them to better support parent decision making. Many already provide information on what they consider to be quality websites, and some purport to discuss the evidence behind different

interventions. While this may be the case, further research is required to determine whether parents benefit from this discussion with their Advisors, and their ability to understand and apply information about evidence, and how they determine what is reliable and trustworthy information, when it comes to making the best decisions for their child and family.

Chapter 3 - Study 2: Evaluation of Autism-Related Websites on the Internet*

The need for this study was identified when during review of the literature for this thesis, it was determined that many parents of children newly diagnosed with ASD accessed the Internet to obtain information about intervention options.

3.1 Introduction

When parents receive a diagnosis of an Autism Spectrum Disorder (ASD) for their child, many access the Internet as a source of information regarding the disorder as well as possible treatment options (Mackintosh, Myers and Goin-Kochel, 2005; Miller, Schreck, Mulick and Butter, 2011; Sabo and Lorenzen, 2008; Stephenson, Carter and Kemp, 2012). In a study of parents of children diagnosed with autism (N=498) 86% accessed the Web for information. Other parents of children with autism were a source of information for 72% of parents, compared to less than half (48%) who obtained information from health professionals (specifically physicians) (Mackintosh et al, 2005; Miller et al, 2011). The Web is always available, whereas health professionals have limited time, and may not be able to adequately impart all of the information that is required to assist parents to make informed decisions about interventions for their child (Godolphin, Towle and McKendry, 2001).

Over the years there has been an exponential increase in the number of autism-related websites available, with searches for information on autism

* This study has been published as: Grant, N., Rodger, S., & Hoffmann, T. (2014). Evaluation of autism-related health information on the Web. *Journal of Applied Research in Intellectual Disabilities*. doi: 10.1111/jar.12127, and this chapter contains the published version of this study.

returning 104,950 sites in 1999 (Charman, 1999) and 17.4 million in 2005 (Reichow, Halpern and Volkmar, 2010). This dramatic increase makes the process of filtering the available websites and determining which provide accurate information particularly daunting and onerous, for parents and health professionals alike. The search for information is further complicated by the number of autism interventions reported to be available. These are described in varying levels of detail across these websites (Green et al., 2006; Stephenson et al., 2012), and often with little or no supporting evidence (Mackintosh et al., 2005; Stephenson et al., 2012).

While the Internet is always available, information found online can vary in quality. Reichow, Steinhoff, Halpern, Naples and Volkmar (2012) found that the sites revealed in web searches using 'autism' as a keyword, were not always the same each time the searches were repeated. Consistency of search results decreased over time, and even more so when more than one search term was used, for example 'autism treatment' or 'autism causes'. The quality of health information provided on the Internet is known to be highly variable (Gagliardi and Jadad, 2002; Valentine, Rajkovic, Dinning and Thompson, 2010). The obvious commercial goals of the Internet, unclear motives of website authors (Stephenson et al., 2012), and lack of important safeguards can lead to parents of children with autism acquiring inaccurate and dubious information (Chowdhury, Drummond, Fleming, and Neufeld, 2002; Gagliardi and Jadad, 2002). This may result in parents making intervention decisions based on information that is misleading, biased or lacking in evidence (Ni Riordain and McCreary, 2009; Stephenson et al., 2012).

After identifying a gap in the literature on this topic, two studies of autism-related websites were conducted in 2009 and 2010 (Reichow, Halpern, Steinhoff, Letsinger, Naples & Volkmar, 2012). The first evaluated characteristics of the top 100 websites selected by entering the keyword 'autism' into three popular search engines. The characteristics evaluated included attribution, authorship, currency, disclaimer, contact information,

promotion of a non-evidence-based treatment, purpose, commercial product or service, reading level, and top-level domain (Reichow et al, 2012). A second study was undertaken to further explore the relationship between website characteristics and quality, as the authors did not feel that conclusions about website quality could be drawn from the data collected in the initial study (Reichow et al., 2012). These studies were being conducted in parallel with the study described in this chapter.

Reichow et al. (2012) evaluated autism-related website content of 30 websites (selected based on a search of Google using autism-related keywords), by participants' completion of a survey. Both sponsored links and ranked sites were included in the sample (Reichow et al, 2012). Participants, primarily researchers/ professionals (N=299) were recruited from the International Meeting for Autism Research (IMFAR) Annual Conference email list. They were asked to rate three websites each, with the characteristics of accuracy and currency as the main dependent variables. These two variables were considered by the authors to be indicative of a good quality website and were also highly correlated (Reichow et al., 2012). Accuracy and currency were rated on a 5-point Likert scale from very inaccurate to very accurate, and a website quality estimate was derived from combining the scores for each site. Statistically significant relationships were found for two characteristics. Website quality was negatively affected by (1) marketing a product or service, and (2) promotion of non-evidence-based practices. Sites developed by government agencies were more likely to be of higher quality, a finding that also supported previous studies of health information sites (Batchelor and Ohya, 2009; Rees, Ford, and Sheard, 2002).

Stephenson, Carter and Kemp (2012) evaluated the quality of treatment information on national autism association websites after identifying that these sites were a logical source of information for parents post-diagnosis. The authors examined reviews of interventions (with a focus on those used in educational settings) for students with autism and rated the strength of evidence for the efficacy of each intervention (strong, marginal, or weak). A

web search was conducted using the keywords 'autism' and 'society' or 'association' and eight sites chosen. The reporting of the empirical evidence for each intervention listed on each site was coded (as positive, neutral, negative, and none). Of the 84 mentions of 33 autism interventions across the eight sites, only 16 ratings of empirical evidence could be determined. It appears that while government organisations are more likely to have better quality content (Reichow et al., 2012), empirical evidence about the effectiveness of treatment options for autism is lacking from many autism-related websites, including those maintained by government agencies.

While Reichow et al. (2012) and Stephenson et al. (2012) have undertaken studies to investigate the quality of treatment information on autism-related websites, there are no published studies that have specifically evaluated the quality of such sites using a tool that is purpose-designed to evaluate the reliability and quality of written health information and treatment choices, such as DISCERN (Charnock, 1998). Screening health information using the DISCERN tool can assist individuals to participate in treatment decisions, and make better informed decisions about treatment options based on the quality of information and good evidence (Charnock, 1998). The inclusion of an item about whether the information provides support for shared decision making in a tool such as the DISCERN further supports the current trend towards patients becoming increasingly involved in their own treatment choices (Charnock, 1998; Elwyn et al, 2013; Godolphin et al, 2001). The current study aimed to analyse the quality of a sample of autism-related websites, in particular treatment information, using a valid and reliable health information evaluation tool.

3.2 Methodology

3.2.1 Design. The study was a cross sectional analysis of autism-related websites.

3.3 Procedure.

3.3.1 Website selection. The source of data for this study was autism-related websites that were considered to be the most readily accessed by Australian parents. Three search engines, Google, Yahoo and MSN, were used to conduct the search for websites. These search engines were chosen as they were identified as being among the most popular search engines used worldwide (Boswell, 2010; Shannon, 2010; Sullivan, 2006). MSN and Yahoo are both powered by Bing and default to the Australian network (i.e. ninemsn and Yahoo!7), therefore search results have an Australian focus, which was the context of the authors of this paper.

3.3.2 Keyword selection. Ten keywords were selected based on discussion amongst the authors who had clinical and research experience of ASD. Keywords chosen were selected based on which words parents of children newly diagnosed with autism might use. These were autistic, ASD, autism, autism spectrum disorder, autism interventions, autism treatment, Asperger disorder, Asperger syndrome, autism therapy, and autism cure.

3.3.3 Selection of websites according to frequency of occurrence in the search. On 22 and 23 April 2013, the ten keywords were sequentially entered into each of the three search engines. Prior to conducting the search, the search history of the computer used for the study was deleted. The top 20 results for each keyword were entered into an Excel spreadsheet. Advertisements, videos, images, and news items were excluded. All other websites that appeared in the search results were included.

A total of 600 Uniform Resource Locators (URL) was obtained. Each URL was shortened to the domain name, and the top 20 websites were obtained by ranking websites according to the number of times each site appeared on the spreadsheet. Any URLs, which appeared once or twice only, were eliminated first. The remaining URLs were sorted in descending order of frequency according to how often each site appeared, resulting in a list of 70

websites. The top 20 most frequently occurring websites were then evaluated by two independent raters using the DISCERN tool. Discrepancies between the raters were resolved through discussion.

3.3.4 Instrument. The DISCERN tool was chosen as it was specifically developed to evaluate written health education materials that contain information on treatment options. In addition, it has a focus on quality information that is based on the best available research evidence and information that can be used to facilitate shared decision making (Godolphin et al, 2001; Needham, Charnock, Gann, and Shepperd, 1999). The DISCERN tool has established inter-rater reliability (Kaicker, Debono, Dang, Buckley, and Thabane, 2010) and has been used widely in similar studies evaluating websites containing interventions for many other health conditions (Batchelor and Ohya, 2009; Kaicker et al, 2010; Ademiluyi and Rees, 2002). It has also been found to reliably assist with the ranking of websites by health professionals (Batchelor and Ohya, 2009), which makes this tool particularly relevant for use in this study.

The DISCERN tool consists of 16 questions that are clustered into three sections. The first section assesses the reliability, dependability, and trustworthiness of the material. Section two addresses the quality of information on treatment choices. The final section evaluates the overall quality of the website in a single question (Charnock, 1998). Questions are rated on a scale from 1 to 5 (where 1 = the information did not meet all the criteria and 5 = all criteria were met) (Charnock, 1998), with an overall maximum score of 80. A score of 3 or less (out of 5) on each individual item indicates that the website only partially meets the criteria for that item.

Two independent raters (an occupational therapist with 11 years clinical experience and a fourth year occupational therapy student) were trained to use the DISCERN tool. Training involved both raters reading the DISCERN Handbook (Charnock, 1998) and discussing the questions prior to using the tool and discussing findings. Once each site was independently rated, those

items where scores were more than one point apart on the five-point scale were discussed. Scores were adjusted if either rater opted to alter their score based on additional information provided by the other rater during this discussion. Differences in interpretation of definitions and missed information (due to the large volume of information contained within the website and associated links) were usually found to be the reason for the score discrepancies. This method of ensuring consistent rating on the DISCERN instrument was also used by Godolphin et al. (2001), and a similar technique was used by Reichow et al. (2012) when evaluating the characteristics of autism-related websites.

3.3.5 Source of information/website references used to support intervention content. Further analysis of each website was undertaken to explore the source of information used to support the website content. Websites were grouped according to the type of references or sources that they provided to support the intervention content presented: 1) no references or sources provided; 2) some references or sources provided but not research references (e.g. expert opinion or non-research article); or 3) research reference provided (as the focus was on intervention content, a systematic review or randomised controlled trial needed to be referenced to be coded in this group).

3.4 Data analysis

A mean overall score for each website, and for each individual DISCERN item across the 20 sites, was calculated by averaging the scores given by the two raters.

3.5 Results

Table 3-1 presents the mean DISCERN score for each website. The mean score for all sites was 46.5, with the collaborative web-based encyclopaedia (www.wikipedia.org) scoring the highest (mean = 67.5). The lowest scoring

site had a mean of 23 and appears to be managed by a privately practicing naturopath who operates in various clinics across Australia.

Table 3-1: Mean Overall DISCERN Scores of Twenty (20) Most Frequently Appearing Autism-Related Websites Across Google, Yahoo and MSN Between 22 and 23 April 2013.

Domain Name	Mean total DISCERN Score (out of 80)	Number of times site appears in search results (out of 600)
www.wikipedia.org	67.5	45
www.raisingchildren.net.au	66.5	31
www.nih.gov	61.0	35
www.autismspeaks.org	60.5	10
www.psychcentral.com	60.5	8
www.autism-help.org	60.0	9
www.about.com	58.0	24
www.thefreedictionary.com	58.0	11
www.autism.net.au	50.5	10
www.autismspectrum.org.au	48.5	15
www.webmd.com	48.0	18
www.kidshealth.org	44.0	7
www.betterhealth.vic.gov.au	41.5	10
www.aspergers.com	33.5	7
www.autismqld.com.au	33.0	9
www.cyh.com	32.5	6
www.education.qld.gov.au	28.5	12
www.ehow.com	27.5	6
www.dictionary.reference.com	27.0	8
www.ultimatehealthsolutions.com.au	23.0	6

Table 3-2 presents the mean scores for the individual items of the DISCERN tool for the 20 sites. The item with the highest mean score was Item 7 (Does it provide details of additional sources of support and information?) and the two items with the lowest mean scores were Item 11 (Does it describe the risks of each treatment) and Item 12 (Does it describe what would happen if no treatment is used?).

Table 3-2: Mean Score for Each DISCERN Item for all 20 Autism-Related Websites

Item No.	Question	Mean (SD, range)
1	Are the aims clear?	2.4 (1.2,1-5)
2	Does it achieve its aims?	2.1 (1.5, 0-5)*
3	Is it relevant?	3.5 (1.2, 1-5)
4	Is it clear what sources of information were used to compile the publication?	3.3 (1.4, 1-4.5)
5	Is it clear when the information used or reported in the publication was produced?	3.3 (1.3, 1.5-5)
6	Is it balanced and unbiased?	3.4 (1.2, 1-5)
7	Does it provide details of additional sources of support and information?	3.8 (1.2, 1-5)
8	Does it refer to areas of uncertainty?	3.2 (1.3, 1-5)
9	Does it describe how each treatment works?	2.9 (1.5, 1-4.5)
10	Does it describe the benefits of each treatment?	2.7 (1.3, 1-4.5)
11	Does it describe the risks of each treatment?	1.5 (1.3, 1-5)
12	Does it describe what would happen if no treatment was used?	1.8 (0.9, 1-3.5)
13	Does it describe how the treatment effects overall quality of life?	2.5 (1.1, 1-4.5)
14	Is it clear that there may be more than one possible treatment choice?	3.5 (1.4, 1.5-5)
15	Does it provide support for shared decision making?	2.9 (1.3, 1-4.5)
16	Total	2.9 (1.2, 1.5-4.5)

*Score of 0 given where response is n/a.

For the source of intervention information on the websites, only six of the 20 websites provided research references when describing intervention options. Four of these six sites were the top four most highly ranked in the search results and all were among the top 10 websites based on DISCERN scores. Of the remaining 14 sites, 8 provided some references or sources for the information (but not research references) and 6 provided no references or sources for the intervention content that was contained on the site.

3.6 Discussion

The current study examined the quality of health information on 20 autism-related websites that are likely to be commonly accessed by parents, particularly in Australia. Evaluation of the sites sampled in this study revealed aspects of health information that were particularly poorly conveyed including: the risks of each treatment, what happens if no treatment is pursued, the benefits of each treatment, how each treatment works, and what effects on overall quality of life should be expected from treatments. Such information should always be conveyed when health information and intervention options are presented, as such information is crucial to informed decision making (National Health and Medical Research Council of Australia (NHMRC), 2006; Needham et al., 1999).

Content managers of autism-related websites also need to better explain the specific aims of the website (and ensure these aims are then fully met by the content that is provided) and be more transparent about the sources of information used to make treatment recommendations (Chowdhury et al., 2002; Stephenson et al., 2012). One interpretation of the DISCERN total score that has been proposed is: excellent (scores of 63–75), good (51–62), fair (39–50), poor (27–38), and very poor (15–26) (Hargrave et al., 2006). Overall the quality of the information on the sites evaluated for this study was fair (with a mean DISCERN score of 46.5 out of possible 80).

Developers and managers of websites that provide health information should follow principles outlined by the HONcode (Health On the Net Foundation,

2011) and if information on intervention options is provided, evaluate this content with a tool such as DISCERN (Charnock, 1998) to ensure that the information provided is high quality and evidence-based (Godolphin et al., 2001; Needham et al., 1999). Tools such as these are available free on the Internet, can be used with minimal training, and have been found to be useful in helping to determine which websites contain good quality information on which to assist with treatment decision making (Khazaal et al., 2009).

As it is not possible to control what information is presented in websites, and as websites are readily accessed by consumers of healthcare services, it is difficult to ensure that consumers only receive accurate and quality health information. Chowdhury, Drummond et al. (2002) suggested that a 'filtering service' for parents would be beneficial, but offered no suggestions for how this would be developed. Given the rapid increase in the number of autism-specific websites it would be difficult for any one service provider or agency to 'filter' information from all the sites that are rapidly becoming available. Producing an up-to-date list of a small number of websites that contain good quality information (which is independently evaluated by a health professional and/or professional using an appropriate tool/checklist) is one option for health professionals/organisations. However as websites (and their content and quality) are constantly changing, any list that is produced is likely to become quickly out-dated. Someone in the organisation that developed the list needs to be allocated responsibility for maintaining the currency of the list.

Another option is helping parents/consumers to be aware of how to determine website quality so that they can be confident about the accuracy of the information obtained. Although checklists to evaluate the quality of health information websites are freely available, parents may not be aware of them or confident in their use. The DISCERN tool, while useful for this study, may not be the quickest or easiest option for parents and other consumers. The six-item Brief DISCERN (Khazaal et al., 2009) is aimed at quickly evaluating the quality of health information materials and may be more appropriate for parents to use. Regardless of which, if any, tool or method parents use to

determine the quality of web-based information, the importance of discussing intervention options with their health professional cannot be understated.

It remains the responsibility of health professionals to; (1) provide parents with health information that is accurate and reliable and (2) help clients understand the information they are accessing on the Internet and its limitations (Butler, 2003; NHMRC, 2006; Schwartz et al., 2006). Autism-related websites should advocate shared decision making and empower parents to make informed decisions about intervention options for their child, in conjunction with their health professional (Godolphin et al., 2001; Needham et al., 1999). Future research that examines the website attributes that are most desired and valued by parents of children with autism, particularly with regard to intervention decision making, would be valuable and inform resource development in this area.

It is important for health professionals to be involved in generating and managing content for autism-related sites to ensure that information is appropriate, unbiased, and evidence-based (Mackintosh et al., 2005). The high score obtained by www.raisingchildren.net.au illustrates such a partnership. It was developed collaboratively, with government funding, by a network of professionals and researchers involved in parenting and healthcare. Such partnerships can help to ensure that the latest research information, typically available to professionals in peer-reviewed journals but less easily available to the general public (Chowdhury et al., 2002; Reichow et al., 2012), is imparted to those making decisions about interventions related to their children's healthcare needs.

One limitation of this study is that it was challenging to comprehensively review the websites. Some of the sites contained countless number of pages, often with links to external sites or to pages within the site that had already been viewed. Some of these websites also contained links to PDF documents that contained good quality information, but were not necessarily authored by the website owner, and therefore not credited to the site. Another challenge

of evaluating websites is that they are subject to change, including removal, at any point in time. During the period of time this paper was being prepared, one site experienced technical difficulties and was unable to be accessed for several months. Another site elected, for a period of time, to show a black screen instead of usual content in a political protest against the United States bill, Stop Online Piracy Act. This is an example of the unpredictable and dynamic nature of the Internet, which can further add to parents' confusion in their search for reliable and trustworthy information.

3.7 Conclusion

This study aimed to evaluate the quality of health information in a sample of 20 autism-relevant websites, using the DISCERN tool. Overall, information quality was fair, with many areas of improvement needed. Particularly lacking were many aspects of information that is needed for making informed decisions about interventions, such as supporting research evidence, and details of expected benefits, risks, and the option of no treatment. Improved website content with information that is grounded in quality research evidence will assist parents of children with autism to make better-informed decisions about interventions into the future.

Chapter 4 - Study 3: Parents' Decision Making Processes and Preferences for Obtaining Information About Autism Treatment*

Study 1 focused on the information parents of children newly diagnosed with autism received when attending interviews with an Autism Advisor, and began to explore what sources of information parents had accessed when searching for information on autism treatment options, particularly in those early stages post-diagnosis, and before consulting with an Autism Advisor. The study outlined in this Chapter aims to further explore how parents make decisions about autism interventions for their child, and what sources of information they used following diagnosis.

The specific research questions addressed in this study were:

1. What information do parents use to make decisions about interventions they pursue for their child with autism?
2. What decision making processes do parents use when making intervention decisions?

The intended purpose of this study was to inform the development of an education resource for parents. A qualitative descriptive approach was considered most appropriate in order to explicate parents' decision making processes and sources of information both accessed and preferred. Focus groups were determined to be the best method to obtain this information (Breen, 2006), however one on one interviews were also used where participants were unavailable for a focus group. Focus groups and interviews were conducted between October 2011 and January 2012. The data were then transcribed and analysed thematically.

* This study has been published as: Grant, N., Rodger, S., & Hoffmann, T. (2016). Parents of children with Autism Spectrum Disorder: Intervention decision making processes and information preferences. *Child: Care Health and Development*. 42, 1, 125 – 134, and this chapter contains the published version of this study.

This chapter will outline the participants, methodology, analysis, and results and discuss these with a view to inform the next stage of the project, which is the development of an information resource aimed at increasing parents' understanding of the autism interventions available.

4.1 Introduction

The number of children being diagnosed with an Autism Spectrum Disorder (ASD) worldwide is increasing (Elsabbagh, Divan, Koh, Shin Kim, Kauchali et al, 2012). In Australia, the context of this study, ASD reportedly affects approximately 1 in 160 children (MacDermott, Williams, Ridley, 2007). Information about the various interventions available is disseminated in many different ways, via numerous sources and in a range of formats. Information about intervention efficacy however, is not typically accessible or comprehensible for parents, and evidence is not always considered by parents when making intervention decisions (Bowker, D'Angelo, & Hicks et al., 2011; Carlon, et al., 2013; Green, Pituch, Ichon et al, 2006).

Autism interventions or autism treatments are specific strategies, therapies or services that focus on improving function and addressing core deficits that are associated with ASDs, such as communication and social interaction deficits, sensory processing difficulties, poor attention and concentration, and obsessions or fixations (Agency for Healthcare Research and Quality (AHRQ), 2011). To find out about interventions, parents obtain information from many different sources including the Internet, books and other print material, as well as from health and education professionals (Mackintosh, Myers, & Goin-Kochel, 2005; Valentine, Rajkovic, Dinning et al., 2010). In Australia, Autism Advisors are funded by the government to provide initial support and access to a Federal Helping Children With Autism (HCWA) funding package. These Advisors are often the first point of contact for parents in Australia post-diagnosis and have the challenge of providing all the initial information parents need to embark on the ASD journey. Advisors generally have one meeting with the family, during which time they discuss funding options, service providers and support services for the family. It is

beyond the scope of the Autism Advisors to provide tailored and targeted information, and instead they typically provide large information packs that attempt to cover as much information as possible.

There is a gap in our understanding of how parents of children with ASD prefer to receive information and how they utilise the information obtained from various sources to inform their intervention decision making. This study aimed to explore how parents make decisions about ASD interventions and what sources and formats of information they use and prefer, The purpose of this study is to better inform clinicians and researchers involved in the dissemination of information to parents of children newly diagnosed with autism about their preferences with decision making.

4.2 Methods

4.2.1 Study design. This is a qualitative study based on semi-structured interviews conducted via individual interviews or via focus groups with parents.

Ethical clearance was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland (Clearance Number 2011000783) (Appendix A).

4.2.2 Participants. Participants were parents or primary carers of a child under the age of 18 years who were reported by the parent to have been diagnosed with an ASD by a specialist medical practitioner (such as a paediatrician or child psychiatrist) and considered eligible to receive ASD services in Queensland, Australia. Participants resided within 150 kilometres of Brisbane, Queensland, had sufficient English language ability to participate in an interview, and were able to attend a focus group or interview in person or by phone between October 2011 and January 2012. Parents of children who did not have a formal diagnosis from a specialist medical professional were excluded from the study.

Convenience sampling was utilised (Carpenter & Suto, 2008; Patton, 1990). All major Queensland-based ASD support organisations (Autism Queensland, Autism Early Intervention Outcomes Unit (AEIOU), and Autism Behavioural Intervention Queensland (ABIQ)) were approached to assist with recruiting participants. Social media was also used to reach potential participants. All participants but one were recruited through social media channels.

4.3 Procedure

Participants were initially invited to attend a focus group at a central location. When minimum numbers required were not achieved, the decision was made to travel to participants' homes or other more convenient location (e.g. school or café). Participants were offered a one-on-one interview in person or via the telephone if they were unable to attend a focus group. Interviews were organised and conducted by the lead author.

Prior to the interview/focus group all participants were asked to sign a consent form (Appendix E) after viewing a Participant Information Sheet for either the one-on-one interview (Appendix F) or focus group (Appendix G). All participants were also asked to complete the demographic and intervention questionnaire, and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Murphy, Davis, Long et al, 1993) tool to provide an estimate of their health literacy. Demographic information was collected via self-report and included parents' age, marital status, employment status, number of hours worked, highest level of education achieved, number and gender of children, number of children diagnosed with an ASD, and the year of diagnosis.

4.3.1 Interview. This study utilized a semi-structured interview, which was audiotaped and then transcribed for analysis. Interview/focus group questions were open-ended (Figure 4-1) and were developed in consultation with experts in the field of ASD and intervention decision making, and with reference to the extant literature. Participants were also asked to list which

ASD interventions they had previously trialled. No prompts were provided by the interviewer for this question.

1. Since you've learnt that your child has autism, how have you learnt about what autism interventions are available?
2. Who provided you with information about autism interventions?
3. What type (and sources) of information did you use to find out about what autism interventions were available?
4. What is your preferred method of obtaining information about autism interventions?
5. Did you look at any particular Internet sites to obtain information?
6. How did you find these sites, or who helped you find them?
7. What about these sites did you find useful?
8. What about these sites didn't you find useful?
9. Have you attended any workshops about autism?
10. What information from these workshops did you find useful?
11. What information from these workshops didn't you find useful?
12. Did you consider the research evidence about whether the various interventions work or not when making decisions about intervention options?
13. How confident do you feel in making decisions about treatment options for your child?
14. Do you feel as though you got enough information to make an informed decision about treatment options?
15. When researchers are testing if an intervention works or not, they need to choose something to measure to see if it improves because of the intervention. For example, when testing if an antibiotic for an infection works, they could choose to measure pain or inflammation levels or how long it takes the person to get better. If we think about the testing of autism interventions, what 'things' would it be important for you to know the intervention made a difference to? Why?
16. In what format/s do you think information should be provided to parents newly diagnosed with autism?
17. If parents were to participate in a workshop aimed at explaining autism interventions and available evidence, how many hours would be appropriate?
18. What size group would be most appropriate?
19. Do you have any other thoughts on how parents can be assisted to make decisions about autism interventions?

Figure 4-1: Interview and focus group questions

4.4 Data analysis

The data analysis approach was multi-staged and conducted in accordance with best practice methods for thematic analysis. The phases of analysis identified by Braun and Clarke (2006) were utilised. Steps were undertaken during data collection as well as data analysis to adhere to the principles of trustworthiness, as described by Krefting (1991). Specific strategies to ensure the study was rigorous were used. Peer checking was used to confirm findings by discussion with a peer (co-author SR) and with the primary sources, namely parents themselves (member checking) (Appendix H) (Leininger, 1994).

4.5 Results

4.5.1 Participant profile and characteristics. Twenty-three (23) parents were recruited (mean age 38 years (range 28-48)). Ten participants were interviewed individually, and 13 were interviewed in one of four groups (group size was 2,2,4, and 5 participants respectively). Participants were all English speaking (mothers, 22; fathers, 1). REALM scores (mean = 64, range 57 – 66) indicated a reading ability above 9th grade US/AUS level for all but one participant who scored between the 7th and 9th grade level. Participants collectively had 53 children (38 male, 15 female), with a mean of 2.3 children (range 1-4) who were aged between 0 and 18 years (mean age 8.5). Of these children, 31 had been diagnosed with an ASD, 28 of which were male. For six families, two children in the family had an ASD diagnosis. For one family, three children had been diagnosed with ASD. The mean length of time since diagnosis was 5 years (range 1-16). Parents reported they had trialled a mean of 4.3 interventions (SD 1.5; range 2 – 7) between diagnosis and the time of interview. Refer to Table 4-1 for more details about intervention choices, the most common being speech therapy, occupational therapy and psychology.

Table 4-1: Number and Type of Interventions Participants (n = 23) Reported Trialling

Intervention	Number of participants trialling this intervention
Speech Therapy	21
Occupational Therapy	21
Psychology	13
Early Intervention	7
Physiotherapy	7
Social Skills Development Group Program (e.g. Minds & Hearts, Pathways)	5
Applied Behaviour Analysis (ABA)	3
Music Therapy	3
Relationships Development Intervention (RDI)	3
Secret Agent Society	2
Medication	2
Sensory Diet	2
AEIOU (ASELCC)	1
Autism QLD (other program)	1
Behavioural Optometrist	1
Feeding Therapy	1
Hanen More Than Words	1
Dietetics	1
Natural Supplements	1
Therapressure	1
Fun with Feelings Program**	1
Total	98

(* Autism Specific Early Learning and Care Center

**emotional development group training program)

4.5.2 The journey post-diagnosis. Thematic analysis of the transcripts revealed two overarching themes. These overarching themes are the emotional and pragmatic journeys undertaken by parents post-diagnosis. These journeys are concurrent, although each is unique, and specific experiences can impact how individuals make decisions throughout their journey.

Subsumed under these journeys were the primary themes of; (1) sources of information used by parents when seeking information, (2) parents' information preferences, and (3) factors influencing intervention decision making. These themes are listed in Figure 4-2 and explored below.

Over-arching Themes			
Emotional Journey		Pragmatic Journey	
Parents' confidence Negative and positive experiences of journey post diagnosis		- Parents' actions and steps toward decision making post-diagnosis	
Primary Themes	Sources of information	Information preferences of parents	Factors influencing intervention decision making
Sub-themes	The Internet Workshops Health professional Therapist and Autism Advisors Other parents of children with autism Other	Format (e.g. Internet, workshop) Person delivering information (e.g. characteristics, qualifications) Content (relevant, tailored) Stage-based Social/networking opportunities	Perceived outcome of treatment Trial and error Family fit – including availability of funding, impact on other family members and time commitment required Evidence and opinions of others

Figure 4-2: Overview of emergent themes

Pragmatically, parents described a journey from the point of diagnosis that involved seeking information on ASD interventions from a number of sources, and a 'trial and error' approach to choosing and evaluating these interventions. Figure 4-3 demonstrates how parents typically gathered information, made a choice, and then either continued with one intervention type (or more commonly several simultaneously), or decided to try one or more others.

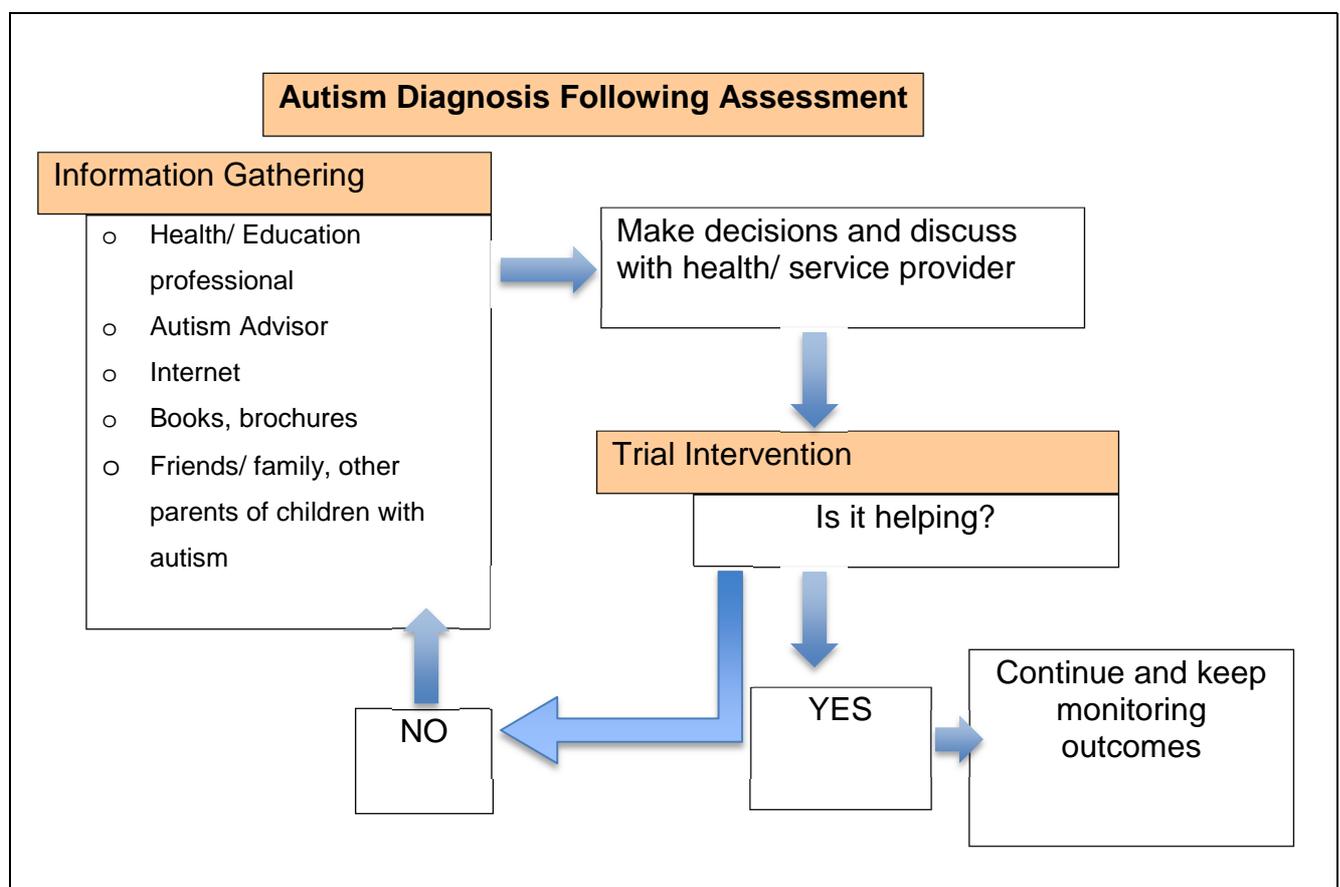


Figure 4-3: The trial and error approach to decision making

This 'trial and error' approach typically started around the time of diagnosis. Upon discovering that there was not one clear path, parents sought further information to support their choices, as described below:

“The only way that I was able to ascertain whether or not it (the intervention) was a useful resource or not a useful resource was [to] actually go through the motions”, (Mother 2).

“I just did a lot of fishing, and it was all online and some with the help of the ABIQ (Autism Behavioural Intervention Queensland), I’d say”. (Mother 5).

“Everything that was suggested, I just threw at him... and then when I eventually settled down, and sort of came to terms with the fact of his diagnosis - then I started looking more rationally”, (Mother 7).

The overarching emotional component of this journey was described by parents in terms of negative and positive experiences post-diagnosis and during the subsequent decision making process. Negative elements of this journey included emotional periods of loss and grief, despair and confusion.

“I had a friend who had her son diagnosed earlier than my son. And so then I went to her. And by this stage it was like most of the time, I was crying... it was such an emotional turmoil of an experience, that I was desperately trying anything”, (Mother 7).

“It was just like ‘whoa’ there’s so much to know. And there’s so much that’s not relevant to me - or is it relevant to me? And when will I find out if it was? So, I ended up abandoning all the information on the Internet because it was too overwhelming”, (Mother 6).

These feelings often evolved however, into acceptance and hope for their child’s future as their journey continued and parental confidence improved. Parents reported that their confidence was generally low to begin with, but improved as they became more familiar with their child’s diagnosis, had opportunities to speak to a number of clinicians and other parents about their child’s diagnosis, and felt empowered to make decisions.

“You have to embrace your new life as being a family. And you have to do the same thing if you have got – if you have a child that is disabled. You have to embrace it”, (Mother 12).

“I have faith in myself... you have to be very determined to jump through a lot of hoops”, (Mother 7).

“If you can have a good team of therapists and work together, it makes life so much easier... And in the end, parents become a bit of a therapist themselves, because of all the information they learn along the way”, (Mother 22).

“Now I feel a lot more confident, but it’s three years on. And I’ve learnt through experience, but initially I had no confidence. I was absolutely terrified of this thing called autism”, (Mother 7).

“I am fairly confident. I tend to use my therapist a bit like, you know, if I have got a question I will email them during the week before I go to my therapy session and, you know - what do you think of this? I guess I would always check with my therapist and get their opinion as well, and yeah, I kind of feel that I am at that stage that I have got enough kind of knowledge and experience to make a pretty good decision now”, (Mother 17).

4.5.3 Sources of information used. Workshops on ASD and ASD interventions were among the most frequently accessed sources of information, however parents reported mixed experiences with, and attitudes towards these. Many parents stated they would have preferred more specific and tailored information. For example,

“Sometimes I find it (the workshop) so basic that because my child is so unusual, and they’re all different, that I can’t apply this”, (Mother 1).

“I’m at the point now where a lot of them - I think, that I’m hearing about at the moment are ones related to what to do just after diagnosis. What is autism? That sort of stuff - which we’ve kind of moved on along from because we’re, sort of, three years into our journey”, (Mother 3).

The time and location of these workshops were also an issue and often a barrier to attendance. Workshops that were deemed successful were often due to the calibre of the speaker, particularly in terms of their perceived knowledge and style of presentation. Presenters who were animated and engaging were seen to be a better source of information and perceived as providing more memorable and useful content.

“The delivery is the key. A lot of other people might have the same knowledge, but you have to be able to present it and make your audience feel comfortable”, (Mother 6).

“These are people that are used to dealing with small children and talking to small children and their parents. They are not used to addressing groups. So I found that was quite interesting, and yeah – that some of them really just couldn’t deliver the information the way that [it] should have been delivered”, (Mother 8).

One of the more positive aspects of the workshop format was the opportunity to network with other parents in similar circumstances. Some had formed continuing friendships in these meetings, and others felt reassured and less isolated as a result of hearing about other parents’ perspectives and experiences.

All participants in this study had searched for information on the Internet and claimed it to be among their preferred sources of information, for example,

“I mainly prefer the Internet, because I can do it at night in my own time, without having to wait for business hours to call somebody or - especially chasing two small kids”, (Mother 18).

Some reported to be overwhelmed by the sheer volume of information available.

“I found the Internet overwhelming and too much”, (Mother 2).

Despite this, parents returned to the Internet frequently - trawling various websites, in order to find information they perceived as useful and relevant. For example,

“You can always go back to it (the Internet)”, (Mother 1).

“I’d find out as much about it – as much as I could about it, over the net and then that’s when I would then talk to somebody else about it”, (Mother 3).

Parents could recall sites they found particularly useful, including the Raising Children Network website (www.raisingchildren.net.au) and the websites belonging to state-based ASD support organisations, such as www.autismqld.com.au. Participants reported the most appealing aspect of these Internet sites was their relevance to the Australian context.

Parents described the trust they have in health professionals, particularly the therapists who work closely with their children, to provide them with intervention recommendations. From the parents’ perspective, the more trustworthy professionals were therapists already working with, or known to the family at the time of diagnosis. Participants appeared to seek advice from trusted professionals in the absence of other reliable sources or perceived lack of decision making support from other sources. For example,

“Because I got the big autism advice pack, and it’s just chock full of information and I just went, I can’t – this is too much for me to take in. So I kind of just went with what the therapists were telling me”, (Mother 11).

“It is always up to you but it is the connection that (you) have with your therapist - I think is enormous”, (Mother 12).

“I have got a team of really good therapists around me, so that makes a big difference”, (Mother 13).

“In an ideal world, preferred method of finding out information would be someone in the education system or a medical professional who said, “This I know works,” or, “let’s take it right down to grassroots and get to know your child and work out what their issues are and do that”, (Mother 13).

Parents generally felt that the medical practitioner (typically a paediatrician) who made the diagnosis should have provided more information at the time of diagnosis and were often dissatisfied with the limited time spent providing relevant information about the condition or intervention options. For example,

“I just met someone the other day whose child was diagnosed just last week. She walked in, the psychiatrist looked at her child and says, “Your child has Asperger’s. Come back in two weeks and see me.” That was it. And so she is now reading, talking to people. Nothing was given to her. She’s still in this big state of shock. “What does this mean?” No information. Nothing”, (Mother 11).

“I think when you’re at the paediatrician and they talk to you about your child having autism, something should happen right then and there in that appointment”, (Mother 3).

Parents reported that the Autism Advisors provided more comprehensive information, however this information conversely, was often considered too much, and too soon post-diagnosis to be properly processed, for example;

“I had to have an interview with the Autism Advisors and they gave me a very, very comprehensive list of everything that was available throughout all of Queensland, which was overly comprehensive. So then once again, at especially in the initial stages of diagnosis, I found that I was being overwhelmed with all this stuff”, (Mother 2).

“She gave me a booklet that was a thing that was stapled together, that was about 10 pages of which – at the interview, I just proceeded to cross things out [other towns] as I was going...”, (Mother 2).

Many parents obtained information by communicating with other parents of children with autism. These other parents were either met through existing connections or through groups formed by parents for the purpose of information sharing and support.

“So then I asked friends. I joined Asperger’s Society. In the first few weeks I joined so many societies. ...”, (Mother 2).

“You’d hear something from another mum and that’s how the information got put across, not so much the teachers themselves or the facilitators of that group, it would tend to be – look I’ve got this great therapist and they deal with this, and I’ve got this, yeah, I’ve had this experience and I went to the GP and they told me that this was available”, (Mother 4).

“I always prefer word of mouth”, (Mother 5).

Other sources of information mentioned by parents included printed materials such as leaflets or pamphlets, or texts aimed at parents about ASD

interventions such as The Australian Autism Handbook (O'Reilly and Smith, 2008, revised 2014).

4.5.4 Information format preferences. Parents' preferred style of information and content changed throughout their journey. Immediately post-diagnosis, parents reported that their preference was for instructive information that provided them with guidance on what they should do next, for example a list of service providers, Internet sites to visit, people to call, or places to go.

"I need the piece of paper that said "One. Call this person. Two, Book your appointments with so and so", (Mother 2).

"I agree it does need to be simple and it also needs to be almost like a checklist", (Mother 20). "I also think initially you do need that little push in the right direction", (Mother 20).

"The most important thing would be what local supports you have. What organisations support you? What parent groups are out there? What services are there to support the actual intervention process?" (Mother 4).

Once parents better understood their child's diagnosis and particular needs, they were more able to process more complex and larger amounts of information. For example,

"I needed something that would go – 'I have done that, I am in control here, I am OK'. And then eventually by the time you go to say, number 10, like you are feeling confident enough to actually make a few phone calls and check out websites on your own without worrying about doing the wrong thing", (Mother 1).

4.5.5 Factors influencing parent decision making. During the interviews, participants were asked if they considered the available research

on the effectiveness of interventions when deciding which interventions they would pursue. Only one parent reported to understand what research evidence was, but found it difficult to incorporate it into the decision making process.

“In that very first workshop again, up at AQ [Autism Queensland], where they did a whole introduction to autism... they talked about the different kinds of research and what they mean. So they broke down - is it anecdotal evidence? and they talked about research studies versus... They have all this different lingo and double blind tests, and then there’s... there was something that was like research studies that was combining a whole bunch of other research studies... The struggle that I found was that when I went looking for the different interventions, I found very little on the Internet, at least that defined for me, what does a speechy [speech therapist] do? I didn’t find anything that told me - this is what a speechy does, this is what a typical session would look like, and these are the typical results...”, (Mother 18).

Typically, parents assumed and trusted that mainstream therapies such as occupational therapy and speech therapy were based on evidence as they are readily available. They described their understanding of evidence to be others’ opinion or testimonials that an intervention is effective. Parents usually did not consider whether an intervention had research to support its effectiveness and no participant accurately explained the term ‘evidence-based’. Of greater priority when selecting interventions were logistical issues such as access to funding, and availability and location of services.

4.6 Discussion

This study has found that parents are choosing interventions seemingly quite randomly and often with no consideration for research evidence. This “trial and error” approach can result in parents selecting interventions that lack supporting evidence, and are possibly inappropriate for their child’s needs. The findings of this study support what is currently understood about what sources of information parents access in order to make treatment choices

(Bowker, 2010; Carlon, Carter, & Stephenson, 2013; Green, 2006; Lipstein, 2012; Valentine et al., 2010;). Parents in the current study frequently accessed the Internet for information, which is consistent with findings from previous studies (Bowker et al., 2010; Mackintosh, 2005; Reichow et al., 2011; Valentine et al., 2010).

Conducting an Internet search for autism-related health information can return thousands of pages of information. Many websites contain poor quality information (Reichow, 2011; Grant et al, 2014; Mackintosh, 2005), which is not conducive to informed decision making. Participants in the present study used websites recommended by other sources, as well as random browsing of search terms relevant to ASD and ASD interventions. Parents of children with ASD use the Internet in a variety of ways, and often tend to become actively involved in online forums and social media groups (Thackeray, 2013). These groups often share useful resources including websites to access. Providing parents with a list of quality websites and giving them information about how to determine the quality of website information would be advantageous (Grant et al., 2014).

This study has found that parents' information needs change over time, depending on where in their 'journey' each family happens to be. Due to the heterogeneous nature of autism spectrum disorders, providing information, particularly in written form or during workshops, that is relevant to all families is challenging. From this study, it is apparent that there is a need for resources that provide tailored information and facilitate decision making based on their individual needs and circumstances. Regardless of the format, it is important that the information provided is current, relevant and accurate. It must also be evidence-based (Mathieu, 2010) and help parents to understand and interpret research evidence (Carlon, 2013; Valentine et al., 2010). Information materials should encourage parents to discuss options with the treating health professionals involved in their child's care. Consideration must be given to the readability of these materials and the literacy ability of the information recipient (Osborne, 2013).

Decision support tools can assist individuals during the decision making process and provide high quality synthesis of the relevant issues to the decision (O'Connor et al., 2009). To date, there are only a small number of decision aids that have been developed to support parents of children diagnosed with ASD to make intervention decisions. These include the web-based Autism Early Intervention Decision Aid that focuses on helping parents choose between evidence-based therapy options (currently under trial) (Grant, 2013); an electronic, printable autism medication decision aid (Autism Treatment Network, 2011); and an electronic brochure available for download developed by the US Agency for Healthcare Research and Quality (AHRQ, 2011) that provides an overview of a number of different interventions, with prompts for things to consider. These decision aids can be accessed via the Ottawa Hospital Research Institute's Patient Decision Aids database (decisionaid.ohri.ca) and have been independently rated according to how closely they adhere to the International Patient Decision Aid Standards (Elwyn et al., 2006). A Cochrane systematic review of decision aids found that they improve individuals' knowledge of their options and potential outcomes, better understand probability outcomes, and reduce decisional conflict (Stacey et al., 2014). No ASD decision aids have been rigorously evaluated, and to date, there has been no research on these decision aids from parents' perspectives.

4.6.1 Limitations of this study. As participants were recruited via convenience sampling, many were from similar geographical areas and of a similar demographic profile, limiting the generalizability of the findings. A greater number of participants from different regions of Australia and of varying educational and reading ability levels may have captured more diversity. The question in which parents were asked to list interventions they had tried was used to determine approximately how many interventions were tried. This question was subject to recall bias and may not accurately reflect the true number of interventions trialled. It is also possible that parents

participating in the focus groups were influenced by or prompted to contribute more information based on the responses of others within the groups.

4.6.2 Clinical and research Implications. Professionals have an important role to play in providing information regarding the evidence base of any interventions they offer and helping parents to better understand the concept of research evidence. If and when changes in the administration of funding packages occurs, it will be even more important that parents receive information at the point of diagnosis, rather than assume that the Advisors or professionals involved in administering funds have a thorough knowledge of best practice specific to autism interventions. Exploration into, and evaluation of methods for helping parents better understand research evidence and the impact of this understanding on their decision making is yet to be explored.

4.7 Conclusion

This study found that when making decisions about interventions for their child following the diagnosis of ASD, parents engaged in both an emotional and a pragmatic journey that was frequently based on decision making by trial and error. Parents accessed a range of information sources and had preferences for information provision that was influenced by the stage of their journey post-diagnosis. Parents' understanding of the concept of research evidence was generally poor and the effectiveness of interventions was not typically considered during the decision making process. This study highlights the need for parents of children with ASD to be supported to make informed intervention decisions.

Chapter 5 - Study 4: Development of an Educational Resource for Parents of Children Newly Diagnosed with Autism

The results from the Studies 1 - 3, as well as the extant literature, were used to inform the development of a decision aid for parents. This resource aimed to assist parents to make informed decisions about early interventions for their child recently diagnosed with ASD. The principles of shared decision making, which suggest that both health professionals and individuals seeking intervention should engage in a partnership in the decision making process (Charles, Gafni, & Whelan, 1997; Coulter & Ellins, 2007; Godolphin, Towle, & McKendry, 2001; Thistlethwaite, 2006), were also used to inform the development of this resource.

Health and early education professionals do not always have the skills, time or inclination to share and explain information about autism interventions with parents in a manner that enables them to make truly well informed decisions (Kertoy, 2011; Osborne & Reed, 2008). Thistlethwaite (2006) proposed that a challenge of engaging in SDM was the extensive amount of time required to adequately discuss intervention options during consultations. Hoffmann, Legare, Simmons et al., (2014) directly refute this myth and refer to three systematic reviews that demonstrate that when SDM occurs, an increased consultation time does not necessarily result (Stacey, Légaré, Col, et al., 2014; Légaré, Ratté, Stacey, et al., 2010; Légaré, Turcotte, Stacey, et al., 2012).

Reid & Fitch (2011) purported that “it is critical that parents have opportunities to receive information and training on what constitutes evidence-based treatment” (p. 509). However, both the literature and previous studies conducted for this thesis demonstrate that in practice this seldom happens. Accommodating the health literacy levels of individuals seeking interventions for themselves or their children (Baker, 2006; Levasseur & Carrier, 2011; Rootman & Ronson, 2005) can facilitate shared decision making and clients taking a more active role in their health management and that of their family

members (Coulter, 2007; Epstein, 2004; Ishikawa, 2010; Ni Riordain, 2009; Pleasant, 2008). Given that practitioners are frequently unable to provide education through training due to time pressures, there is a need for an educational resource for parents that can be accessed in advance or following consultations with their practitioners. In so doing, the aim is to help them learn more about the range of interventions that may be beneficial for their child with ASD and to assist them to make appropriate decisions in collaboration with their health practitioner for their child and family. The resource (the Autism Early Intervention Decision Aid) designed as part of Study 4 aimed to meet this need.

The primary aim of Study 5 (Chapter 6) in this thesis is to conduct a preliminary analysis of the decision aid for parents of children with ASD. This chapter begins with an overview of the decision aid that was developed, and why the format was chosen. Justification is provided for major elements of the decision aid.

5.1 Selecting the Best Platform to Present the Information

Chapter 4 outlined the results of Study 3 which was undertaken to determine how parents prefer to receive information about autism interventions, what sources of information they prefer, and the strategies they use in order to search for information. That study (Study 3), along with a number of others (Carlson, 2014; Chiarella, 2009; Coulter & Ellins, 2007; Sabo & Lorenzen, 2008) found that parents increasingly prefer to use the Internet to find information about ASD interventions. Many parents found that the Internet was accessible at all times, and provided them with an opportunity to explore web content at their leisure. It also provided the opportunity to obtain more up to date information than is available in print. Printed materials can become quickly out-dated (Mulligan et al., 2010), while websites can be updated regularly ensuring currency, provided website authors take the time to do so.

In her review of the literature, McMullan (2005) concluded that there were two main reasons as to why people turned to the Internet for health information.

These included; (1) individuals were not satisfied with the information presented to them by their health care professionals, and (2) to be reassured that they have all the information available to them (McMullan, 2005). As mentioned in Chapter 1, an increasing number of people in Australia have Internet access. In 2009, around 72% of Australian homes were able to access the Internet (Australian Bureau of Statistics (ABS), 2009). By the time this study was completed, this number had increased to 83% (Australian Bureau of Statistics (ABS) 2014). This number is expected to increase yet again with the anticipated introduction of the National Broadband Network (NBN) across the country, with one third of Australia's homes and businesses scheduled to be connected by the end of 2015 (Australian Government Department of Broadband, 2012). For these reasons, it was decided that a website would be the best format for information delivery.

An Internet based resource, specially a decision aid, was chosen to best meet the information preferences of the target audience, however it was also decided that the content must also be accessible in written format if required (as parents in the previous study (Study 3) indicated a preference for multiple formats if at all possible. Hence, the final product website included buttons on each page that allow for the page contents to be printed as a PDF.

5.2 Decision Aids

Decision aids are typically documents that have been developed to help individuals make decisions about their healthcare (for example, try medication or participate in a structured exercise program) (Epstein et al., 2004; O'Connor, 2010; O'Connor et al., 2009; Thistlethwaite, 2006; Volk et al., 2013). The content can be presented in various formats (for example, brochure/handout, website or app). Decision aids should encourage individuals to discuss their intervention choices with their healthcare practitioner, and help them to clarify any unknown terminology or confusing concepts. Paired with discussion with a health practitioner, decision aids can improve an individual's understanding of their health condition, knowledge about their intervention options, and also improve agreement between patient

preferences and intervention decisions made (Coulter & Ellins, 2007), which is a desirable outcome for this research project. Another benefit of using decision aids is that they are a cost effective means of communicating complex information (Coulter & Ellins, 2007).

The format of a decision aid was chosen for this study, as it is an appropriate way of conveying information about intervention options, with a specific focus on facilitating the decision making process (Hoffmann, Legare, Simmons et al., 2014; Stacey, Bennett, Barry, Col, Eden, Holmes-Rovner et al. 2011). A Cochrane systematic review of patient decision aids found that they improve individuals' knowledge of their options and potential outcomes, help them to better understand the probability of outcomes, and reduce decisional conflict (Stacey et al., 2014). Many studies across a number of health conditions have demonstrated the effectiveness of decision aids in helping patients to make decisions about treatment options (Coulter & Ellins, 2007; Elwyn, 2006; O'Connor, 2009; Thistlethwaite, 2006). No studies however, have been conducted to determine the effectiveness of ASD-specific decision aids. See Section 5.2.2 for more information on the evaluation of autism related decision aids.

Coulter et al. (2013) recommended key features that need to be incorporated into decision aids during the development process, which were taken into consideration in the design of the Autism Early Intervention Decision Aid developed for this study. These included; “scoping and design; development of a prototype; ‘alpha’ testing with patients and clinicians in an iterative process; ‘beta’ testing in ‘real life’ conditions (field tests); and production of a final version for use and/or further evaluation” (Coulter et al. 2013).

5.2.1 The International Patient Decision Aid Patient Standards (IPDAS). Decision aid criteria have been refined over the years by the International Patient Decision Aid Patient Standards (IPDAS). The IPDAS Collaboration established in 2003, was comprised of an international group of researchers, practitioners and stakeholders. The purpose of the collaboration

was to establish a framework of criteria for patient decision aids that intends to enhance their quality and effectiveness. The set of criteria was developed to improve Patient Decision Aid content, development, implementation, and evaluation. Over 500 decision aids have been evaluated by the Collaboration and these are listed in a database on the IPDAS website (www.iPtDAs.ohri.ca). Figure 5-4 depicts the IPDAS guidelines and how they apply specifically to the decision aid developed in this thesis.

The IPDAS guidelines specify that certain information must be included in the patient decision aid in order to meet the criteria of being a 'good quality' decision aid (Elwyn, et al., 2013). These criteria include ensuring that all treatment options are presented, the pros and cons of the options are made available, and the likelihood that these treatment options are going to be effective is presented (Elwyn et al., 2013; O'Connor et al., 2009). The information must be presented in a balanced manner to mitigate the risk of bias (Abhyankar, Volk, Blumenthal-Barby, Bravo, Buchholz, Ozanne, etc., 2013), and any conflict of interest should be disclosed (Barry, Chan, Moulton, Sah, Simmons, & Braddock, 2013).

5.2.2 Evaluation of autism related decision aids. Prior to the development of the Autism Early Intervention Decision Aid for this study, two other decision aids were identified that aimed to help parents make autism intervention decisions. These included an electronic, printable autism medication decision aid (Autism Treatment Network, 2011); and an electronic brochure (available for download) developed by the US Agency for Healthcare Research and Quality (AHRQ, 2011) that provides an overview of a number of different interventions, with prompts for things to consider. These decision aids can be accessed via the Ottawa Hospital Research Institute's Patient Decision Aids database (decisionaid.ohri.ca) and have been independently rated according to how closely they adhere to the International Patient Decision Aid Standards (Elwyn et al, 2006). No ASD decision aids have been rigorously evaluated, and to date, there has been no research on these existing decision aids, any evaluation of their utility or parents'

perspectives about them. Thus, the development of the Autism Early Intervention Decision Aid and subsequent randomised controlled trial (Study 5) conducted as part of this PhD project (See Chapter 6) was considered a valuable contribution to this field of research.

Other resources have been developed to assist with the decision making process. Thompson (2011) created the Autism Intervention Responsiveness Scale (AIRSTM) to assist parents and carers to decide which early interventions are best suited to their child, with consideration of the child's particular characteristics. Thompson (2011) suggested that once the tool is administered, the scores can be used to determine whether or not the child would benefit from one of four early intervention approaches. These include Discrete Trial Intervention (DTI) alone, Beginning with DTI and slow transition to some Incidental Interventions, Beginning with DTI followed by transition to mostly Incidental Interventions, and Incidental Teaching/ Therapy alone. While this tool features several aspects of a good decision making tool, the range of intervention options on offer is limited and relates primarily to behavioural interventions, and is therefore not as comprehensive as other decision support tools.

5.3 Selection of Content and Format for the Autism Early Intervention Decision Aid

Throughout the development of the Autism Early Intervention Decision Aid, parents of children with ASD were consulted. A focus group was conducted in July 2012 with a group of five parents, previously involved in earlier stages of the research project. The aim of this focus group was to obtain feedback on an early draft of the decision aid content and to discuss information that might be either included/ excluded from the website. A copy of the presentation developed for this group can be found in the Appendix I.

The parents were provided with a brief update on progress with the project since they were last interviewed. The participants were each given a printed copy of the presentation slides and a sheet of paper on which to record their

notes and comments. They were provided with information about decision aids and their intended purpose. They agreed that the decision aid format was appealing. The parents were provided with a list of questions that may be included in the decision aid for consideration. At this stage of the project, the questions were intended to be a downloadable or printable document that could be taken to and discussed with a health professional or early intervention practitioner. Later on as a result of parent feedback, and the knowledge that parents prefer more prescriptive information (Valentine et al., 2010), the decision was made to develop an interactive questionnaire as a component of the decision aid (detailed in paragraphs to follow), that when answered, would provide parents with a list of 'best fit' intervention options based on their responses. When the focus group parents were interviewed however, it was unknown what resources would be available to further develop the website, and therefore a list of questions that could be printed was thought to be the most likely format at that time. The evolution of the website will be discussed later in this chapter.

The order of the questions as they appeared in the initial presentation (Appendix I) were reported by the group to be leading and illogical, as they failed to organise characteristics of autism into "like groups". Some members of the group suggested that the questions be grouped by the child's area of function or skill, such as fine motor skills or self care, and give consideration to the child's severity of autism symptoms. As it is important to consider characteristics of the child for whom the intervention is being selected (Thompson, 2011) the suggestions of the group were applicable. The parents felt the questions provided in the first iteration were difficult to read and interpret, and one participant suggested that the questions be rewritten to accommodate those with a much lower reading level. Decision aid readability is further discussed in the next section.

5.4 Decision Aid Readability

Information resources should take into consideration individuals with lower reading levels (Ishikawa & Kiuchi, 2010). Readability (Chiarella, 2009) as well

as the ability to tailor information to each families' specific needs (Kertoy, 2011) are important considerations when developing educational resources. The readability of the decision aid was a very important factor, as individuals with low literacy levels may have difficulty understanding the content and will therefore not have the information they need in order to make informed decisions.

The Autism Early Intervention Decision Aid content was assessed for readability using a web-based version of the SMOG, a widely used instrument for assessing readability of health information developed by McLaughlin (1969). After determining that the content was above the desired reading level (should be below 7th grade), a sample of content was chosen at random before and after the content was revised and edited by the supervisory team and a number of independent reviewers. Despite reworking the content a number of times, and seeking the assistance of an independent assistant and a copywriter (home page only), we were unable to reduce the required reading level to below 8th grade. This was attributed to the necessary inclusion of large, multisyllabic and somewhat difficult to read words, such as 'intervention', 'sensory processing' and 'social-emotional' that describe, and are specific to autism characteristics and interventions.

The use of diagrams and images were included and aimed to support the text and provide visitors to the website with other cues to help them understand and respond to the content. Links to videos that further explained each of the interventions were also included. The use of videos can help users with low health literacy levels to better understand concepts (McCaffery, Holmes-Rovner, Smith, Rovner, Nutbeam, Clayman, et. al., 2013). The inclusion of video links was also suggested by parents who participated in the 2012 focus group. Video links were chosen based on the authors opinion of how well the video explained the relevant intervention strategies and how well the video content aligned with the website content.

5.5 Development of the Interactive Questionnaire Component

As aforementioned, the Autism Early Intervention Decision Aid includes an interactive questionnaire component. These questions were developed in consultation with the parent focus group, the thesis advisory team, and a number of experts in the field.

By October 2012, the decision aid questions and format had been revised and these were (1) sent to the abovementioned parent group members via email for feedback, and (2) discussed with a number of experts, Professors Margot Prior and Jacqui Roberts on separate occasions to obtain further feedback. Professors Prior and Roberts are the authors of the first Australian Guidelines on best practice and Early Intervention (EI) (Prior & Roberts, 2006, 2012) and were therefore considered to have an excellent understanding of the needs of the population for whom this resource was being developed.

The questions were again refined, and with further input from Professors Prior, Roberts and doctoral supervisor Professor Sylvia Rodger, a scoring matrix was developed. This involved a grade, or weight, being attributed to each of the interventions according to how closely the intervention addressed the autism characteristics listed in each of the questions. Once the scoring matrix was finalised and agreed upon by all parties, the web developer who had been engaged to develop the Autism Early Intervention Decision Aid website was asked to write the algorithm for the interactive questionnaire. The algorithm was developed with the added functionality of enabling any administrator of the website to adjust the list of interventions and/ or how they are weighted if required in the future (for example, in the event of the emergence of new research evidence, or changes to the interventions availability in Australia). However, throughout the course of the randomised controlled trial, these settings were to remain unchanged. The information provided to Professors Prior and Roberts in order to obtain their opinion on how the included interventions should be weighted appears in Appendix J.

The hard copy (printable) version of the decision aid is provided in Appendix L, and shows how each of the possible responses to the questions are scored.

When the interactive questionnaire is submitted online, those interventions that best address the characteristics of autism identified by the respondent as being most important are listed in the output. Website users are also given the option to print or email the results for their own use. The questions that eventually appeared on the Autism Early Intervention Decision Aid website are listed in Figure 5-1.

1. How important is it that your child has good self-esteem (appropriate social-emotional skill development)?
2. How important is it that your child receives assistance developing relationships?
3. How important is it that your child develops better social skills? e.g. turn taking, sharing, active listening
4. Is it important that your child develop better communication skills? e.g. asking for things, answering yes/ no etc.
5. How important is it that your child receives assistance with learning and to develop academic skills?
6. How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? e.g. self care (toileting, dressing), play or recreational activities.
7. How important is it that your child better understand his/ her emotions? e.g. anger, frustration
8. How important is it that your child improves his/ her fine motor skills? e.g. holding a pencil, using cutlery etc.
9. How important is it that your child better manages his/ her sensory processing? e.g. tolerance to noise/ light etc.

Figure 5-1: Interactive questionnaire questions

The questions finally selected were based on the themes revealed from analysis of the parent interviews (See Chapter 4), and were designed to prompt parents to consider specific characteristics of ASD and skill areas or behaviours that they would like to be improved by intervention. Additional questions were originally included in the draft, but were removed after consulting with Professors Prior and Roberts. These additional questions focused on difficult behaviours and also the use of medication to treat symptoms. The question regarding the management of difficult behaviours was removed as it was thought that difficult behaviours were not a 'characteristic' of autism to be addressed, but more a result of characteristics of autism not being well managed. The question asking whether parents would consider using medication was removed for a number of reasons. Firstly, little evidence exists to support the use of biomedical interventions such as medication to address core characteristics of ASD, and secondly, a decision aid for medication use with autism is already available (Autism Treatment Network, 2011). A link to this medication decision aid is included on the Autism Early Intervention Decision Aid website for parents to access if interested.

One of the challenges faced by parents previously described by Valentine et al. (2010) was the fact that parents have a range of interventions to choose from, but not all of those preferable to the family will be readily available, either due to cost, location or other factors. Parents are often required to evaluate several additional options when they discover they cannot access their first option (Valentine et al., 2010). To help overcome this challenge, an additional feature of the Autism Early Intervention Decision Aid was added. This was the ability to further filter the interactive questionnaire results by the approximate cost of the interventions, time required each week to participate, and the location (home, clinic or either) of intervention. The information for these filters was obtained from www.raisingchildren.net (a credible source of autism information relevant to the Australian context (Grant et al., 2014)) and websites specific to each intervention option available in Australia. These filters were chosen based on feedback obtained from parents (see Study 3,

Chapter 4), and other studies (Valentine et al., 2010), that indicated that parents often choose interventions based on factors related to cost, location, time required, and not based on what they understand about autism intervention evidence.

5.6 The Inclusion of Shared Decision Making Principles

Parents may not always be aware of the risks and benefits of the various options available. This is compounded by the reluctance of some people to ask many questions during consultations with health professionals (Gigerenzer et al., 2008). To encourage discussion, a list of questions to ask healthcare providers was also included on the Autism Early Intervention Decision Aid website. These questions were taken directly from The Early Intervention for Children with Autism Spectrum Disorders: “Guidelines for Good Practice”(Roberts & Prior, 2012), and are designed to encourage parents to ask important questions of their treating health and educational professionals at a crucial stage in the decision making process. These questions are outlined in Figure 5-2.

1. What are the specific aims of the program?
2. Are there any medical or physical risks?
3. What assessments of individual children are carried out prior to the intervention?
4. What is the evidence base for this intervention?
5. What evaluation methods have been used to assess the outcome of intervention?
6. Do the proponents of the treatment program have a financial stake in its adoption? (i.e. do the people who are promoting the type of therapy make money out of the program?)
7. What is known about the long-term effects of this treatment?
8. How much does it cost?
9. How much time will be involved?

Figure 5-2: Questions parents should ask their healthcare providers following an autism diagnosis for their child

(Roberts & Prior, 2012, <http://www.casg.org.au/casg/documents/casg-info-hotline/G/Guidelines%20for%20Good%20Practice%202012.pdf>, accessed 1/6/15).

5.7 Selection of Interventions for Inclusion in Decision Aid

The decision aid focused on early intervention therapies, to best reflect the population most likely to search for autism treatments. These are parents of children under the age of seven (7) years who have been recently diagnosed with ASD (Department of Families Housing Community Services and Indigenous Affairs (FaHCSIA), 2010)). Children are usually diagnosed with autism around three (3) years of age although, as mentioned in Chapter 1, greater awareness of ASD, and improvement in diagnostic procedures has led to an increase in diagnoses of children as young as 18 months (Lai et al., 2014; Valentine et al., 2010).

There are numerous autism interventions available, as revealed from searching the literature and a study of autism health information sites (Grant, Rodger, & Hoffmann, 2013; Green et al., 2006; Reichow et al., 2011; Reichow, Naples, Steinhoff, Halpern, & Volkmar, 2012). The interventions selected for inclusion in this decision aid were those that; (a) were available in Australia, (b) had been tested in a clinical setting for effectiveness, and (c) had information on a website that could be linked to the decision aid, so that parents could obtain further information if desired. The full list of included interventions can be found in Figure 5-3 below. These interventions and the category under which they are each assigned were taken from the Early Intervention for Children with Autism Spectrum Disorders: “Guidelines for Good Practice” (Prior & Roberts, 2012) that was published at the time this decision aid was being developed.

<p>Family-based including parent training</p> <p>Hanen 'More Than Words'</p> <p>Pre-schoolers with Autism – manualised parent training program</p> <p>Triple P – Stepping Stones adaptation</p>	<p>Service based treatments specific to autism</p> <p>Sensory Considerations, Environmental Management, Routines and planned change, Visual supports, Autism friendly communication, Motivation (SERVAM)</p>
<p>Therapy-based Interventions</p> <p>Speech Generating Devices (SGD) and other Augmentative & Alternative Communication (AAC)</p> <p>Signing and Makaton</p> <p>Picture Exchange Communication System (PECS)</p>	<p>Comprehensive programs, combined approaches and developmental approaches</p> <p>Early Intensive Behavioural Intervention (EIBI)</p> <p>Early Start Denver Model (ESDM)</p> <p>Learning Experiences and Alternate Program for Preschoolers and their Parents (LEAP)</p>
<p>Single element components addressing one aspect of autism</p> <p>Play and Learning Social Skills Program (PALS)</p> <p>Toilet Time</p> <p>Music Therapy</p> <p>Alert Program for Self Regulation</p> <p>Social Stories</p>	<p>Treatment and Education of Autistic and Communication Related Handicapped Children (TEACCH)</p> <p>Social Communication, emotional regulation and transactional support (SCERTS)</p> <p>Developmental, Individual Difference, Relationship-based (DIR)/ Floortime Approach</p> <p>Relationships Developmental Intervention (RDI)</p>
<p>Therapies not specific to autism, but which may benefit children with autism</p> <p>Circles of Support</p>	<p>The P.L.A.Y project – Play and Language for Autistic youngsters</p>

Figure 5-3: Interventions included in the decision aid

These interventions focus on a range of developmental areas impacted by ASD that may include emotional self-regulation, cognitive function, communication skills and self-care. Some purport to focus on many different areas, such as TEACCH (Schopler, & Reichler, 1971), while others will only address one very specific area of functioning such as self care toileting e.g. Toilet Time. The evidence for early intervention methods based on the principles of Applied Behaviour Analysis (ABA) are well known (National Autism Center, 2009; Thompson, 2011a), however evidence also exists for the other interventions listed above. Some of the evidence is only emerging, however sufficient information exists to assist with the decision making process.

The main sources of information for intervention information were the Guidelines for Good Practice (Prior & Roberts, 2012) and the Review of Early Intervention Therapies for Autism Spectrum Disorders undertaken by representatives of the Australian Society for Autism Research (ASfAR) (Prior, Roberts, Rodger, & Williams, 2011). It is understood, via correspondence with Ms Jennifer Reynolds from the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), that the autism interventions funded under the early intervention scheme, are based on the original guidelines developed by Prior and Roberts (Prior & Roberts, 2006) as well as feedback obtained from providers around the time the funding was introduced. All interventions from these documents were selected for inclusion in the decision aid, except for Preschool Autism Communication Trial (PACT). PACT was currently not offered by any provider in Australia at the time of development of the aid. Building Blocks, Developmental Social Pragmatic model (DSP), Playlinks, Sleepwise and Long Day Care were also omitted as they were not widely available or were only exclusively available at specific centres.

One of the challenges of presenting the decision aid intervention information was ensuring information was balanced. Abhyankar, Volk, Blumenthal-Barby, Bravo, Buchholz, Ozanne et al., (2013) conducted a review of 10 articles that

reported to evaluate the balance of different decision aids. These articles each measured balance using a five-point Likert-type scale, which were completed from the perspective of the patient or user. Abhyanker et al (2013) reported that 70 to 96 percent of respondents within these studies regarded information presented in a side-by-side format as being balanced. Because of the large number of interventions being included in this aid, presenting the information in a side-by-side display was not possible. In lieu of this option, the intervention information was presented in the same way on each webpage (for example, same table format for presenting cost, location and time information, same sub-headings for listing evidence and other facts), so that direct comparisons could be made by the user. Personal accounts and anecdotes, while a feature of some decision aids were not included in the Autism Early Intervention Decision Aid. No evidence exists to indicate that the use or effectiveness of same enhances the utility of the aid (Bekker, Winterbottom, Butow, 2013). To adhere to the IPDAS guidelines that cover disclosure (Barry, Chan, Moulton et. Al., 2013), funding and sponsorship information was included in the decision aid content.

5.8 Challenges of Providing Education to Parents of Children with ASD

Valentine et al. (2010) based on their research, advised that the best way of providing information to parents is in-person during professional consultations. Practitioners are a trusted information source (Grant et al. 2015), but are challenged to keep up to date with the research evidence in order to adhere to EBP principles (Glasziou & Haynes, 2005). Another challenge of information provision is that ASD is a heterogeneous condition and characteristics are experienced by individuals in vastly different ways at different stages of their lives. This can make it difficult for practitioners to provide relevant information for all possible cases (Cardon & Azuma, 2011; Mesibov & Shea, 2010).

The content of the Autism Early Intervention Decision Aid website was given a great deal of consideration. There is already a comprehensive collection of information on the Internet about autism, however many of the sources were considered to be untrustworthy and possibly misleading (Grant et al., 2014;

Reichow et al., 2011). Some websites can have hidden agendas, such as attempting to sell particular products or methods. Others may have not been kept up to date and therefore have information that is no longer relevant or accurate. By disclosing date of publication and the sources used to generate content for the website on each page that content appears, the risk of providing information that is out of date or incorrect is mitigated. The website copy in its entirety can be found in Appendix M. Please note that the website copy was drafted and published prior to the release of the DSM-5. The website will be updated on completion of this PhD.

One of the challenges of developing a decision aid for parents of children with autism is that there are numerous interventions available (Gagliardi & Jadad, 2002; Grant et al., 2014; Green et al., 2006; Reichow et al., 2011). In Australia, there are at least 20 different types of interventions that are available for children aged 0 – 7 years, and have at least some supporting research evidence (Prior & Roberts, 2012), and should therefore be included in an autism decision aid. Presenting all of the required information for each of the interventions was extremely challenging. Information on the likely success of treatment was also difficult to include, as the success of the intervention is dependent on many different factors, for example, the combination and severity of autistic characteristics, family situation, the nature and frequency of service delivery and service provider (for example, home or centre based) (Thompson, 2011b).

One of the challenges parents face when choosing a therapist or service provider, is determining the qualifications and experience of the therapist, and their capability in providing the agreed upon intervention. For example, HCWA approved providers must be an occupational therapist, speech and language pathologist or psychologist with more than two years experience working with children on the autism spectrum. Providers must demonstrate that they have sufficient training and experience to deliver the approved services, however it is not known how many health professionals actually deliver the interventions in their 'pure' or intended form. An occupational therapist for example, may use

discrete trial training strategies, sensory based strategies (such a fidget toys, or weighted products, along with RDI techniques, because they consider that is what the child would benefit from. A speech and language pathologist may use a combination of techniques during therapy sessions, but also provide Hanen More Than Words training to the parents as an additional strategy. Parents may search the Internet or seek information from other sources on specific interventions, based on the recommendations of the Autism Early Intervention Decision Aid or other recommendations, however few therapists advertise their services specific to these intervention types. This is confusing for parents. The onus lies with the providers of these services to ensure that parents understand what training and experience they have to deliver specific interventions. In the event that specific interventions are not delivered, and instead an eclectic or combination of strategies is used, the evidence supporting these strategies should be discussed with the parents so that an informed decision can be made.

5.9 Evaluation of the Autism Early Intervention Decision Aid by the Ottawa Hospital Research Institute (OHRI)

The Autism Early Intervention Decision Aid developed for this project was submitted to OHRI for inclusion in the OHRI database in September 2013. The independent evaluation of the Autism Early Intervention Decision Aid developed for the RCT is shown in Figure 5-4.

Title	Autism Early Intervention Decision Aid.						
Health condition	Autism						
Type of decision aid	Treatment						
Options included	21 different interventions.						
Audience	Parents of children under 7 years old newly diagnosed with an Autism Spectrum Disorder.						
Developer	Nicole Grant						
Where was it developed?	nicole@gatewaytherapies.com.au The University of Queensland Australia						
Year of last update or review	2013						
Format	Web, paper						
Language	English						
How to obtain	Web-based, password protected decision aid. The password protection will be removed on completion of the RCT. Email nicole@gatewaytherapies.com.au to request access. Available here.						
<p>The assessment (based on IPDAS) of this decision aid indicates that it meets:</p> <table border="0"> <tr> <td></td> <td>9 out of 11 of the content criteria</td> </tr> <tr> <td></td> <td>8 out of 9 of the development process criteria</td> </tr> <tr> <td></td> <td>0 out of 2 of the effectiveness criteria</td> </tr> </table>			9 out of 11 of the content criteria		8 out of 9 of the development process criteria		0 out of 2 of the effectiveness criteria
	9 out of 11 of the content criteria						
	8 out of 9 of the development process criteria						
	0 out of 2 of the effectiveness criteria						

Checklist

Content	Answer
1. The decision aid describes the condition (health or other) related to the decision.	Yes
2. The decision aid describes the decision that needs to be considered (the index decision).	Yes
3. The decision aid lists the options (health care or other).	Yes
4. The decision aid describes what happens in the natural course of the condition (health or other) if no action is taken.	Yes
5. The decision aid has information about the procedures involved (e.g. what is done before, during, and after the health care option).	Yes
6. The decision aid has information about the positive features of the options (e.g. benefits, advantages).	Yes

7. The decision aid has information about negative features of the options (e.g. harms, side effects, disadvantages).	Yes
8. The information about outcomes of options (positive and negative) includes the chances they may happen.	No
9. The decision aid has information about what the test is designed to measure.	NA
10. The decision aid describes possible next steps based on the test results.	NA
11. The decision aid has information about the chances of disease being found with and without screening.	NA
12. The decision aid has information about detection and treatment of disease that would never have caused problems if screening had not been done.	NA
13. The decision aid presents probabilities using event rates in a defined group of people for a specified time.	NA
14. The decision aid compares probabilities (e.g. chance of a disease, benefit, harm, or side effect) of options using the same denominator.	NA
15. The decision aid compares probabilities of options over the same period of time.	NA
16. The decision aid uses the same scales in diagrams comparing options.	NA
17. The decision aid asks people to think about which positive and negative features of the options matter most to them.	Yes
18. The decision aid makes it possible to compare the positive and negative features of the available options.	No
19. The decision aid shows the negative and positive features of the options with equal detail.	Yes
Development Process	Answer
20. Users (people who previously faced the decision) were asked what they need to prepare them to discuss a specific decision.	Yes
21. The decision aid was reviewed by people who previously faced the decision who were not involved in its development and field testing.	Yes
22. People who were facing the decision field tested the decision aid.	Yes
23. Field testing showed that the decision aid was acceptable to users (the general public & practitioners).	Yes
24. Field testing showed that people who were undecided felt that the information was presented in a balanced way.	Yes
25. The decision aid provides references to scientific evidence used.	Yes
26. The decision aid reports the date when it was last updated.	Yes
27. The decision aid reports whether authors of the decision aid or their affiliations stand to gain or lose by choices people make after using the decision aid.	Yes
28. The decision aid (or available technical document) reports readability levels.	No
Effectiveness	Answer

29. There is evidence that the decision aid (or one based on the same template) helps people know about the available options and their features.	Unknown
30. There is evidence that the decision aid (or one based on the same template) improves the match between the features that matter most to the informed person and the option that is chosen.	Unknown

*The outcome of the Randomised Control Trial (Study 5) outlined in Chapter 6 will be submitted to OHRI for consideration, so that the Effectiveness items on the Checklist above can be updated.

Figure 5-4: Screenshots of OHRI review of the autism early intervention decision aid (<http://decisionaid.ohri.ca/Azsumm.php?ID=1579>)*

5.10 Conclusion

Shared decision making requires access to good quality information, as well as the opportunity to discuss intervention decisions with a knowledgeable practitioner. It is imperative that the practitioner has a good knowledge of the intervention options available, and is able to discuss the risks and benefits of each. It is commonly assumed that health practitioners have a better understanding of the evidence than their patients, but this is not often the case (Gigerenzer et al., 2008). As Gigerenzer et al. (2008) stated, if neither the patients (or their parents and carers) or practitioner have knowledge or understanding of the options and their evidence, it is impossible for shared decision making to take place. The Autism Early Intervention Decision Aid should be used by both parents and practitioners involved in the child's care to ensure decisions are made based on a shared understanding of interventions being considered.

It is important to note that intervention outcomes can vary between children with ASD for a number of reasons, including intensity (dose) and mode of delivery of intervention (individual/ group sessions, home/ centre-based therapy sessions), as well as individual child characteristics such as age, cognitive/intellectual ability, social interest and responsiveness, joint attention skills, social referencing skills, language ability, motor and verbal imitation skills, presence of anxiety/ fearfulness, engagement in stereotypic and ritualistic behaviour, and potential presence of comorbid attention-deficit/

hyperactivity disorder (Thompson, 2011a). While the interactive questions within the Autism Early Intervention Decision Aid attempt to help parents narrow down the interventions based on autism characteristics, tailoring for individual differences could not be incorporated into the decision aid.

5.10.1 Acknowledgements. There were many people involved in the development of the Autism Early Intervention Decision Aid website. These are listed onsite according to the nature of their contribution.

First and foremost, we thank those parents who were involved in the surveys, focus groups and interviews undertaken in the lead up to the development of this website. Their generosity and sharing of their time, stories and ideas has been integral to the development of this site. If anyone finds this website at all helpful, it will be because of them.

For their expertise and assistance with content and question development: Professor Sylvia Rodger, The University of Queensland and Cooperative Research Centre for Living with Autism (Autism CRC), Professor Tammy Hoffmann, The University of Queensland and the Centre for Research in Evidence-Based Practice, Bond University, Professor Jacqueline Roberts, Griffith University, Emeritus Professor Margot Prior, The University of Melbourne.

For their assistance with concept development, information gathering, technical expertise and data entry: Mr Justin Grant, Mrs Donna Joosten, Ms Kristena Lowry, and Mr Dominic Turner-Jones.

For their feedback regarding the content and function of the site during the pre-trial period: Mrs Ngaire Stirling, Ms Helen Wilkins, Dr Fiona Jones, and Dr Ann Kennedy-Behr.

For her assistance with content editing: Dana Flannery Hayes.

Website developed by IT2K/Website Blue. Additional website support provided by LBM Designs.

5.10.2 Funding Declaration. Any available funds provided as part of the PhD budget were exhausted prior to commencing this stage of the project. A crowdsourcing website (Pozible) was used to raise most of the funds required to pay for the technical development of the Autism Early Intervention Decision Aid website (www.autismdecisionaid.com.au). Major sponsor Springfree Trampoline contributed significantly to the project, along with a number of independent businesses and individuals who generously donated funds. Without their contribution, this website would not have come to fruition.

The hosting and other administrative costs continue to be supported by a number of sponsors including Australian HomeCare, Springfree Trampoline and Gateway Therapies. The PhD candidate and Autism Early Intervention Decision Aid site owner/ administrator is the owner/ manager of Gateway Therapies, a private paediatric therapy practice in Brisbane, Australia.

Chapter 6 - Study 5: Pilot Randomised Controlled Trial of a Web-based, Interactive Early Intervention Patient Decision Aid for Parents of Children Newly Diagnosed with Autism*

The final stage of the project addressed the research question: does a purpose-designed patient decision aid for parents reduce their decisional conflict and increase their self-efficacy for intervention decision making?

6.1 Introduction

Parents of children who are newly diagnosed with Autism Spectrum Disorder (ASD) frequently report being overwhelmed and confused by the information they receive following the diagnosis (Grant, Rodger, & Hoffmann, 2015; Valentine, Rajkovic, Dinning, & Thompson, 2010). Many turn to the Internet for advice, largely because it contains a wealth of information that is readily available and accessible at any time (Carlson, Carter, & Stephenson, 2013; Chiarella, 2009; Coulter & Ellins, 2007; Sabo & Lorenzen, 2008). While there are some websites that contain useful and accurate information, many of the websites that are reached by parents when searching for autism intervention information contain information that is out-of-date, inaccurate or not relevant to their individual circumstances (Grant, Rodger, & Hoffmann, 2014; Reichow et al., 2011).

Parents of children with autism often report feeling conflicted and confused about intervention decisions for their child (Grant et al., 2015; Valentine et al., 2010). Decisional conflict can occur when an individual feels uninformed about their choices and is unclear about the risks and benefits of the options available. They can feel conflicted about their own beliefs and values in the

* This study has been submitted to *Focus on Autism and Other Developmental Disabilities* as: Grant, N., Rodger, S., & Hoffmann, T. (2016). A pilot randomised controlled trial of a web-based decision aid about early intervention options for parents of children newly diagnosed with Autism Spectrum Disorder, and this chapter contains the version of this study currently under review.

context of intervention decisions, and unsupported to make the decision to choose a particular course of action (O'Connor, 2010).

One way of reducing decisional conflict and improving confidence with decision making is by providing individuals with decision aids (O'Connor, Bennett, Stacey, Barry et al., 2009) which are evidence-based tools designed to support individuals during intervention decision making by presenting the options, and the pros and cons of each (Hoffmann, Legare, Simmons et al., 2014). The numerous intervention options that are available for children with ASD can make it difficult for parents to decide between the options, and knowing which is right for their child is challenging. Good communication between parents and their therapists about intervention options is crucial, and a decision aid can help to facilitate this process and ensure that there is agreement between all individuals involved in the child's care.

To the best of our knowledge, there have been no previous studies of using a decision aid to help parents of children with autism make informed decisions about early intervention options. This study was a pilot randomised controlled trial to evaluate the effectiveness of a web-based decision aid on reducing parents' decisional conflict and improving their confidence and self-efficacy in making autism intervention decisions for their child.

6.2 Participants and Methods

6.2.1 Design. The study was a parallel-group wait-list randomised controlled trial.

6.2.2 Participants. Participants were eligible to participate if they were: parents of a child who was ≤ 7 years old with an Autism Spectrum Disorder (ASD) who had been diagnosed by a relevant medical practitioner in the 12 months prior; receiving (or eligible to receive) Helping Children With Autism (HCWA) funding; and living in Australia. The HCWA funding package is

available for eligible Australian families who have a child diagnosed with an ASD by a Paediatrician or Child Psychiatrist before their sixth birthday.

After an expression of interest to participate in the trial was received, the Gilliam Autism Rating Scale - 2 (Gilliam, 2006) (Part 1 only) was administered by the trial coordinator by phone to ensure that the children met the diagnostic criteria for autism. No children were scored as being unlikely to meet the criteria for an ASD diagnosis.

6.2.3 Ethical approval. Ethical approval (Appendix A) was obtained from The University of Queensland Behavioural & Social Sciences Ethical Review Committee (Human research ethics approval number: 2011000783). Prospective trial registration occurred with the Australian New Zealand Clinical Trials Registry (CTRN12613000490774).

6.2.4 Recruitment and Randomisation. Recruitment occurred between August 2013 and January 2014 and convenience sampling was used (Carpenter and Suto, 2008; Patton, 1990). Various strategies were used to create awareness of the study and invite expressions of interest. This included: advertising in the newsletters of state-based autism associations in Australia; advertising via noticeboards and newsletters of other autism-specific agencies (Autism Behavioural Intervention Queensland, Autism Early Intervention Outcomes Unit Foundation (AEIOU), the Olga Tennison Autism Research Centre in Melbourne (OTARC)); and stories about the study in local newspapers and on the local radio (in Brisbane and other cities around Australia).

Facebook has been successfully used to recruit participants for other studies (Frisinger, 2011), therefore a project Facebook page (www.facebook.com/autismdecisionaid) was established and paid Facebook advertising was used to promote posts to an audience that met set criteria. These criteria included being an adult resident in an Australian city, with interests identified by Facebook as being related to Autism Spectrum

Disorders and Early Intervention. Parents who were searching for autism information online could also potentially discover the trial website (www.autismdecisionaid.com.au). Its home page was publically available (the rest of the site was password-protected) and listed contact details for the trial coordinator if they wished to find out more about the trial or express an interest in participating.

Following receipt of expression of interest, Participant Information Sheets (Appendix N) and Consent Forms (Appendix O) were provided by the first author (NG), either via email or a website link that contained these forms. Concealed allocation occurred as once each participant provided signed consent, their name was provided to an off-site researcher (TH) who randomised them using a computer-generated random numbers table. Details of each participant's group allocation were provided to an independent research assistant who advised participants of their allocation via email or telephone.

6.2.5 Administration of baseline and follow-up measures. The researcher who was blind to group allocation (NG) contacted participants to complete the baseline assessment via telephone where possible. Where a participant was unavailable by telephone, or reported to have limited time to complete a telephone interview (n=5), questionnaires were sent by email or mail, and a stamped, return addressed envelope was provided. The assessment consisted of a demographics questionnaire (Appendix S), which included the Rapid Estimate of Adult Literacy in Medicine (REALM) (a measure of the participant's reading ability (Murphy, Davis, Long, Jackson, & Decker, 1993), and the outcome measures (Appendix P).

Follow up interviews, approximately three to five months later, were conducted by the same researcher (NG) either by telephone, or where requested, by sending the questionnaires via email or post.

6.3 Intervention

When participants in the intervention group were notified of their group allocation, they were given the link and password to the password-protected web-based Autism Early Intervention Decision Aid (www.autismdecisionaid.com.au) and asked to view the website contents at their leisure over a minimum period of three months.

The development of the decision aid followed the criteria outlined in the 2010 International Patient Decision Aid Standards (Volk et al, 2013). The interventions included in the aid were selected from those listed on the website of the Australian Government (Department of Families Housing Community Services and Indigenous Affairs (FaHCSIA, 2010) which oversees the administration of the HCWA funding, and indicates which autism interventions are 'in scope', meaning they have good research evidence to support their use and are approved to be funded under the scheme. In addition to having evidence of their effectiveness, the selected interventions were considered to be available in Australia. The interventions considered 'In Scope' by FaHCSIA were based on the Review of Early Intervention Therapies for Autism Spectrum Disorders undertaken by representatives of the Australian Society for Autism Research (ASfAR) (Prior, Roberts, Rodger, & Williams, 2011) and are included in the Early Intervention for Children With Autism Spectrum Disorders: Guidelines for Good Practice (Roberts & Prior, 2012).

The website includes an interactive 8-item questionnaire (see Figure 6.1) that asks the user how important it is that an intervention improves various functional areas such as academic skills, self care skills, and other life skills typically affected by autism spectrum disorders.

When the questions are answered, the ten autism interventions that best fit the responses provided are listed (see Figure 6.2). These are selected from a list of 21 possible interventions that are featured on the website.

Questionnaire	Very important	Important	A little important	Not very important	Not at all important
How important is it that your child better understand and appropriately react to their own feelings and the feelings of others e.g anger, frustration? (Social-emotional development)	<input type="radio"/>				
How important is it that your child receive assistance developing relationships?	<input type="radio"/>				
How important is it that your child develop better social skills? E.g turn taking, sharing, active listening	<input type="radio"/>				
How important is it that your child develop better communication skills? E.g asking for things, answering yes/ no etc	<input type="radio"/>				
How important is it that your child receive assistance with learning and to develop academic skills?	<input type="radio"/>				
How important is it that your child receive assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g self care (toileting, dressing), play or recreational activities.	<input type="radio"/>				
How important is it that your child improve his/ her fine motor skills? E.g holding a pencil, using cutlery etc	<input type="radio"/>				
How important is it that your child better manage his/ her sensory processing e.g tolerance to noise/ light etc?	<input type="radio"/>				
					<input type="button" value="Submit"/>

Figure 6-1: Screenshot of questionnaire from the autism early intervention decision aid website

The website also includes other information about autism spectrum disorders, for example, how a diagnosis is made and where parents can obtain further information about the condition, and Australian intervention service providers. Throughout the development of the decision aid, parents of children with ASD, as well as experts within the field of autism research were consulted and piloted the aid. Feedback received helped to inform the content and format of the final website.

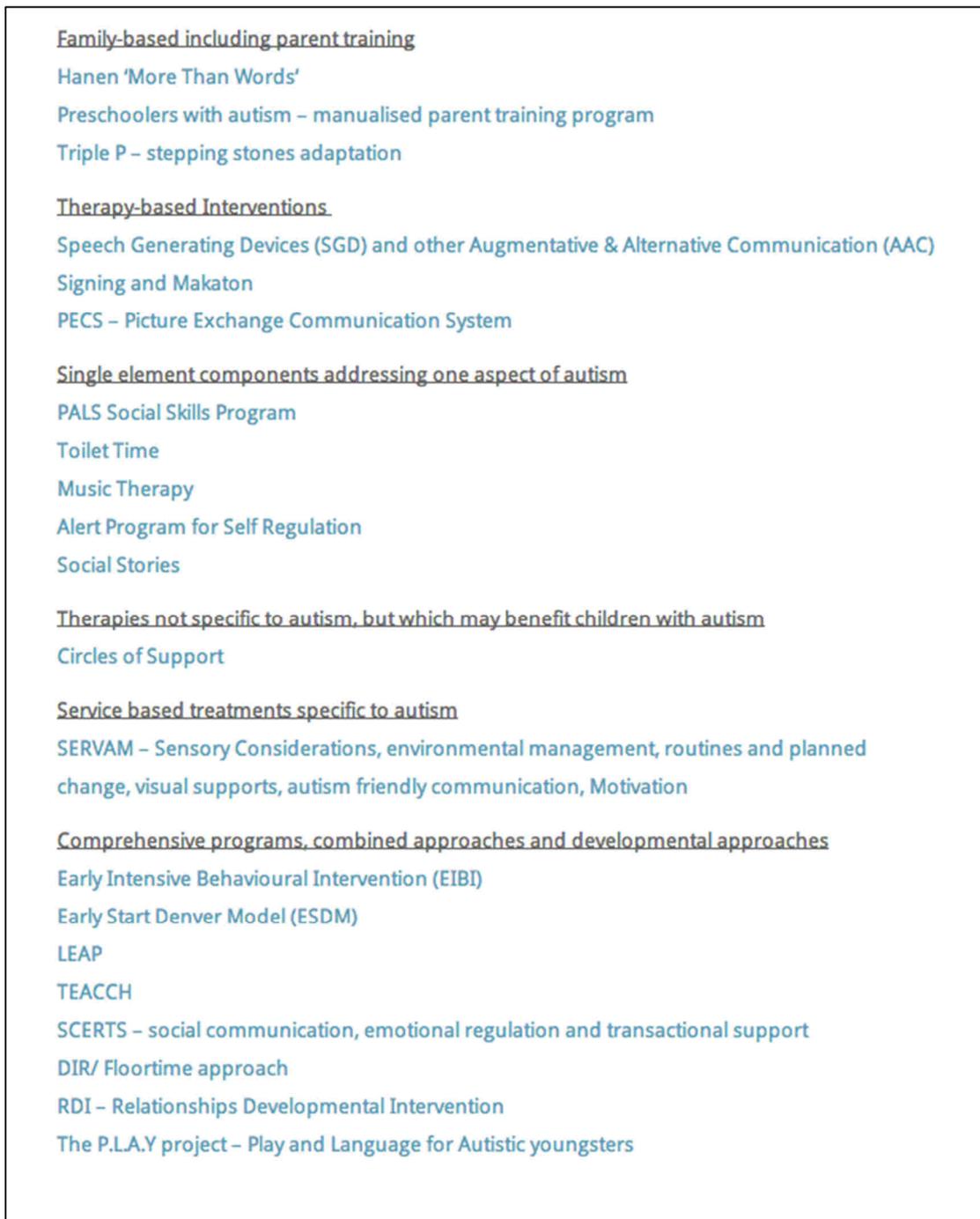


Figure 6-2: Screenshot of autism interventions listed on the autism early intervention decision aid website

6.4 Control condition

Participants were asked to continue as usual, namely access their usual sources of information and support over the next three months and advised that after the trial was completed, they would be provided with access details to the decision aid website, which would be made publicly available following trial completion.

6.5 Sample Size and Power Calculations

The required sample size could not be accurately calculated due to lack of intervention effects for this type of intervention in this population in the existing literature. A statistical software program (G Power) was used to determine that with an assumption of 80% power and 0.5 level of significance, a total sample size of 113 would have a medium effect size of 0.23. To account for anticipated rates of attrition, approximately six additional participants were required for each group, giving a total required sample size of 125.

6.6 Outcome Measures

The primary outcome was decisional conflict, measured using the 16-item Decisional Conflict Scale (DCS) (O'Connor, 2010) (Appendix Q), which determines participants' self-efficacy with decision making, factors affecting decision making, and satisfaction levels in relation to decisions made. For each item, participants were asked to indicate on a 5-point scale (0 = strongly agree, 4 = strongly disagree), how much they agreed with the statements about decision making specifically in relation to autism interventions. A total score for the DCS and scores for five subscales (Uncertainty, Informed, Values Clarity, Support, Effective Decision) were calculated. Scores for each subscale range from 0 to 100, with low scores indicating low decisional conflict.

Secondary outcomes were parental decision making self-efficacy and parental competence. As no existing measures of self-efficacy in making decisions about autism existed, self-efficacy was measured using a single question ("how confident do you feel making decisions about autism interventions for

your child”), answered using a 10-point Likert scale (1=not at all confident and 10 = extremely confident).

Parenting competence was measured using the Parenting Sense of Competency Scale (PSOC) (Gibaud-Wallston, 1978) (Appendix R). It is a self-report 16-item questionnaire, which addresses a range of factors including parents' perceived competence, problem-solving ability, parental frustration, anxiety and motivation. The PSOC has previously been used in studies of parents whose children have an autism diagnosis, particularly in the context of stress and parenting competency (Keen, Couzens, Muspratt, & Rodger, 2010). Parents are asked to consider each statement, and then indicate how much they agree or disagree with that statement on a 6-point Likert scale. Scores can be obtained for two PSOC subscales, Satisfaction and Efficacy, as well as an overall score for parents' sense of competence. The Satisfaction items (1, 6, 7, 10, 11, 13,15) are scored according to how much the respondent agrees with the statement (for example, Strongly Disagree = 1, Strongly Agree = 6). The Efficacy items (2, 3, 4, 5, 8, 9, 12, 16), and are reverse coded, meaning that the response “Strongly Disagree” would receive a score of six, and “Strongly Agree” would receive a one. An overall score of 16- 50 indicates low competence, 51-69 indicates moderate competency, and 70-96 indicates high parental competency.

6.7 Data Analysis

Analyses were performed using IBM SPSS Statistics Version 19.0. Data were analysed on an intention-to-treat (ITT) basis (Gupta, 2011), with the Last Observation Carried Forward method (Unnebrink & Windeler, 2001) used to deal with missing follow-up data. Between-group mean differences and 95% confidence intervals were calculated using Analysis of Covariance, with follow up scores adjusted for baseline scores. This method ensured that follow up scores were not affected by baseline differences or imbalance (Vickers, 2001). Within group mean differences and 95% confidence intervals were calculated using paired sample t-tests.

6.8 Results

During the recruitment phase, 125 individuals expressed interest in participating by contacting the lead researcher to obtain more information about the study. Of these, 40 declined to participate further and four did not meet inclusion criteria. Eighty-one individuals indicated that they met the inclusion criteria after reviewing the Participant Information Sheet, and were subsequently randomised. Figure 6-3 describes the flow of participants through the study.

Of the 81 participants randomised, data for 71 were analysed. Baseline data for four participants could not be located post-trial, which meant that their follow-up data could not be included in the ANCOVA tests. For each of these participants, the pre-trial questionnaires were posted to a nominated address, as they had indicated that a phone call would not be convenient. These questionnaires were posted along with a stamped, return-addressed envelope, but were never returned.

Three participants randomised to the Intervention group were unable to be contacted to obtain baseline data. These participants had provided consent for the trial and agreed to a time for the baseline interview, yet interviews did not occur as two participants did not subsequently respond to phone or email contact attempts and one withdrew from the study.

Baseline characteristics of the groups were similar, as shown in Table 6-1. All participants were female, and aged between 26 and 44 years. Mean REALM (health literacy) scores were 65.0 (intervention group) and 65.3 (control group), which equates to a reading level of above the 9th grade.

The median duration (number of weeks) between administration of pre- and post-trial outcome measures was 18 (IQR 15-26) for the control group, and 22 (IQR 17-27) for the intervention group.

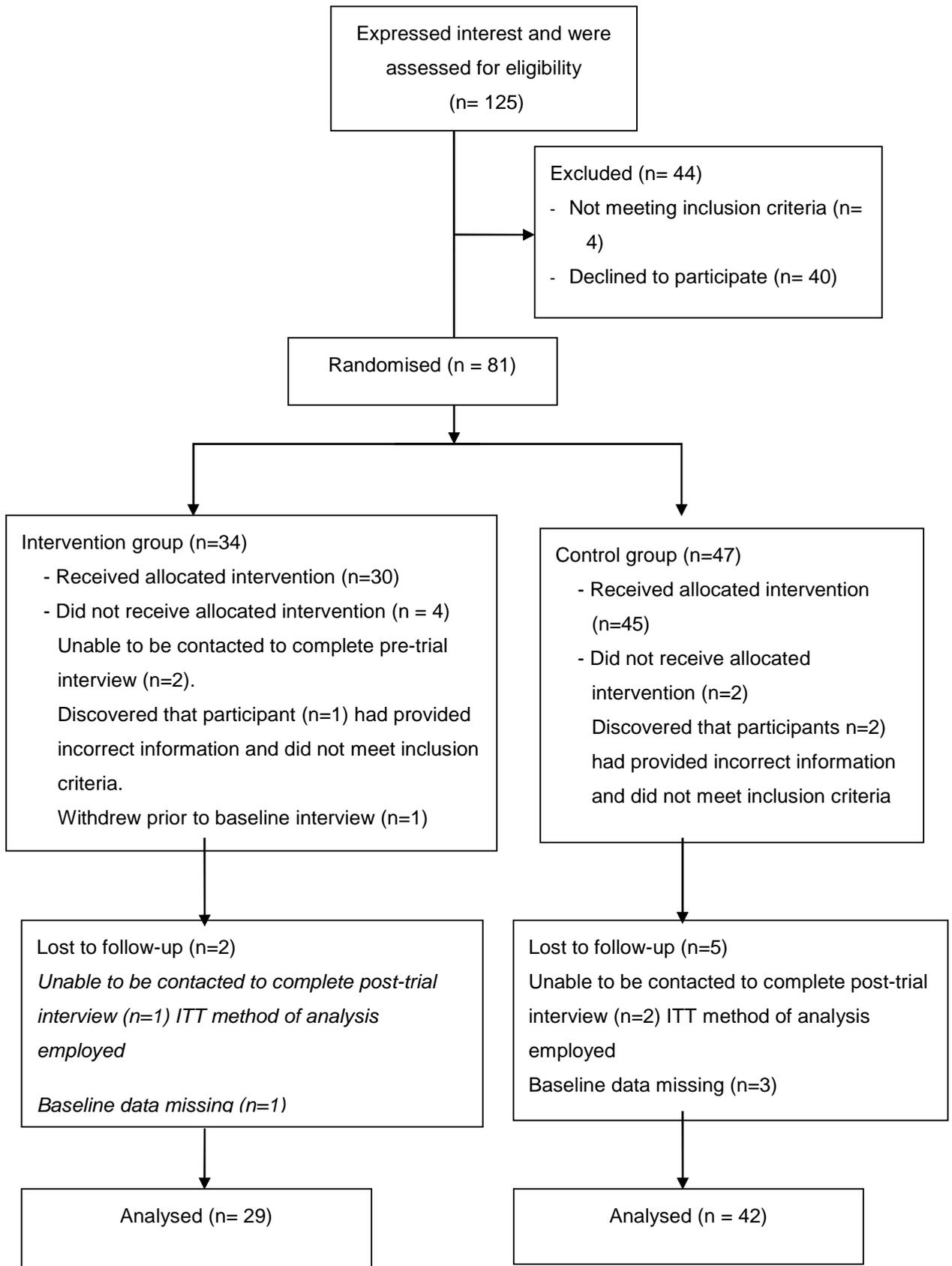


Figure 6-3: Flow of participants through trial

Table 6-1: Baseline Characteristics of Parents in the Intervention and Control Groups.

Characteristic	Intervention Group (n = 29)	Control Group (n = 42)
Mean (range, SD) age of participants (yrs)	36.6 (26 – 41, 4.9)	35.6 (27 – 44, 4.8)
Female	100	100
State/Territory of residency		
QLD	48.3	35.7
VIC	31.0	28.6
NSW	17.2	21.5
WA	0	7.1
TAS	3.5	0
SA	0	7.1
ACT	0	0
NT	0	0
First language		
English	89.7	97.6
Other	10.3	2.4
Mean (range, SD) REALM score	65.0 (57-66, 2.0)	65.3 (62-66, 0.9)
Marital status		
De Facto	6.9	9.5
Divorced/ separated	10.3	4.8
Married	82.8	78.6
Never married/ single	0	7.1
Usual area of employment		
Domestic duties	17.2	11.9
Student	0	2.4
Clerical, Sales or Service	17.2	21.5
Worker	0	7.1
Tradesperson	27.7	14.3
Manager or Administrator	6.9	7.1
Associate Professional	31.0	35.7

Professional

Mean number of children in each family total (range, SD)	2.2 (1 – 5)	2.3 (1 – 4)
Mean number of children in each family diagnosed with ASD (range, SD)	1.2 (1 – 2)	1.2 (1 – 2)
Gender of children diagnosed with ASD (n, %)		
Male	24 (68)	39 (78)
Female	11 (32)	11 (22)

6.8.1 Between group differences at follow up. Table 6-2 outlines the results of this trial. The baseline mean total Decisional Conflict scores for both groups fell within the low to moderate range of decisional conflict according to the tool's score ranges (O'Connor, 2010). Follow-up scores on this measure were lower for both groups, indicating decisional conflict reduced over time, although the differences between the groups at follow-up were not significantly different. There were also no significant differences between the groups at follow-up in any of the DCS subscales.

Table 6-2: Pre and Post-Trial ANCOVA results

Outcome measure (score range)	Mean (SD) baseline scores		Mean (SD) follow up scores		ANCOVA results	
	Intervention	Control	Intervention	Control	Between-group difference adjusted mean (95% CI)	p value
	group	group	group	group		
Confidence (1-10)	6.4 (1.7)	6.6 (2.0)	7.4 (1.7)	7.4 (1.9)	- 0.1 (-0.8 to 0.6)	.85
DCS total (3.13 to 79.0)	40.7 (17.4)	36.7 (16.5)	33.6 (16.6)	33.0 (15.6)	1.7 (-4.2 to 7.7)	.57
DCS uncertainty (0 to 100)	51.3 (21.0)	48.2 (22.8)	41.7 (20.2)	44.7 (24.2)	4.5 (-4.8 to 13.8)	.34
DCS Informed (0 to 100)	41.7 (20.4)	40.7 (20.8)	33.8 (16.7)	37.4 (21.8)	4.0 (-3.8 to 12.0)	.31
DCS Values/ Clarity (0 to 75)	29.5 (16.8)	30.2 (21.2)	26.4 (15.8)	29.6 (18.3)	3.0 (-4.8 to 10.8)	.46
DCS Support (0 to 100)	41.8 (21.6)	39.2 (23.1)	34.5 (22.4)	36.4 (24.6)	3.6 (-5.1 to 12.3)	.42

DCS Effectiveness (0 to 75)	33.1 (17.7)	28.2 (15.1)	29.8 (12.8)	28.1 (16.6)	0.85 (-5.1 to 6.8)	.78
PSOC Total (16 to 78)	52.7 (11.1)	47.3 (9.5)	47.8 (9.7)	48.1 (12.4)	5.0 (1.4 to 8.5)	.06
PSOC Satisfaction (9 to 50)	30.8 (7.0)	28.6 (7.5)	28.5 (7.6)	28.6 (8.5)	1.8 (-0.8 to 4.5)	.17
PSOC Efficacy (7 to 34)	21.9 (5.4)	19.1 (4.1)	19.3 (5.1)	19.3 (5.2)	1.6 (-0.6 to 3.7)	.16

Mean decision making confidence scores improved for both groups from baseline to follow-up, but the between-group difference at follow-up was not significant. The mean scores were 6.4 (intervention group) and 6.6 (control group) at baseline, and at follow up were 7.4 for each group. The scores indicate participants on average reported a moderate to high level of confidence with decision making both before and on completion of the trial.

At baseline, participants in the intervention group had a mean score on the Parental Sense of Competency Scale (PSOC) (Gibaud-Wallston, 1978) that falls within the moderate competency range, whereas the mean score for control group participants was slightly (5 points) lower, putting it within the low competency range, according to the PSOC's score cut-offs. At follow-up, the between-group difference was not statistically significant. There were also no significant differences at follow-up for either of the PSOC subscale scores.

6.8.2. Within group differences at follow up. Paired Sample t tests were performed to explore the changes in the sample as a whole over time. The results of these tests are provided in Table 6-3.

Table 6-3: Paired Sample t-tests Pre-Post Trial for Group as a Whole

Outcome measure (score range)	Mean (SD) difference	95% CI	p value
Confidence (1-10)	- 0.9 (1.7)	-1.3 to -0.5	.000*
DCS Total (3.1 to 79.0)	5.1 (14.6)	1.7 to 8.6	.004*
DCS Uncertainty (0 to 100)	6.0 (22.9)	0.6 to 11.4	.031*
DCS Informed (0 to 100)	5.2 (19.8)	0.5 to 9.9	.031*

DCS Values/ Clarity (0 to 75)	1.6 (22.2)	-3.7 to 6.9	.547
DCS Support (0 to 100)	4.7 (20.0)	-0.05 to 9.4	.052
DCS Effectiveness (0 to 75)	1.4 (15.0)	-2.2 to 4.9	.438
PSOC Total (16 to 78)	1.5 (7.9)	-0.3 to 3.4	.103
PSOC Satisfaction (9 to 50)	0.9 (5.8)	-0.5 to 2.3	.189
PSOC Efficacy (7 to 34)	1.0 (5.0)	-0.2 to 2.2	.114

Using this method of analysis, the group as a whole demonstrated increased scores over time on the Confidence scale (indicating improved confidence with decision making). Also on the DCS Total scale, a significant result was obtained, indicating reduced decisional conflict over time for the group overall. Other significant results were obtained for the Uncertainty and Informed DCS subscales, indicating that participants overall trended towards feeling more certain about decisions being made, and better informed about their options.

6.9 Discussion

This pilot randomised trial aimed to examine the effectiveness of a web-based decision aid on the decisional conflict and decision making self-efficacy of parents of children who are newly diagnosed with autism. There were no statistically significant differences between the groups at follow-up for any of the outcome measures.

There was a small increase in the mean score for self-efficacy in making decisions about ASD interventions for both groups. This is consistent with

existing research that suggests that as parents have the opportunity to search for information about autism, become more familiar with the condition, and adjust to the diagnosis, they also report feeling more confident with making decisions for their child's intervention needs (Grant, Rodger & Hoffmann, 2016). Increased confidence with decision making however, may not necessarily mean that parents better understand the intervention options available, including risks and benefits, or likely outcome, or available research evidence.

Other researchers have explored the utility of various sources of information in helping parents of children newly diagnosed with autism to make intervention decisions. Mulligan et al. (2010) conducted a qualitative study that evaluated a hard copy book for parents of children with autism that was authored by a social worker together with a parent who had a child with an autism diagnosis. The book aimed to serve as a beginner's guide to autism, including content on autism characteristics, and intervention information, and targeted parents whose children were aged between 5 and 13 years of age and had been diagnosed with autism between 2 and 11 years prior. A purposive sample of 13 participants (all mothers) participated in a focus group to provide feedback regarding the book with regards to its accessibility, usefulness, content accuracy, and tone. Participants liked the book format, because it could be picked up and read at any time, and parents could bookmark pages of particular interest. Criticisms of this format included the absence of more specific information about local services and the fact that the information would become quickly out-dated as new treatment options emerge, and research continues to be undertaken. This was one of the reasons for deciding to use a web-based, rather than paper-based, decision aid in the current study.

6.9.1 Strengths and weaknesses of the study. A major limitation of this study was the small sample size, which likely underpowered the trial. Despite using multiple recruitment strategies, including extending the duration of recruitment as long as possible within the PhD timeframe constraints, recruitment was arduous and parents gave many reasons for choosing not to

be involved. These included having no time to participate, the perceived amount of effort required, and fear of being further overwhelmed as a result of yet more 'information overload'. Several studies have found that parents of children with ASD experience higher levels of stress than other parents, including those who also have special needs and developmental disorder (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2004; Schieve, 2007). After this pilot study, it is not possible to make conclusions about the effectiveness of the decision aid that was tested and a future trial, of a larger sample size, is needed.

Other studies in other countries of parents of children with ASD have experienced similar recruitment challenges. A study undertaken by Chamak, Bonniau, Oudaya, & Ehrenberg in 2011 which explored the diagnostic experiences of parents of children with ASD in France reported a response rate of less than 50%. Authors of a Canadian study (Mulligan, Steel, Macculloch, & Nicholas, 2010) also commented on the challenges of recruiting from this population. They specifically avoided recruiting participants whose children were less than two years post diagnosis, as they feared "burdening parents too soon after diagnosis" (p. 123).

A parallel mixed methods study, with a qualitative component involving interviews with parents in the intervention group would have provided useful information about their use of the decision aid, including the number of times accessed, time spent on each page and perceived utility of the decision aid as a decision making tool. During the follow-up interview, some participants commented to the lead researcher that they found the website useful overall, however more specific information was not volunteered or requested due to the already limited time parents reported to have available to participate in the study. Google Analytics was used to track information such as the number of visitors to the website, and the amount of time those visitors spent on specific pages of the site throughout the duration of the trial. The site was password protected to prevent participants allocated to the control group from viewing the contents, and to minimise the risk of capturing data from visitors to the

website that were not trial participants. The data obtained from Google Analytics was not included in this thesis however, as it could not be guaranteed that the password was not compromised. More sophisticated website tracking, that could guarantee the data captured was that of the trial participants, would be beneficial in future research.

Another limitation of this study was the lack of representation of individuals with low health literacy levels. All but one participant in the trial had health literacy levels equivalent to or above 9th grade. It would be interesting to see the trial repeated to include individuals with much lower health literacy levels.

A strength of this study is, as far as we are aware, the first randomised trial of a decision aid about intervention options developed for parents of children newly diagnosed with an ASD. The development of the decision aid was informed by preliminary studies about parents' informational needs and preferences and was piloted with ASD experts and parents of children with ASD prior to commencing the trial.

6.9.2 Implications for future research. A web-based format was chosen, as the Internet is one of the most preferred sources of autism intervention information for parents following diagnosis. However, parents tend to explore information in a range of formats (Grant et al., 2015) and future research is required to determine the feasibility and effectiveness of providing the decision aid in a different format (for example in printed form) and the optimal timing of providing it (for example, before commencing therapy sessions). The use of decision support tools is optimal if they are accompanied by discussion with a treating practitioner, and may be viewed before, during, or after consultations (Hoffmann, Legare, Simmons et al., 2014). Many decision support tools are designed to be used to facilitate discussion and shared decision making with health professionals. Therefore, expanding the intervention so that the decision aid is recommended by/used in conjunction with the intervention provider and evaluating this as an intervention, needs to be considered/included in future research.

6.10 Conclusion

This pilot trial of a web-based decision aid for parents of children recently diagnosed with an ASD to assist them with making decisions about early intervention was unable to show a significant difference on any of the outcomes. It is unclear if this finding is due to the small sample size and likely low power of the study. While it is undisputed that parents should have access to good quality, accurate and relevant information that supports decision making, the optimal format and timing of providing this information and decision making support remains unknown.

Chapter 7 - Discussion and Conclusion

In the time since this project commenced in July 2010, autism research has flourished worldwide. In recent years, biological markers shedding some light on the causes of some manifestations of autism have been discovered (Pramparo, Pierce, Lombardo, & et al., 2015). There is a greater understanding of some ASD risk factors, which have a biological and/ or environmental basis (Lai et al., 2015). Diagnostic methods have also improved, along with an increase in the rate of prevalence, although there is still much debate about whether the increase is due to an actual increase in numbers, greater awareness of the condition amongst the public and health and childhood professionals, and/ or more sensitive and frequent screening (Williams et al., 2014).

A particularly notable and somewhat controversial development in recent years was the release of the new diagnostic criteria for ASD in 2013. The diagnostic criteria for autism were reviewed, and the DSM-5 (American Psychiatric Association, 2013) was released, with significant changes to how autism characteristics are categorised and defined. The new diagnostic manual asks diagnosticians to ascribe a severity level according to the amount of support required by the individual and how severely their functioning is impaired. These levels are described as follows; Level 1, Requiring Support; Level 2, Requiring Substantial Support; and Level 3, Requiring Very Substantial Support (American Psychiatric Association, 2013) however these levels are relatively subjective as viewed by the diagnosing clinician. There is still much debate within the literature about whether or not this method of classification appropriately conveys the extent of the challenges faced by children and adults diagnosed with this condition, and also the sensitivity of the new diagnostic procedures (Gibbs, Aldidge, Chandler, Witzlsperger, & Smith, 2012; McPartland, Reichow & Volkmar, 2012). While the new diagnostic criteria have been found to improve their specificity (McPartland, et al., 2012), there remains the possibility that children who have reasonable cognitive skills and those who previously would have been diagnosed as having Pervasive Development

Disorder Not Otherwise Specified (PDD-NOS) or Asperger's Disorder under the DSM-IV criteria, will be excluded and therefore ineligible for specific funding and services (Gibbs, Aldidge, Chandler, Witzlsperger, & Smith, 2012; McPartland, Reichow & Volkmar, 2012).

The current situation in Australia with regards to children with autism accessing services is not well understood due to changes in diagnostic procedures, and the restructure of federal funding schemes and associated provision of intervention services. There is not much recent data beyond the one or two NDIS trial sites, where it is known that ASD has been the single most frequent diagnosis of children accessing NDIS services for early intervention (46% in South Australia) (National Disability Insurance Agency, 2015). This has led the NDIA to commission a report and revised guidelines on early intervention services and the evidence base. This report was undertaken by Professors Williams and Roberts however it had not been made public at the time of completion of this thesis.

The pace at which autism research findings have been published in recent years has made the process of keeping abreast of current intervention information challenging both for professionals and parents (Goldstein, Tager-Flusberg, & Lee, 2015). New evidence regarding the effectiveness of the numerous autism interventions available is constantly emerging (National Autism Center, 2009, 2015; Bowker, D'Angelo, Hicks, & Wells, 2010; Research Autism, 2010a, 2010b, Reichow, Doehring, Cicchetti, & Volkmar, 2011). There is an ever-increasing amount of information available to parents and health professionals about different interventions via the Internet and social media. The research conducted for this thesis suggests that parents will primarily search the Internet, in addition to accessing books, consulting other parents of children with ASD, liaising with health professionals already known to them, and turning to numerous other sources of information in order to make intervention decisions (Mackintosh, Myers & Goin-Kochel, 2005; Bowker et al., 2010; Valentine et al., 2010; Reichow et al., 2011).

Making decisions about autism interventions is even more difficult when parents are not only faced with adjusting to a new diagnosis (one that will likely affect their child and family for a lifetime) but also faced with a vast number of possible interventions. Furthermore, parents in this study and in other studies have reported feeling unsupported in making these intervention decisions immediately post-diagnosis, particularly at a time when they want the most input and advice from experienced health professionals (Carlson, et al., 2013; Crane, Chester, Goddard, Henry, & Hill, 2015; Valentine, 2010).

The research for this PhD thesis posed four research questions that were addressed across five studies:

1. What information do parents use to make decisions about ASD interventions for their child?
2. What decision making processes do parents use when making intervention decisions?
3. What is the quality of the web-based information that parents access?
4. Does an interactive, web-based decision aid impact on how parents make decisions, by reducing decisional conflict and increasing decision making self-efficacy?

Study 1 (Chapter 2) addressed the first two research questions that sought to understand what information parents used to make intervention decisions for their child with ASD and what decision making processes they used. The study aimed to determine what types of information parents were given by Autism Advisors during their initial consultations, as these Advisors are typically the first point of contact for many Australian families post-diagnosis and they provide a conduit to intervention services. It also aimed to investigate what types of information parents accessed themselves.

Study 1 found that the Advisors discussed the intervention options available and provided at least some information on research evidence supporting the use of a number of interventions. Despite being given some information on research evidence by Advisors and having some, but often limited access to

research evidence via the Internet and other sources of information, parents reported that they did not always consider research evidence when making decisions about which intervention option they pursued. Decision making was reportedly a complex process that required balancing a range of aspects/factors such as time requirements, cost, and location of services, (Grant et al., 2015) as was also found by others (Valentine et al., 2010, Carlon, 2014). Parents reported that they valued highly the opinion of therapists and other practitioners on whose opinion they relied (Grant et al., 2014; Valentine et al., 2010). They also prioritised the views of other parents over research evidence (which appeared to be poorly understood). One limitation of Study 1 was that the information about research evidence came from Advisors' reports on what they did during consultations rather than direct observations or recording of these conversations.

Study 1 also revealed that parents primarily used the Internet to seek information on autism interventions, which supports the existing literature on this topic based on studies in Australia and the United States (Bowker et al., 2010; Mackintosh, Myers & Goin-Kochel, 2005; Reichow et al., 2011; Valentine et al., 2010). These results prompted further enquiry into the quality of web-based information specific to autism interventions that Australian parents were likely to access.

Study 2 (Chapter 3) addressed the third research question regarding the quality of the web-based information that parents access. In this Study, the quality of twenty autism-related websites that Australian parents were most likely to find when searching for this information on the Internet were evaluated. The DISCERN tool used in this study (Charnock, 1998) was initially developed to evaluate the quality of print based patient health education materials provided by medical practitioners. The tool, which is publicly available online (www.discern.org.uk), was considered appropriate for use in Study 2 as it addressed research evidence, authorship, pros and cons of treatment, and support for shared decision making within the site content. DISCERN was used to evaluate the quality of the autism-related websites

which were found when conducting a search of the Internet using 10 commonly known autism-specific keywords in April 2013, for example 'autism intervention' 'autism cure' and 'autism treatment'.

Study 2 (Grant et al., 2014, 2015) found that while there were some high quality Australian websites, such as (www.raisingchildren.net), many of the websites contained information that was inaccurate, out-dated and/or potentially misleading. Only six out of the 20 websites evaluated cited research evidence that supported the claims made about intervention effectiveness. The key weaknesses of the websites included lack of clear information about the benefits and risks, and the overall impact of treatment on quality of life, and there was often little or no information about shared decision making. The findings of this study reinforced the need for parents to develop skills in health literacy if they are to make informed intervention decisions for their child with ASD and to better understand the strength and weaknesses of websites that they access.

One of the challenges for authors of website content is how websites are ranked and displayed in search results. When looking for information on autism, most people enter keywords, such as those used in Study 2, into Internet search engines. The participants in Study 1 were found to primarily use keyword searches, and occasionally went directly to websites recommended by health professionals and other trusted people in their networks. These keywords may include terms such as Autism, Asperger's Disorder, Autism Cure and Autism Treatment. Internet sites that have good rankings on these search engines will appear highest in search results. Good ranking can be achieved through the use of Search Engine Optimisation (SEO) strategies. This means that the websites with the best information are not always going to appear on the first few pages of search results unless web authors have utilised SEO strategies. First page presentation can be purchased through products such as Google Adwords, clever copywriting, and other SEO strategies. The Autism Early Intervention Decision Aid (Grant, 2013) developed as part of this PhD research, contains high quality content

based on research evidence, and the content is relevant to the Australian context. The Autism Early Intervention Decision Aid website is publically available (www.autismdecisionaid.com.au) however, because the site is not optimised for search engines, and has fewer visitors than other ASD-related websites, it does not always appear in searches for autism information. If funding were available, it would be worthwhile paying for the site to be optimised by an SEO expert, or promoted more broadly through larger and more influential autism peak bodies and organisations. Alternatively, the content and interactive questionnaire embedded in the decision aid (including the algorithm to determine the questionnaire results) could be incorporated into an already established high quality website.

In addition to website authors providing the research evidence that underpins claims made about treatment efficacy, parents should be educated to better understand and evaluate the information they are finding on the Internet. The DISCERN tool used for this study is now publicly available in full and there is also a shorter version (the Brief DISCERN) (Khazaal et al., 2009) that parents can be encouraged to use as well (Charnock & Shepperd, 2004). In addition, a version has been made available on the Autism CRC website health hub (www.autismcrc.com.au). For individuals searching the Internet for health-related information, learning to assess web-page credibility may result in improved health literacy, and better treatment decision making (Chiarella, 2009; Schwarz, 2011). It has also been found to be empowering and encourages individuals to take a more active role in their health care decisions (Coulter & Ellins, 2007; Mathieu, 2010).

To further explore parents' decision making processes and information preferences following an autism diagnosis for their child, Study 3 was conducted. This was a qualitative study of 23 parents of children diagnosed with autism, which explored the information parents use to make decisions about ASD interventions for their child, and the decision making processes parents used when making intervention decisions.

Study 3 revealed that when considering intervention options for their child post-diagnosis, parents embarked on a journey that had concurrent emotional and pragmatic elements. The pragmatic elements included searching for information, and interrogating a number of information sources such as trusted health professionals, other parents who had children with an autism diagnosis, and Internet sites, particularly those with forums such as Facebook. Parents often adopted a 'trial and error' approach to choosing interventions, which were typically selected based on availability, cost and proximity of services. The emotional journey often began with a period of feeling confused and overwhelmed. At this early stage, parents reported preferring information that was more prescriptive and brief. Mulligan et al. (2010), Osborne & Reed (2008), and Valentine et al. (2012) also found that parents' informational needs changed over time, with more prescriptive or instructive information preferred immediately post-diagnosis. Once parents adjusted to the ASD diagnosis, and become more knowledgeable about the condition and what it meant for their child and family, parents sought information more broadly, from a wider range of sources, including reading hard copy brochures and texts, attending workshops, participating in Internet based groups and forums, and most commonly, accessing the Internet to search for even more information. By this stage, parents reported feeling more confident and better able to make intervention decisions. What was not determined from this study was if there is a typical timeframe for parents to move through the various stages post-diagnosis and what factors may contribute to, or impact on this progression. While these journeys are likely to be very individual with regard to timeframes, a better understanding of factors impacting on or contributing to progression of understanding would be useful to health and educational professionals who support families during this post-diagnosis period.

One key theme that emerged from this study was the trust that parents had in their health professionals, and an expectation that these professionals would provide accurate, evidence based, and relevant intervention information. Parents assumed that all interventions provided by professionals such as

Occupational Therapists and Speech and Language Pathologists were evidence-based because the providers were registered health professionals.

The research undertaken within this thesis found that parents assumed that health and educational professionals are trained to provide evidence-based interventions during completion of their coursework prior to graduation in their chosen discipline. And hence that interventions provided by registered professionals are evidence based, whether or not this is the case. It is during their pre-registration education that students need to be taught how to convey health information to clients/ patients and how to facilitate the decision making process especially when intervention options are limited (as is the case in particular geographic areas especially in regional and rural Australian locations) and when there is a range of conflicting information about intervention efficacy. Upon graduation, and at regular intervals during clinical practice, health professionals have an obligation to engage in ongoing professional development activities including training in the skills of SDM and keeping up to date on research evidence, particularly evidence relevant to the interventions they deliver as part of their service provision.

Parents also considered information provided by other parents when making intervention decisions, and often felt that anecdotal reports that an intervention had “worked” for a particular child was evidence of its effectiveness and hence relevant for their child. Research evidence was generally not considered by parents. It is therefore incumbent on health professionals to stay abreast of research, practice evidence-based healthcare and shared decision making, and to be competent in conveying research evidence to their patients/ clients in a manner that they can understand, and reach collaborative decisions.

One of the greater challenges faced by health professionals when imparting research information to parents is the lack of agreement between expert panels, and autism peak bodies/organisations on how ASD interventions should be classified (regarding the broad type of intervention and the ASD characteristics addressed). There have been many attempts to classify and

evaluate the efficacy of autism interventions (National Autism Center, 2009, 2015; Bowker, D'Angelo, Hicks, & Wells, 2010; Research Autism, 2010a, 2010b, Reichow, Doehring, Cicchetti, & Volkmar, 2011; Prior et al, 2011) and there continues to be inconsistent interpretation of the existing research evidence. This leads to differing and sometimes contradictory recommendations regarding autism interventions. It is imperative, therefore, that intervention decisions be made in consultation with individuals and their families, to determine which evidence-based interventions are a 'good fit' for their family and are more likely to achieve their specific intervention goals. This requires a consummate ability by professionals to facilitate parents engagement in goal setting for their child and family. Knowing these priority goals allows for a better matching of interventions with family objectives/goals.

It is clear from Study 3 that navigating information on the Internet, and from other sources, especially immediately post-diagnosis, can be confusing and oftentimes overwhelming. Valentine et al. (2010) described this experience as being a "burden of choice", and the acquisition of information as being distressing and enormously complex. The overall aim of the research in this thesis was to help parents of children diagnosed with autism to make informed intervention decisions by improving their health literacy about evidence. Further research on the benefits of improved health literacy and/or reduced decisional conflict in terms of parental well-being would be of value.

Following review of the literature and based on the results of the earlier studies, it was decided that a web-based decision aid would be the best format in which to provide research information to parents to help with their intervention decision making. Chiarella et al. (2009) proposed that an Internet-based resource would be useful to help parents find information about autism interventions. Parents certainly prefer this format, and other studies have suggested there is a strong relationship between Internet use and development of parental self-efficacy (McMullan, 2005).

Study 4 involved the development of the web-based Autism Early Intervention Decision Aid, and the process used for this was described in Chapter 5. The decision aid was developed with consideration for the International Patient Decision Aid Standards (IPDAS) (Elwyn, O'Connor, Stacey, Volk, Edwards, & Coulter, 2006), and principles of shared decision making. SDM encourages a partnership between health professionals and individuals during decision making; and decision aids can be used by individuals, and their families in collaboration with health professionals to help them make informed intervention decisions.

Where Internet sites are used for the provision of information on health interventions, the information included should ideally be relevant to local users and able to be personalised as much as possible (Mulligan et al., 2010; Valentine et al., 2010). The Autism Early Intervention Decision Aid (Grant, 2013) developed for this study included evidence-based interventions known to be available in Australia and additional content, for example, links to ASD-specific organisations that were based in Australian states and territories. The decision aid also featured a questionnaire about ASD characteristics that parents were interested in addressing, that when completed would provide a list of interventions that best fit the responses provided. As parents typically considered cost, location and the time required for participation in interventions, questionnaire results could be further filtered according to parents' preferences against these criteria. In this way, the decision aid was developed to be tailored to the users' requirements. With more time and funding, the decision aid could potentially be further developed to include a database of providers, with information on what evidence-based strategies they utilise, and with links to their websites for more information.

The decision aid developed as part of this PhD and other educational resources can be used by parents to obtain autism intervention information that is relevant, trustworthy and evidence-based, that can then be discussed with their child's treating healthcare professionals. The intention is for Internet-

based and other education materials to supplement, not replace information provided by healthcare professionals (McMullan, 2005).

Guidelines such as those developed by Prior and Roberts, Australia (2006, 2012), Scottish Intercollegiate Guidelines Network (SIGN) (2007), the Ministries of Health and Education, New Zealand (2008), and the Academy of Medicine Singapore - Ministry of Health Clinical Practice (2010), are at times accessed by parents, albeit that their target audience is professionals rather than parents. These often contain jargon, and the format and content may be beyond the understanding of parents with poor literacy and low levels of health literacy skills, those who have English as a second language, or experience other issues affecting their ability to process and understand complex written information (Sabo & Lorenzen, 2008). These resources are best used as an adjunct to consultation with an experienced practitioner. Valentine et al. (2010) suggest that the best way of providing information to parents is in-person, and decision aids that follow the IPDAS criteria are designed with this purpose. The decision aid developed in Study 4 of this project aimed to improve parents' health literacy about evidence, and encouraged them to discuss their intervention decisions with their health practitioner. A preliminary evaluation of the effectiveness of the decision aid was conducted via a pilot randomised controlled trial (Study 5), summarised in Chapter 6. Future research needs to be conducted to evaluate the utility and effectiveness of the tool in conjunction with health professional involvement.

Study 5 addressed the fourth and final research question regarding whether an interactive, web-based decision aid reduces parents' decisional conflict and increases decision making confidence. The RCT included 81 participants randomised into control and intervention groups, with 71 completing the trial. The intervention group was provided with access to a password protected decision aid, and were asked to view the website at their convenience over the following three months. Parents in the control group accessed usual sources of information, and were provided with access to the decision aid on completion of the trial when it was made publically available.

The primary outcome measure for the trial was decisional conflict, measured using the Decisional Conflict Scale (DCS) (O'Connor, 2010) and Secondary outcome measures were parental confidence measured on a 10-point Likert scale and parental self-efficacy measured using the Parental Sense of Competency Scale (PSOC) (Gibaud-Wallston, 1978).

The results of the trial found no statistically significant differences between the groups for any of the outcome measures. The results for the groups overall suggest that parental confidence related to decision making does improve over time, possibly because parents adjust to, and become more experienced with their child's autism diagnosis and have the opportunity to obtain information from a range of sources. This is consistent with the findings of the earlier qualitative studies undertaken as part of this PhD research (Grant et al., 2015a, 2015b).

While the results of the pilot RCT were not statistically significant, with possible reasons described in Chapter 6, the conduct of a larger study with a bigger sample size and hence sufficient power may yield different results. It would also be worthwhile to conduct a similar study that includes a decision aid accompanied by access to one-on-one support from a trusted practitioner (as previously mentioned) at various timeframes post-diagnosis. Until future research is performed, it is hoped that the information outlined in this thesis will be of use to other practitioners who are entrusted with the task of providing early intervention services to families with a child with ASD commencing on their autism journey post diagnosis.

Valentine et al. (2010) proposed that parents of children newly diagnosed with autism are forced to make intervention choices that require significant background research on their part. This is a sentiment echoed by others;

“Parents become highly educated – of necessity, not of choice.”
(Ministries of Health and Education, 2008, p7).

However there is not one single model of engaging parents in the decision making process that will meet all parents' needs. There is a need to explore alternative methods of facilitating informed decision making and communicating intervention options and their underlying evidence to parents of children newly diagnosed with ASD. In the pilot RCT (Study 5) there was no opportunity within the PhD timeframe to conduct qualitative interviews with parents about their use of the decision aid website to find out about its utility from their perspectives. This would likely have provided useful insights and should be considered when designing future research in this area.

7.1 Implications for future practice

To ensure that parents of children diagnosed with autism are able to interpret and understand the information they are provided, decision aids and other materials are best provided by health and early intervention professionals and used in consultation with them (Charles, et al., 1997; Thistlethwaite, 2006).

Shared decision making refers to the process of patients and health professionals working together to make intervention decisions after discussing all possible options, in addition to identifying the potential benefits and harms of each, the patient's values and preferences, and their (or their child's) individual circumstances (Hoffmann et al., 2014). The expertise of the health professionals providing the support is important if parental stress is to be alleviated and decision making self-efficacy improved (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Shared decision making occurring is dependent upon the skills and knowledge of the practitioner to impart information that is accurate, relevant and evidence based. Several resources exist to help clinicians and therapists to better convey autism intervention information. One in particular that is relevant to the Australian context is the text entitled 'Working with Parents of a Newly Diagnosed Child with an Autism Spectrum Disorder: A Guide for Professionals' (Keen & Rodger, 2012).

Another is "Understanding Autism: The Essential Guide for Parents" (Williams & Roberts, 2015). Professionals need to be abreast of adult learning strategies, health literacy concepts and principles of shared decision making,

as well as being cognisant of the contemporary literature related to autism early intervention techniques and approaches. The latter being a challenging task given the recent explosion of autism research and publications.

The results of this PhD research have raised further questions about how health professionals can be monitored to ensure the provision of intervention services that are in line with best practice evidence-based principles. With the roll out of the National Disability Insurance Scheme (NDIS) in Australia over the coming years, and the anticipated increase in intervention service providers available, there will most likely be an even greater focus on evidence based practice and research efficacy and the need for practitioners to be able to justify the intervention approaches they offer. It still remains unclear how the NDIS aims to monitor or manage this reality and how potential autism intervention providers will be assessed and accredited.

Autism Advisors who are in the position of providing parents of children newly diagnosed with ASD with intervention information immediately post-diagnosis, should similarly be required to keep up to date with the research evidence about autism interventions and be specifically trained to effectively impart information about health and early education interventions and their supporting evidence to parents. It is unknown what training Advisors undergo in order to fulfil their role, however currency in their knowledge of autism research evidence should be considered an essential component of their training, and be updated at regular time points thereafter.

As parents seek information from their Advisors, healthcare and educational professionals as well as the Internet, it is important that the authors of websites providing the content/information on autism intervention options ensure that they comply with the criteria for good quality health information provision. This should also be a requirement of organisations and peak bodies who facilitate workshops, produce DVDs, author brochures and text, and other parent education materials. Some of these principles include accuracy and currency

of health information material (Reichow et al., 2012), use of language that accommodates individuals who may have poor health literacy (Chiarella, 2009; Ishikawa & Kiuchi, 2010), relevance to users (Mulligan et al., 2010; Valentine et al., 2010), and facilitation of shared decision making (Charnock & Shepperd, 2004; Chiarella, 2009; Schwarz, 2011).

With the pending transition of clients from the Helping Children with Autism (HCWA) funding scheme to the NDIS scheme, there will likely be added confusion for parents as they attempt to understand the support that is available to them. During this time, it will be crucial that websites providing information to parents about these schemes, transitions in funding, and brochures or other print material explaining the different schemes, be written in a way that adheres to patient education principles, and again, explains the intervention options available and the evidence supporting them. A point of contact, similar to the role of the Autism Advisor needs to be made available, and these roles filled by health and/ or early educational professionals who have a good understanding of SDM, and are appropriately trained to support parents whose child has been newly diagnosed with autism.

7.2 Implications for future research

This study has added to our understanding of what is known about the decision making journey post-diagnosis, and how parents access and use autism-related information to make these decisions. There is still much to be learned about how best to disseminate intervention information and research evidence to parents at different time points in their journey post-diagnosis.

Abhyankar, Volk, Blumenthal-Barby, Bravo, Buchholz, Ozanne et al., (2013) stated that providing health information in a balanced manner is important to consider when designing decision aids, but that more research is required to investigate how this balance can be achieved and measured. Study 2 in this thesis used the DISCERN tool to evaluate autism websites, and found that much of the information that is presented on autism websites is biased.

Huh and Cude (2004) conducted a study using content analysis to determine if websites containing information on prescription medications were fair and balanced. The United States Food and Drug Administration (FDA) (Food and

Drug Administration Center for Drug Evaluation and Research (CDER), 1999) have a “fair-balance” disclosure policy that dictates that printed information should be presented in a balanced manner, including disclosure of the risks and benefits. Huh and Cude (2004) analysed website information specifically, and measured “fair balance” according to what type of content appeared on each website (for example, information on benefits and risks), as well as how individuals could access the information (for example on the home page, or in another section). The authors found that only 29 out of the 60 (48.3%) websites listed both risks and benefits. When analysing these 29 sites further, they found that there were imbalances in the way risk and benefit information was presented, for example, 48.3% (n= 14) of the websites had the benefits in larger font than the risks. They also determined that of these 29 sites, there were differences between the number of words describing risks versus benefits, and the location of the risk information was not always on the homepage alongside the benefits. This type of content analysis could also be undertaken to determine whether balance exists in autism-related health information websites. Hawk and Evans (2013) proposed that a website found to be biased or imbalanced does not necessarily mean that the information is incorrect, just that individuals accessing the information need to take the possible presence of bias into consideration when making healthcare decisions.

The pilot RCT conducted in this thesis aimed to test the effectiveness of a decision aid using the Decisional Conflict Scale (DCS) as the primary outcome measure. This tool was chosen as it was known to be effective in measuring decisional conflict with regard to medical/health treatment decisions (Kryworuchko, Stacey, Bennett, & Graham, 2008; O’Connor, 2010) and has been found to be commonly used in trials where the effectiveness of decision aids are being investigated (Sepucha, Borkhoff, Lally, Levin, Matlock, Jenn Ng, Ropka, Stacey, Joseph-Williams, Wills & Thompson, 2013). While the results of the current RCT study were not significant, this tool was able to detect a change in both groups overall, so it is believed that it was an appropriate choice for this study and would be a useful tool for inclusion in future research

on this topic. The secondary outcome measures, in particular the Parenting Sense of Competency Scale (PSOC) (Gibaud-Wallston, 1978) however may not have been as sensitive in addressing the research question the trial was hoping to answer. It would be important to see this trial repeated with a larger sample size to ensure results are statistically significant, and with the inclusion of more sensitive/ appropriate outcome measures, ideally tools purposefully designed to measure parental confidence and self-efficacy in relation to autism intervention decision making. An outcome measure that could analyse whether or not parents made decisions based on their evaluation of the research evidence available would also be useful and would need development.

The field of research exploring the concept of shared decision making is quite young, however there is an increasing number of tools to measure elements of SDM that are being developed and evaluated (Scholl, Koelewijn-van Loon, Sepucha, Elwyn, Legare, Harter, & Dirmaier, 2011). Scholl et al. (2011) conducted a review of SDM instruments and suggested that a theoretical measurement framework for consistency of measured SDM constructs across research groups is required, as there are variations in validity of many of the tests included in their study. Kryworuchko, Stacey, Bennett & Graham (2008) concluded that “selecting relevant and high quality outcome measures remains challenging and is an important area for further research in the field of shared decision making” (p.497). Sepucha et al. (2013) reviewed 86 studies that utilised instruments that aimed to measure decision making processes and/ or decision quality constructs specific to decision aids. They found that 17 different measurements were used to measure decision making process constructs in these studies, with the Decisional Conflict Scale (DCS) being the most commonly used (n=47). They found that not one of the tools in their study measured all key decision making processes and constructs which included decision making process constructs (recognise decision, feel informed about options and outcomes, feel clear about goals and preferences, discuss goals and preferences with healthcare provider, and be involved in decisions), and decision quality constructs (knowledge, realistic expectations, values-choice agreement). Sepucha et al. (2013) found that there was no

consensus or standardisation of measurement for either the decision making process or decision quality constructs. They concluded that more work was required to develop and evaluate decision aid measurement instruments, and further exploration of theoretical issues to advance future research was urgently required.

Beyond supporting parents through good quality health-related websites, more research is required to determine how best to convey good quality health information across the variety of formats and sources of information from which parents seek autism intervention information. Trusted sources of information for parents of children when newly diagnosed with autism include medical and health practitioners already known to the family. More research is required to determine how well these professionals understand autism research evidence, and how this evidence is relayed to parents at different time points post-diagnosis. It would be important and relevant to see if health professionals provide different information to different individuals, and if so, how they modify or tailor the information provided for different parents and on what basis.

Research questions may include:

- 1) What autism intervention research information is provided to parents during the initial consultation, and at different time points thereafter;
- 2) How do health professionals choose the type, volume, and format of autism research information provided to parents; and,
- 3) Do health professionals seek to understand the health literacy levels of parents of children newly diagnosed with autism prior to discussing autism intervention research and intervention options?

More research is required to understand the extent to which health professionals involved in the decision making process with parents post autism diagnosis, understand and utilise SDM in consultations. Hoffmann et al. (2014) stated that Australia is lagging behind other countries in shared decision making research, in a number of areas including training, resources, and

implementation, so a study of these concepts within the Australian context would be particularly valuable. The findings of this type of study could be used to inform the training and education of medical and health professionals, to ensure effective communication between all parties involved in the decision making process, and ensure better quality, more balanced information is available for parents on which to base their decisions (Hoffmann et al., 2014).

7.3 Conclusion

One of the main findings of this thesis was that access to a decision aid alone does not necessarily lead to improved confidence and improved self-efficacy, and/ or decrease decisional conflict with regards to intervention decision making. The pilot RCT conducted revealed that parental confidence with decision making tends to improve over time with access to a range of information and as parents become more experienced with the diagnosis and intervention options. Increased confidence however, does not also mean increased health literacy about autism interventions.

It was apparent from the earlier studies described in this thesis (Studies 1 and 3) and in studies conducted by other researchers in this field (Bowker, D'Angelo, & Hicks et al., 2011; Carlon, et al., 2013; Green, Pituch, & Ichon, et al., 2006), that parents do not generally consider research evidence when making intervention decisions, and instead make choices based on a range of other factors including cost, availability and location of service providers. While anecdotal reports from parents who participated in the pilot RCT claimed the Autism Early Intervention Decision Aid was useful, their understanding of research evidence and knowledge of autism interventions was not evaluated. Future research should ideally factor investigation of these aspects into the research design.

The RCT conducted in this thesis used the Decisional Conflict Scale (DCS) (O'Connor, 2010) as the primary outcome measure as it was known to be effective in measuring decisional conflict with regard to treatment decisions. The secondary outcome measures, in particular the Parenting Sense of Competency Scale (PSOC) (Gibaud-Wallston, 1978) however may not have

been as sensitive in addressing the research question the trial was hoping to answer. The PSOC for example explores general parenting competence, and while commonly used with parents of children with ASD, is not specific to decision making competence. It would be important to see this trial repeated with the inclusion of more sensitive and appropriate outcome measures, ideally tools purposefully designed to measure parental confidence and self-efficacy in relation to autism intervention decision making. The trial should also be repeated with a larger sample size to confirm or challenge the current results.

A major theme that emerged from the research undertaken as part of this PhD thesis was that parents' informational and support needs change over time post-diagnosis. Their decision making journey post-diagnosis of autism for their child is typically one that includes choosing interventions by trial and error. A resource that is more sensitive to these ever changing informational needs would be valuable, to ensure that parents are well informed and supported to make decisions that are right for their child and family, and that these are made with consideration for the benefits and potential risks of all the options available. Repeating the trial and including practitioner involvement and support at appropriate intervals, would also be worthwhile in future. Parents need to be optimally supported through all stages of their journey with their child post-diagnosis, and a resource or series of resources and supports designed to do this in conjunction with health practitioner support continues to be much needed.

Imagine.

Your child has just been diagnosed with autism spectrum disorder. Sitting in your son's paediatrician's office, you are feeling numb, and then your stomach begins to churn. You've been waiting a year for this news, and while you suspected this was going to happen, it hits you. A wave of panic rises. You can hear the doctor's voice, but only every other word is clear. Lifelong, challenges, different. But then after a few minutes, you start to hear more. He is telling you about Early Intervention options that are available, which sounds very

promising. And the paediatrician tells you that there are lots of different types of interventions to help your son thrive, but he will help you choose the one that fits your family's needs best. By using a process of shared decision making, he talks to you about your hopes, fears and goals for your son. After some discussion about this and weighing up Daniel's current age, developmental level and your desire for him to start communicating his needs and wants, he discusses speech pathology and PECS with you. He hands you a list, and on that list is the name of some private providers and an organisation that apparently can help you. You take a few deep breaths. He tells you it's going to be ok. While you are still not sure, at least you have a starting point and can take the first step in constructively helping Daniel. You walk out relieved that you have a place to start.

References

- Abhyankar, P., Volk, R., Blumenthal-Barby, J., Bravo, P., Buchholz, Ozanne, E., & Stalmeier, P. (2013). Balancing the presentation of information and options in patient decision aids: an updated review. *BMC Medical Informatics and Decision Making*, 13, S6.
- Ademiluyi, G., Rees, C. E., & Sheard, C. E. (2003). Evaluating the reliability and validity of three tools to assess the quality of health information on the Internet. *Patient Education and Counseling*, 50(2), 151-155. doi: Doi: 10.1016/s0738-3991(02)00124-6
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4th ed., text rev.)*. Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: Author.
- Australian Bureau of Statistics (ABS). (2009). *Household Use of Information Technology, Australia, 2008 - 2009*. Canberra.
- Australian Bureau of Statistics (ABS). (2014). *Household Use of Information Technology, Australia, 2012 - 2013*. Canberra.
- Autism QLD. (2011). <http://www.autismqld.com.au>. Accessed 2011.
- Autism Speaks. (2010). Autism Speaks TM 100 Day Kit. In Autism Speaks (Ed.).
- Autism Treatment Network. (2011). Autism: Should my child take medicine for challenging behaviour? A decision aid for parents of children with autism spectrum disorder. Autism Treatment Network, Health Resources and Services Administration, Maternal and Child Health Research Program. (Ed.).
- Baker, D. W. (2006). The Meaning and the measure of health literacy. *Journal of General Internal Medicine*, 21(8), 878-883. doi: 10.1111/j.1525-1497.2006.00540.x
- Baranek, G. T. (2002). Efficacy of sensory and motor interventions for children with autism. *Journal of Autism & Developmental Disorders*, 32(5), 397.

- Barry, M., Chan, E., Moulton, B., Sah, S., & Braddock, C. (2013). Disclosing conflicts of interest in patient decision aids. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S3.
- Batchelor, J. M., & Ohya, Y. (2009). Use of the DISCERN Instrument by patients and health professionals to assess information resources on treatments for asthma and atopic dermatitis. *Allergology International*, 58, 141-145.
- Beaumont, R., & Sofronoff, K. (2008). A multi-component social skills intervention for children with Asperger Syndrome: The Junior Detective Training Program. *The Journal of Child Psychology and Psychiatry*, 49, 743-753.
- Bee, L. S. (2010). Academy of Medicine Singapore-Ministry of Health Clinical Practice Guidelines: Autism Spectrum Disorders in Pre-school Children. *Singapore Medical Journal*, 51(3), 255 - 265.
- Bekker, H., Winterbottom, A., Butow, P., Dillard, A., Feldman-Stewart, D., Fowler, F., & Volk, R. (2013). Do personal stories make patient decision aids more effective?: a critical review of theory and evidence. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S9.
- Bent, C.A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *Medical Journal of Australia*. 202 (6): 317-320.
- Blackburn, C., & Read, J. (2005). Using the Internet? The experiences of parents of disabled children. *Child: Care Health and Development*, 31(5), 507-515.
- Boswell, W. (2010). The Most popular Search Engines on the Web. Retrieved 6 December 2010, from <http://websearch.about.com/od/enginesanddirectories/tp/most-popular-search-engines.htm>
- Bondy A. S., & Frost L. A. (1994). The Picture Exchange Communication System. *Focus on Autism and Other Developmental Disabilities*, Vol. 9, No. 3, 1-19
- Bowker, A., D'Angelo, N. M., Hicks, R., & Wells, K. (2010). Treatments for Autism: Parental choices and perceptions of change. *Journal of Autism*

- and Developmental Disorders*. 41(10):1373-82. DOI: 10.1007/s10803-010-1164-y
- Breen, R. L. (2006). A practical guide to focus-group research. *Journal of Geography in Higher Education*, 30(3), 463-475. doi: 10.1080/03098260600927575
- Butler, L., & Foster, N. E. (2003). Back Pain Online: A cross-sectional survey of the quality of web-based information on low back pain. *SPINE*, 28(4), 395-401.
- Cardon, T. A., & Azuma, T. (2011). Deciphering single- subject research design and Autism Spectrum Disorders. *The Asha Leader*. 6, Vol. 16, online only. doi:10.1044/leader.FTR4.16072011.np
- Carlson, 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(2), 369-381. doi: <http://dx.doi.org/10.1016/j.rasd.2012.10.009>
- Carter, M., & Preston, D. (2009). A review of the efficacy of the Picture Exchange Communication System intervention. *Journal of Autism and Developmental Disorders*. 9(10):1471-86. doi: 10.1007/s10803-009-0763-y.
- Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. *American Journal of Occupational Therapy*, 62(4), 416-429.
- Centers for Disease Control and Prevention. (2014). *Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010*. MMWR Surveillance Summaries.
- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism*, 15(83), 83-97.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681-692. doi: 10.1016/s0277-9536(96)00221-3

- Charman, T. (1999). Autism resources and information on the Internet or World Wide Web. *Autism*, 3(1), 97-100.
- Charnock, D. (1998). The DISCERN Handbook Quality criteria for consumer health information on treatment choices. www.discern.org.uk/discern.pdf
- Charnock, D., & Shepperd, S. (2004). Learning to DISCERN online: applying an appraisal tool to health websites in a workshop setting. *Health Education Research*, 19(4), 440-446.
- Chiarella, D. (2009). Health literacy: using Web 2.0 to create an autism resource. *Journal of Consumer Health on the Internet*, 13(3), 281-286.
- Chowdhury, J., Drummond, J., Fleming, D., & Neufeld, S. (2002). Content analysis of online autism specific sites. *Journal on Developmental Disabilities*, 9(2), 157-165.
- Coates, H. (2009). Autism spectrum disorders: wading through the controversies on the Web. *Medical Reference Services Quarterly*, 28(3), 259-267.
- Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *BMJ*, 335.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1910640/>
- Coulter, A., Stilwell, D., Kryworuchko, J., Mullen, P., Ng, C., & van der Weijden, T. (2013). A systematic development process for patient decision aids. *BMC Medical Informatics & Decision Making*, 13(Suppl), S2.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2015). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*. doi: 10.1177/1362361315573636
- Davenport, T. (2011). Autism Behavior Checklist. In S. Goldstein & J. Naglieri (Eds.), *Encyclopedia of Child Behavior and Development* (pp. 182-183): Springer US.
- Davis, T. C., Michielutte, R., Askov, E. N., Williams, M. V., & Weiss, B. D. (1998). Practical assessment of adult literacy in health care. *Health Education & Behavior*, 25(5), 613-624. doi: 10.1177/109019819802500508

- Department of Families Housing Community Services and Indigenous Affairs (FaHCSIA). (2010). Retrieved 24/11/2010, 2010, from http://www.fahcsia.gov.au/sa/disability/progserv/people/autism_panel/Pages/default.aspx
- Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Living with children diagnosed with autistic spectrum disorder: parental and professional views. *British Journal of Special Education*, 37(1), 13 - 23.
- Drug and Therapeutics Bulletin. (2013). An introduction to patient decision aids. *BMJ*, 347, f4147.
- Elwyn, G., Frosch, D., Volandes, A., Edwards, A., & Montori, V. (2010). Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. *Medical Decision Making*, 30, 701 - 711.
- Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *BMJ*, 341, c5146.
- Elwyn, G., O'Connor, A., Bennett, C., Newcombe, R., Politi, M., Durand, M., & Edwards, A. (2009). Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPtDASi). *PloS One*, 4, e4705.
- Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., Coulter, A., (IPDAS Collaboration). (2006). Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ*, 333(7565), 417.
- Elwyn, G., Scholl, I., Tietbohl, C., Mann, M., Edwards, A., Clay, C., & Frosch, D. (2013). "Many miles to go ...": A systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S14.
- Elwyn, G., Tilburt, J., & Montori, V. M. (2013). The ethical imperative for shared decision making . *European Journal of Person Centered Healthcare* ; 1: 129-131.

- <http://www.bjll.org/index.php/ejpch/article/download/645/686> (accessed Oct 2015).
- Elwyn G., Lloyd, A., May, C., van der Weijden, T., Stiggelbout, A., Edwards, A., Frosch D. L., Rapley, T., Barr, P., Walsh, T., Grande, S. W., Montori, V., & Epstein, R. (2014). Collaborative deliberation: a model for patient care. *Patient Education and Counselling*. Nov;97(2):158-64. doi: 10.1016/j.pec.2014.07.027. Epub 2014 Aug 13.
- Epstein, R. M., Alper, B. S., & Quill, T. E. (2004). Communicating evidence for participatory decision making. *JAMA: The Journal of the American Medical Association*, 291(19), 2359-2366. doi: 10.1001/jama.291.19.2359
- Food and Drug Administration Center for Drug Evaluation and Research (CDER). (1999, August 9). Guidance for industry: Consumer-directed broadcast advertisements. Federal Register, 64(152), 43197–43198, (Docket 97D-0302).
- First, M. B. (2008). Autism and Other Pervasive Developmental Disorders Conference (February 3-5, 2008). [http://www.dsm5.org/research/pages/autismandotherpervasivedevelopmentaldisordersconference\(february3-5,2008\).aspx](http://www.dsm5.org/research/pages/autismandotherpervasivedevelopmentaldisordersconference(february3-5,2008).aspx)
- First, M. B. (Ed.). (1994). *Quick Reference to the Diagnostic Criteria from DSM-IV*. Washington, DC: American Psychiatric Association.
- Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism*, 9, 299-316. doi: 10.1177/1362361305054410
- Flippin, M., Reszka, S., & Watson, L. R. (2010). Effectiveness of the picture exchange communication system (PECS) on communication and speech for children with autism spectrum disorders: a meta-analysis. *American Journal of Speech-Language Pathology*, 19(2), 178-195. doi: 10.1044/1058-0360(2010/09-0022)
- Floyd, E. F., & Mcintosh, D. (2009). Current practice in psychopharmacology for children and adolescents with autism spectrum disorders. *Psychology in the Schools*, 46(9), 905 - 909.

- Freeman, B. J. (1997). Guidelines for evaluating intervention programs for children with autism. *Journal of Autism and Developmental Disorders*, 27(6), 641-651. doi: 10.1023/a:1025850715183
- Gagliardi, A., & Jadad, A. R. (2002). Examination of instruments used to rate quality of health information on the Internet: chronicle of a voyage with an unclear destination. *BMJ*, 324(7337), 569-573. doi: 10.1136/bmj.324.7337.569
- Gibbs, V., Aldidge, F., Chandler, F., Witzlsperger, E. & Smith, K. (2012). Brief Report: An Exploratory Study Comparing Diagnostic Outcomes for Autism Spectrum Disorders Under DSM-IV-TR with the Proposed DSM-5 Revision. *Journal of Autism and Developmental Disabilities*, DOI 10.1007/s10803-012-1560-6.
- Gigerenzer, G., Gaissmaier, W., Kurz-Milcke, E., Schwartz, L. M., & Woloshin, S. (2008). Helping doctors and patients make sense of health statistics. *Association for Psychological Science*, 8(2), 53-96.
- Gilliam, J. E. (1995). Gilliam Autism Rating Scale: GARS: examiner's manual. Austin: PRO-ED.
- Glasziou, P., & Haynes, B. (2005). The paths from research to improved health outcomes. *Evidence-based Medicine*, 10 (February 2005).
- Godolphin, W., Towle, A., & McKendry, R. (2001). Evaluation of the quality of patient information to support informed shared decision making . *Health Expectations*, 4(4), 235-242. doi: 10.1046/j.1369-6513.2001.00144.x
- Grant, N. (2013). Autism Decision Aid, <http://www.autismdecisionaid.com.au>
- Grant, N., Rodger, S., & Hoffmann, T. (2015). Evaluation of autism-related health information on the web. *Journal of Applied Research in Intellectual Disabilities*. 28, 4, 276 – 282.
- Grant, N., Rodger, S., & Hoffmann, T. (2016). Parents of children with Autism Spectrum Disorder: Intervention decision making processes and information preferences. *Child: Care Health and Development*. 42, 1, 125 – 134
- Grant, N., Rodger, S., & Hoffmann, T. (2016). A pilot randomised controlled trial of a web-based decision aid about early intervention options for parents of children newly diagnosed with Autism Spectrum Disorder.

Focus on Autism and other Developmental Disabilities. (Submitted on 27 January 2016, Under Review).

- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27* (1), 70-84.
- Greenspan, S. I., Brazelton, T. B., Cordero, J., Solomon, R., Bauman, M. L., Robinson, R., Breinbauer, C. (2008). Guidelines for early identification, screening and clinical management of children with Autism Spectrum Disorders. *Pediatrics, 121*, 828-830.
- Goldstein, N. D., Tager-Flusberg, H., & Lee, B. K. (2015). Mapping collaboration networks in the world of autism research. *Autism Research, 8*(1), 1-8. doi:10.1002/aur.1393
- Gupta, S. K. (2011). Intention-to-treat concept: A review. *Perspectives in Clinical Research, 2*(3), 109-112.
- Gray C. A., & Garand J. D. (1993). "Social Stories: improving responses of students with autism with accurate social information". *Focus on Autistic Behavior 8* (1): pp. 1–10. doi:10.1177/108835769300800101.
- Hawk, C., & Evans, W. (2013). *Consumer Health Information and Literacy. Health Promotion and Wellness: An Evidence-Based Guide to Clinical Preventive Services*, Lippincott Williams & Wilkins, Philadelphia.
- Health On The Net Foundation. (2011). HON Code of Conduct (HONcode) for medical and health Websites. from <http://www.hon.ch/Conduct.html>
- Hoffman, A., Volk, R., Saarimaki, Stirling, C., Li, L., Harter, M., & Llewellyn-Thomas, H. (2013). Delivering patient decision aids on the Internet: Definitions, theories, current evidence, and emerging research areas. *BMC Medical Informatics and Decision Making, 13*(Suppl 2), S13.
- Hoffmann, T., Bennett, S., & Mar, C. D. (2010). *Evidence-Based Practice: Across the health professions*. Australia: Elsevier.
- Hoffmann, T. C., Légaré. F., Simmons, M. B., McNamara, K., McCaffery, K., Trevena, L. J., Hudson, B., Glasziou, P.P., & Del Mar, C. B. (2014). Shared decision making: what do clinicians need to know and why should they bother? *Medical Journal of Australia. 201* (1): 35-39. doi: 10.5694/mja14.00002

- Hoffmann, T. C., Montori, V. M., & Del Mar, C. (2014). The connection between evidence-based medicine and shared decision making. *JAMA*, 312(13), 1295-1296. doi: 10.1001/jama.2014.10186
- Huh, J., & Cude, B. J. (2004). Is the information “fair and balanced” in direct-to-consumer prescription drug websites? *Journal of health Communication*, 9, 529 – 540 DOI: 10.1080/10810730490882667
- Ishikawa, H., & Kiuchi, T. (2010). Health literacy and health communication. *BioPsychoSocial Medicine*, 4(1), 18.
- Jordan, C. (2010). Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disability*, 48(3), 220 - 227.
- Joseph-Williams, N., Newcombe, R., Politi, M., Durand, M., Sivell, S., Stacey, D., & Elwyn, G. (2013). Toward minimum standards for certifying Patient Decision Aids: A modified Delphi consensus process. *Medical Decision Making*. Accessed online.
- Kaicker, J., Debono, V. B., Dang, W., Buckley, N., & Thabane, L. (2010). Assessment of the quality and variability of health information on chronic pain websites using the DISCERN instrument. *BMC Medicine*, 8(59).
- Kertoy, M. K. (2011). Providing families with relevant information: How can we improve our service system? *Physical & Occupational Therapy in Pediatrics*, 31(3). doi: doi:10.3109/01942638.2011.589726
- Keen, D., Couzens, D., Muspratt, & Rodger, S. (2010) The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, 4 2: 229-241. doi:10.1016/j.rasd.2009.09.009
- Keen, D. & Rodger, S. (2012) Working with Parents of a Newly Diagnosed Child with an Autism Spectrum Disorder: A Guide for Professionals, Jessica Kingsley Publishers.
- Khazaal, Y., Chatton, A., Cochand, S., Coquard, O., Fernandez, S., Khan, R., & Zullino, D. (2009). Brief DISCERN, six questions for the evaluation of

- evidence-based content of health-related websites. *Patient Education and Counseling*, 77(1), 33-37. doi: DOI: 10.1016/j.pec.2009.02.016
- Kim, P., Eng, T. R., Deering, M. J., & Maxfield, A. (1999). Published criteria for evaluating health related web sites: review. *BMJ*, 318.
- Kim, J., Wigram, T., & Gold, C. (2009). Emotional, motivational and interpersonal responsiveness of children with autism in improvisational music therapy. *Autism*, 13(4), 389-409. PMID: 19535468
- Krug, D. A., Arick, J., & Almond, P. (1980). Behavior checklist for identifying severely handicapped individuals with high levels of autistic behaviour. *Journal of Child Psychology and Psychiatry*, 21(3), 221-229. doi: 10.1111/j.1469-7610.1980.tb01797.x
- Kryworuchko, J., Stacey, D., Bennett, C. & Graham, I.D. (2008). Appraisal of primary outcome measures used in trials of patient decision support. *Journal of Patient Education and Counselling*. Dec. 73 (3). 497 – 503. Doi: 10.1016/j.pec.2008.07.011.
- Lai, M.-C., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. *The Lancet*, 383(9920), 896-910. doi: 10.1038/mp.2012.106.
[http://dx.doi.org/10.1016/S0140-6736\(13\)61539-1](http://dx.doi.org/10.1016/S0140-6736(13)61539-1)
- Le Couteur, A., Lord, C., & Rutter, M. (2003). Autism Diagnostic Interview-Revised (ADI-R). Retrieved Mar. 5, 2009, from Autism Genetic Resource Exchange, Los Angeles, CA. Web site: <http://www.agre.org/program/aboutadi.cfm>.
- Légaré F, Ratté S, Stacey D, et al. (2010). Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Systematic Reviews*; (5): CD006732.
- Légaré F, Turcotte S, Stacey D, et al. (2012). Patients' perceptions of sharing in decisions: a systematic review of interventions to enhance shared decision making in routine clinical practice. *Patient*. 5: 1-19.
- Leskovec, T. J., Rowles, B. M., & Findling, R. L. (2008). Pharmacological treatment options for Autism Spectrum Disorders in children and adolescents. *Harvard Review of Psychiatry*, 16(2), 97-112. doi: doi:10.1080/10673220802075852

- Levasseur, M., & Carrier, A. (2010). Do rehabilitation professionals need to consider their clients' health literacy for effective practice? *Clinical Rehabilitation*, 24(8), 756-765. doi: 10.1177/0269215509360752
- Levasseur, M., & Carrier, A. (2011). Integrating health literacy into occupational therapy: Findings from a scoping review. *Scandinavian Journal of Occupational Therapy*, 0(0), 1-10. doi: doi:10.3109/11038128.2011.588724
- Levy, S., & Hyman, S. (2008). Complementary and alternative medicine treatments for children with Autism Spectrum Disorders. *Child Adolescent Psychiatric Clinics of North America*, 17, 803-820.
- Lord C, Rutter M, Goode S; et al. (1989). "Autism diagnostic observation schedule: a standardized observation of communicative and social behavior". *Journal of Autism and Developmental Disorders*,19 (2): 185–212.
- Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, 32(2), 246-258. doi: 10.1177/0272989x11421528
- Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2005). Sources of information and support used by parents of children with Autism Spectrum Disorders. *Journal on Developmental Disabilities*, 12(1), 41-52.
- Mancuso, J. M. (2009). Assessment and measurement of health literacy: An integrative review of the literature. *Nursing & Health Sciences*, 11(1), 77-89. doi: 10.1111/j.1442-2018.2008.00408.x
- Mandell, D., & Lecavalier, L. (2014). Should we believe the Centers for Disease Control and Prevention's autism spectrum disorder prevalence estimates? *Autism*, 18(5), 482-484. doi: 10.1177/1362361314538131
- Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with Autism Spectrum Disorders. *Mental Retardation and Developmental Disabilities*, 11, 110-115.

- Mathieu, E. (2010). The Internet and medical decision making: Can it replace the role of health care providers? *Medical Decision Making*, 30 (5 Suppl), 14s-16s. doi: 10.1177/0272989x10381228
- McCaffery, K., Holmes-Rovner, M., Smith, S., Rovner, D., Nutbeam, D., Clayman, M., . . . Sheridan, S. (2013). Addressing health literacy in patient decision aids. *BMC Medical Informatics & Decision Making*, 13 (Suppl), S10.
- McCarthy, M. (2014). Autism diagnoses in the US rise by 30%, *CDC reports* (Vol. 348).
- McMullan, M. (2005). Patients using the Internet to obtain health information: How this affects the patient-health professional relationship. *Patient Education and Counseling*, 63, 24-28.
- McPartland, J.C., Reichow, B. & Volkmar, F.R. (2012). Sensitivity and Specificity of Proposed DSM-5 Diagnostic Criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4), 368-383.
- Mesibov, G., & Shea, V. (2010). Evidence-Based Practices and Autism. *Autism*. 15(1), 114-133.
- Miller, V. A., Schreck, K. A., Mulick, J. A., & Butter, E. (2011). Factors related to parents' choices of treatments for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders, In Press, Corrected Proof*. doi: DOI: 10.1016/j.rasd.2011.03.008
- Miller-Kuhaneck, H. (2004). *Autism: A Comprehensive Occupational Therapy Approach* (2nd ed.). Richmond, VA: Carter Printing.
- Ministries of Health and Education. (2008). *New Zealand Autism Spectrum Disorder Guidelines*. Wellington, Ministry of Health.
- Montori, V., LeBlanc, A., Buchholz, A., Stilwell, D., & Tsapas, A. (2013). Basing information on comprehensive, critically appraised, and up-to-date syntheses of the scientific evidence: a quality dimension of the International Patient Decision Aid Standards. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S5.
- Mulligan, J., Steel, L., Macculloch, R., & Nicholas, D. (2010). Evaluation of an information resource for parents of children with autism spectrum

- disorder. *Autism: The International Journal of Research & Practice*, 14(2), 113-126. doi: 10.1177/1362361309342570
- Murphy, P. W., Davis, T. C., Long, S. W., Jackson, R. H., & Decker, B. C. (1993). Rapid Estimate of Adult Literacy in Medicine (REALM): A quick reading test for patients. *Journal of Reading*, 37(2), 124-130.
- National Autism Center. (2009). The National Autism Center's National Standards Report. Massachusetts: National Autism Center.
<http://www.nationalautismcenter.org/national-standards-project/history/>
- National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Randolph, MA.
- National Disability Insurance Agency (2015). Building the National Disability Insurance Scheme PROGRESS REPORT: YEAR TWO. Published July 2015.
- National Health and Medical Research Council of Australia (NHMRC). (2006). *Making decisions about tests and treatments: Principles for better communication between healthcare consumers and healthcare professionals*. Canberra: Australian Government Printer.
- Needham, G., Charnock, D., Gann, R., & Shepperd, S. (1999). DISCERN: An instrument for judging the quality of written consumer health information on treatment choices. *Journal of epidemiology and community health* (1979), 53(2), 105-111. doi: 10.2307/j50000490
- O'Connor, A. (1993 (updated 2010)). *User Manual - Decisional Conflict Scale (16 item question format) [document on the Internet]* Retrieved from http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf
- O'Connor, A., Bennett, C., Stacey, D., Barry, M., Col, N., Eden, K., & Rovner, D. (2009). Decision aids for people facing health treatment or screening decisions (Review). *The Cochrane Collaboration*, (3).
- O'Hare, A. (2010). Grappling with the grey evidence. *Developmental Medicine & Child Neurology*, 979.
- O'Reilly, B., & Smith, S. (2008). *Australian Autism Handbook: The essential resource guide for autism spectrum disorders*. Edgecliff, NSW: Jane Curry Publishing.

- Osborne, L. A., & Reed, P. (2008a). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism, 12*(3), 309-324. doi: 10.1177/1362361307089517
- Ospina, M., Krebs, S. J., Clark, B., Karkhaneh, M., Hartling, M., Tjosvold, L., & Smith, V. (2008). Behavioural and developmental interventions for Autism Spectrum Disorder: A Clinical systematic review. *PloS One, 3*(11).
- Oswald, D. P., & Sonenklar, N. A. (2007). Medication use among children with Autism Spectrum Disorders. *Journal of Child and Adolescent Psychopharmacology, 17*(3), 348-355. doi: 10.1089/cap.2006.17303
- Patterson, S. Y., Smith, V., & Jelen, M. (2010). Behavioural intervention practices for stereotypic and repetitive behaviour in individuals with autism spectrum disorder: a systematic review. *Developmental Medicine & Child Neurology, 52*(4), 318-327.
- Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5 Pt 2), 1189-1208.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Di Pietro, N. C., Whiteley, L., & Illes, J. (2012). Treatments and services for neurodevelopmental disorders on advocacy websites: Information or evaluation?. *Neuroethics, 5*(2), 197-209.
- Pleasant, A., & Kuruvilla, S. (2008). A tale of two health literacies: public health and clinical approaches to health literacy. *Health Promotion International, 23*(2), 152-159.
- Pollock, N. (2009). Sensory integration: A review of the current state of the evidence. *Occupational Therapy Now, 11*(5), 6-10.
- Posey, D. J., Stigler, K. A., Erickson, C. A., & McDougle, C. J. (2008). Antipsychotics in the treatment of autism. *Journal of Clinical Investigation., 118*(1), 6-14.
- Pramparo, T., Pierce, K., Lombardo, M. V., & et al. (2015). Prediction of autism by translation and immune/inflammation coexpressed genes in toddlers from pediatric community practices. *JAMA Psychiatry*. doi: 10.1001/jamapsychiatry.2014.3008

- Prior, M., Roberts, J. M.A., Rodger, S., Williams, K.& Sutherland, R.(2011). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia.
- Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social Skills interventions for children with Aspergers Syndrome or High-Functioning Autism: A review and recommendations. *Journal of Autism & Developmental Disorders*, 38(2), 353-361. doi: 10.1007/s10803-007-0402-4
- Rees, C. E., Ford, J. E., & Sheard, C. E. (2002). Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. *Patient Education and Counseling*, 47(3), 273-275. doi: Doi: 10.1016/s0738-3991(01)00225-7
- Reichow, B., Doehring, P., Cicchetti, D. V., & Volkmar, F. R. (Eds.). (2011). *Evidence-Based Practices and Treatments for Children with Autism*. New York: Springer.
- Reichow, B., Halpern, J., Steinhoff, T., Letsinger, N., Naples, A., & Volkmar, F. (2011). Characteristics and quality of autism websites. *Journal of Autism and Developmental Disorders*, 1-12. doi: 10.1007/s10803-011-1342-6
- Reichow, B., Halpern, J., & Volkmar, F. R. (2010). Evaluation of quality benchmarks and characteristics of autism websites. *Yale Child Study Center*.
- Reichow, B., Naples, A., Steinhoff, T., Halpern, J., & Volkmar, F. R. (2012). Brief Report: Consistency of Search Engine Rankings for Autism Websites. *Journal of Autism and Developmental Disorders*, 42(6), 1275-1279.
- Reichow, B., Volkmar, F., & Cicchetti, D. (2008). Development of the evaluative method for evaluating and determining evidence-based practices in autism. *Journal of Autism and Developmental Disorders*, 38(7), 1311-1319. doi: 10.1007/s10803-007-0517-7
- Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of Early Intensive Behavioral Interventions for young children with autism based on the

- UCLA Young Autism Project Model. *Journal of Autism & Developmental Disorders*, 39(1), 23-41. doi: 10.1007/s10803-008-0596-0
- Reid, D. H., & Fitch, W. H. (2011). Training staff and parents: Evidence-based approaches. *International Handbook of Autism and Pervasive Developmental Disorders, Autism and Child Psychopathology Series*, 509-519.
- Research Autism. (2010a). Interventions: Treatments and Therapies for Autism Spectrum Disorders. Retrieved 3/9/10
- Research Autism. (2010b). Treatments and Therapies for Autism Spectrum Disorders Currently Under Scientific Evaluation. Retrieved 3/9/10
- Rimland, B., & Edelson, S. (1995). Brief report: A pilot study of auditory integration training in autism. *Journal of Autism and Developmental Disorders*, 25 (1), 61-70. doi: 10.1007/bf02178168
- Roberts, J., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia.
- Roberts, J., & Prior, M. (2012). *Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice' 2012*. <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/early-intervention-for-children-with-autism-spectrum-disorders-guidelines-for-good-practice-2012>
- Roberts, J., Williams, K., Carter, M., Evans, D., Parmenter, T., Silove, N., & Warren, A. (2011). A randomised controlled trial of two early intervention programs for young children with autism: Centre-based with parent program and home-based. *Research in Autism Spectrum Disorders*, *In Press, Corrected Proof*. doi: DOI: 10.1016/j.rasd.2011.03.001
- Rodger, S., Ashburner, J., Cartmill, L., & Bourke-Taylor, H. (2010). Helping children with autism spectrum disorders and their families: Are we losing our occupation-centred focus? *Australian Occupational Therapy Journal*. 57: 276–280. doi: 10.1111/j.1440-1630.2010.00877.x

- Rootman, I., & Ronson, B. (2005). Literacy and health research in Canada: Where have we been and where should we go? *Canadian Journal of Public Health*, 96(00084263), S62-S62-77.
- Rudy, L. J. (2008). Review: First 100 Days Kit from Autism Speaks. Retrieved 12/11/2010
- Sabo, R. M., & Lorenzen, J. M. (2008). Webhealth topics. Consumer health Web sites for parents of children with autism. *Journal of Consumer Health on the Internet*, 12(1), 37-49.
- Sanders, R. Q. (2008). *How to talk to parents about autism*. New York: W.W. Norton and Company, Inc.
- Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, 119 (Suppl 1), S114-121. doi: 10.1542/peds.2006-2089Q
- Schlosser, R. W., & Wendt, O. (2008). Effects of augmentative and alternative communication intervention on speech production in children with autism: a systematic review. *American Journal of Speech-Language Pathology*, 17(3), 212-230.
- Scholl, I., Koelewijn-van Loon, M., Sepucha, K., Elwyn, G., Legare, F., Harter, M., & Dirmaier, J. (2011). Measurement of shared decision making – a review of instruments. *Policy and practice developments in the implementation of shared decision making: An international perspective*. 105(4), 313-324.
- Schopler, Lansing, Reichler & Marcus (2004). Psychoeducational Profile Third Edition (PEP-3), Pro-Ed, USA.
- Schopler E, Reichler RJ, DeVellis RF, Daly K (1980). "Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS)". *Journal of Autism and Developmental Disorders* 10(1): 91–103. doi:10.1007/BF02408436
- Schopler, E. and Reichler, R. (1971). "Parents as Co-therapists in the Treatment of Psychotic Children". *Journal of Autism and Childhood Schizophrenia* 1(1): pp. 87–102. doi:10.1007/BF01537746
- Schwartz, L., Woloshin, S., Black, W., & Welch, H. (1997). *Annals of Internal Medicine*, 127, 966.

- Schwarz, J. (2011). Augmenting Web Pages and Search Results to Help People Find Trustworthy Information Online. Accessed online.
- Scottish Intercollegiate Guidelines Network (SIGN). (2007). *Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. A National Clinical Guideline*. Edinburgh: Scottish Intercollegiate Guidelines Network.
- See, C. M. (2012) The Use of Music and Movement Therapy to Modify Behaviour of Children with Autism. *Pertanika Journal of Social Sciences & Humanities*, 20(4): 1103 – 1116
- Seida, J. K., Ospina, M. B., Karkhaneh, M., Hartling, L., Smith, V., & Clark, B. (2009). Systematic reviews of psychosocial interventions for autism: an umbrella review. *Developmental Medicine & Child Neurology*(51), 95-104.
- Selby, M., Boyer, C., Scherrer, J., & Appel, R. (1998). The Health on the Net code of conduct for medical and health websites. *Computers in Biology and Medicine*, 28(5), 603-610.
- Sepucha, K., Borkhoff, C., Lally, J., Levin, C., Matlock, D., Ng, C., & Thomson, R. (2013). Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. *BMC Medical Informatics & Decision Making*, 13 (Suppl), S12.
- Sepucha, K., Fowler, F., & Mulley, A. (2004). Policy support for patient-centered care: the need for measurable improvements in decision quality. *Health Aff (Millwood)*, *Suppl Variation*, VAR54 - 62.
- Shannon, R. (2010). Search Engines. Retrieved 6 December 2010, from <http://www.yourhtmlsource.com/promotion/searchengines.html>
- Singleton, K., & Krause, E., M.S. (2009). Understanding cultural and linguistic barriers to health literacy. *Online Journal of Issues in Nursing*, 14(3). <http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol142009/No3Sept09/Cultural-and-Linguistic-Barriers-.aspx>
- Sinha, Y., Silove, N., Wheeler, D., & Williams, K. (2009). Auditory integration training and other sound therapies for autism spectrum disorders (Review). *The Cochrane Library* (1).

- Stacey, D., Bennett, C., Barry, M., Col, N., Eden, K., Holmes-Rovner, M., . . . Thomson, R. (2011). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 10, CD001431.
- Stacey D, Légaré F, Col NF, et al. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*; (1): CD001431. doi: 10.1002/14651858.CD001431.pub4.
- Stacey, D., Kryworuchko, J., Belkora, J., Davison, J., Durand, M., Eden, K., & Street, R. (2013). Coaching and guidance with patient decision aids: A review of theoretical and empirical evidence. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S11.
- Sullivan, D. (2006). Nielsen NetRatings Search Engine Ratings. Retrieved 6 December 2010, 2011, from <http://searchenginewatch.com/2156451>
- Szatmari, P. (2011). New recommendations on autism spectrum disorder. *BMJ*, (342:d2456).
- The National Autistic Society for NIASA. (2003). *National Autism Plan for Children*. London: The National Autistic Society for NIASA.
- The Raising Children Network. (2010). Parent Guide to Therapies FAQ. Retrieved 1 June 2011 from http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html
- The Raising Children Network. (2011). Parent Guide to Therapies. Retrieved 1 June 2011, from http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html
- Thistlethwaite, J. (2006). Shared decision making and decision aids. A literature review. *Australian Family Physician*, 35 (7), 537 - 540.
- Thompson, T. (2011a). *Individualized autism intervention for young children blending discrete trial and naturalistic strategies*. Baltimore: Paul H. Brookes Pub.
- Thompson, T. (2011b). Predicting Intervention Outcome *Individualised Autism Intervention for Young Children Blending Discrete Trial and Naturalistic Strategies*. Baltimore: Paul H. Brooks Pub.

- Trevena, L., Davey, H., Barratt, A., Butow, P., & Caldwell, P. (2006). A systematic review on communicating with patients about evidence. *Journal of Evaluation in Clinical Practice*, 12, 13 - 23.
- Trevena, L., Zikmund-Fisher, B., Edwards, A., Gaissmaier, W., Galesic, M., Han, P., & Woloshin, S. (2013). Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S7.
- Unnebrink, K., & Windeler, J. (2001). Intention-to-treat: methods for dealing with missing values in clinical trials of progressively deteriorating diseases. *Statistics in Medicine*, 20(24), 3931-3946.
- Valentine, K. (2010). A consideration of medicalisation: choice, engagement and other responsibilities of parents of children with autism spectrum disorder. *Social Science & Medicine*, 71(5), 950-957.
- Valentine, K., Rajkovic, M., Dinning, B., & Thompson, D. (2010). Occasional Paper No. 35 Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers.
<http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Documents/op35/OP35.pdf>
- Van Selm, M., & Jankowski, N. W. (2006). Conducting online surveys. *Quality and Quantity*, 40(3), 435-435-456. doi: 10.1007/s11135-005-8081-8
- Vickers, A. J., & Altman, D. G. (2001). Analysing controlled trials with baseline and follow up measurements. *BMJ : British Medical Journal*, 323(7321), 1123-1124.
- Volk, R., Llewellyn-Thomas, H., Stacey, D., & Elwyn, G. (2013). Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S1.
- Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for Autism Spectrum Disorders. *Pediatrics*, 127(5), e1302-e1311.

- Warren, Z., Veenstra-VanderWeele, J., Stone, W., Bruzek, J., Nahmias, A., Foss-Feig, J., & McPheeters, M. (2011). *Therapies for Children With Autism Spectrum Disorders. Comparative Effectiveness Review No. 26. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2007-10065-I) AHRQ Publication No. 11-EHC029-EF.* Rockville, MD: Agency for Healthcare Research and Quality, US Department of Health and Human Services.
- Washington, T. A., Fanciullo, G. J., Sorensen, J. A., & Baird, J. C. (2008). Quality of chronic pain websites. *Pain Medicine*, 9(8), 994-1000.
- Whelan, T., Levine, M., Willan, A., et al. (2004). Effect of a Decision Aid on Knowledge and Treatment Decision Making for Breast Cancer Surgery: A Randomized Trial. *JAMA*. 292(4):435-441.
doi:10.1001/jama.292.4.435.
- Whipple J. (2004). Music in intervention for children and adolescents with autism: a meta-analysis. *Journal of Music Therapy*. 41(2):90-106.
PubMed PMID: 15307805.
- Williams, K., MacDermott, S., Ridley, G., Glasson, E. J., & Wray, J. A. (2008). The prevalence of autism in Australia. Can it be established from existing data? *Journal of Paediatrics and Child Health*, 44(9), 504-510.
doi: 10.1111/j.1440-1754.2008.01331.x
- Williams, K. & Roberts, J. M. A. (2015). *Understanding autism : the essential guide for parents.* Wollombi, NSW: Exisle Publishing
- Woloshin, S., & Schwartz, L. (1999). *Effective Clinical Practice*, 2, 176.
- Woloshin, S., Schwartz, L. M., & Welch, H. G. (2008). *Know Your Chances Understanding Health Statistics.* Berkley, CA: University of California Press.
- World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines.* Geneva.

Appendix A - Confirmation of Ethics Approval for Research Project



THE UNIVERSITY OF QUEENSLAND
**Institutional Approval Form For Experiments On Humans
Including Behavioural Research**

Chief Investigator: Ms Nicole Grant

Project Title: Assisting Parents Of Children With Autism To Make Intervention Decisions By Improving Their Health Literacy About Interventions And Their Evidence

Supervisor: Prof Sylvia Rodger, Dr Tammy Hoffmann

Co-Investigator(s): None

Department(s): School of Health and Rehabilitation Sciences

Project Number: 2011000783

Granting Agency/Degree: Olga Tennison Autism Research Centre, La Trobe University, Victoria

Duration: 31st March 2015

Comments:

**Name of responsible Committee:-
Behavioural & Social Sciences Ethical Review Committee**

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

**Name of Ethics Committee representative:-
Associate Professor John McLean
Chairperson
Behavioural & Social Sciences Ethical Review Committee**

Date

11/8/2011

Signature



THE UNIVERSITY OF QUEENSLAND
Institutional Human Research Ethics Approval

Project Title: Assisting Parents Of Children With Autism To Make Intervention Decisions By Improving Their Health Literacy About Interventions And Their Evidence - 04/02/2013 - AMENDMENT

Chief Investigator: Ms Nicole Grant

Supervisor: Prof Sylvia Rodger, Dr Tammy Hoffmann

Co-Investigator(s): None

School(s): School of Health and Rehabilitation Sciences; Centre for Research in Evidence-Based Practice (CREBP), Faculty of Health Sciences and Medicine, Bond University

Approval Number: 2011000783

Granting Agency/Degree: Olga Tennison Autism Research Centre, La Trobe University, Victoria

Duration: 31st March 2015

Comments:

Note: If this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:

Behavioural & Social Sciences Ethical Review Committee

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:

Associate Professor John McLean

Chairperson

Behavioural & Social Sciences Ethical Review Committee

Signature

Date

Appendix B - Study 1: Participant Information Sheet



Participant Information Sheet for Completion of Autism Advisor Survey

INFORMATION FOR SURVEY RESPONDENTS

Research project title: Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Lay title: Helping parents decide on interventions for their child

Chief investigator: Nicole Grant, School of Health and Rehabilitation Sciences. The University of Queensland

Co-investigators: Professor Sylvia Rodger, Head of School, Division of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland, and Dr Tammy Hoffmann, School of Health and Rehabilitation Sciences, The University of Queensland

Your participation in this research project would be greatly appreciated.

The aims of this study are to investigate:

1. What information do parents use to make decisions about the interventions they access for their children with Autism Spectrum Disorder (ASD)?
2. What decision making processes do parents use in making intervention decisions?

3. What is the quality of the information parents' access in terms of quality of evidence provided, particularly web-based information?
4. Does a purpose-designed workshop on health literacy relevant to ASD change parents' likely intervention decisions and in what ways?

This part of the study is specifically for Autism Advisors working with parents and carers of children newly diagnosed with ASD. Advisors are asked to complete a two part electronic survey. The questions in Part A ask you to reflect on your previous experiences with parents/ carers of children recently diagnosed with autism. Part B is to be completed once you have asked ten (10) parents/ carers a series of questions. Completion of both parts of the survey will take approximately 20-30 minutes.

Before commencing the electronic survey you will be required to ask 10 parents four (4) questions about their Internet use during your initial consultation with them. We will provide you with a brief data collection sheet to help you record this information. You will use this information to complete the electronic survey once all 10 parents have been interviewed. The data collection sheet, link to the survey, and additional instructions are attached. Your consent to participate in the study is assumed if you decide to complete this survey.

Parents must provide their verbal consent before their responses to the survey questions are collected. Instructions for obtaining parent consent are included on the data collection sheet attached.

Should you have any questions in relation to the study please contact Nicole Grant on 0417 879 461 or Professor Sylvia Rodger on (07) 3365 1664.

The information that you provide in this survey will remain confidential and the information you provide based on parent responses and your own, will be de-identified. You are requested to return this survey anonymously. Strict confidentiality with the study data will at all times be maintained by ensuring

password protection of electronic information and storage of hard copies in a locked filing cabinet.

This study has been cleared by The University of Queensland human ethics committee in accordance with the National Health and Medical Research Council's guidelines. If you wish to speak with someone not involved, please contact the UQ ethics officer, Mr Michael Tse on (07) 3365 3924.

Please retain this letter for your records. Thank you again for your participation in this project.

Yours sincerely,

A handwritten signature in blue ink that reads "ngrant". The signature is written in a cursive style and is centered within a light blue rectangular box.

Nicole Grant

Doctor of Philosophy Candidate

Ph. 0417 879 461

mail: nicole.grant@uqconnect.edu.au

Appendix C - Study 1: Information for Survey Respondents



ADDITIONAL INFORMATION AND DATA COLLECTION SHEET FOR AUTISM ADVISORS

Research project title: Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Chief investigator:

Nicole Grant
School of Health and Rehabilitation Sciences
The University of Queensland

Co-investigators:

Professor Sylvia Rodger
Head of School
Division of Occupational Therapy
School of Health and Rehabilitation Sciences
The University of Queensland

Dr Tammy Hoffmann
School of Health and Rehabilitation Sciences
The University of Queensland

Thank you for agreeing to participate in this study, the details of which are outlined in the Participant Information Sheet previously issued. The following spreadsheet is provided to assist you to record the information required for completion of the Autism Advisor – Parent’s Use of the Internet survey.

As outlined on the Participant Information Sheet, prior to recording parent responses to the questions below, verbal consent from parent participants is required. Please read the following statement to parent participants:

“We are involved in a PhD research project for a student at the University of Queensland, that looks at how parents make decisions about which interventions they choose for their child. I would like to ask you a few questions about your experience with finding information about autism on the Internet. If you say yes, your responses will be noted and provided to the researcher. No identifying information about you will be forwarded with your responses. Do you consent to being asked these few questions, and for your responses to be noted by me in writing?”

Please only proceed with the questions if parents provide verbal consent to participate in this part of the study.

Once you have interviewed ten (10) parents of children newly diagnosed with autism, please complete the survey, which can be accessed via the following link – <http://www.zoomerang.com/Survey/WEB22BTFEK4FUB/>.

Please contact the undersigned on phone 0417 879 461 with any queries or concerns. Thank you in advance for your assistance with this project.

Kind regards,

A handwritten signature in blue ink that reads "ngrant". The signature is written in a cursive style and is positioned on a light blue rectangular background.

Nicole Grant
Doctor of Philosophy Candidate
The University of Queensland

Appendix D - Study 1: Data Collection Sheet

AUTISM ADVISOR DATA COLLECTION SHEET

Parent No.	Have you accessed the Internet to obtain information regarding autism interventions? (Circle Yes or No)	If you did, what terms or words did you use to search for information?	What search engine (e.g. Google, Yahoo, Bing) did you use to conduct your search?	What websites did you visit?
1	Yes / No			
2	Yes / No			
3	Yes / No			

4	Yes / No			
5	Yes / No			
6	Yes / No			
7	Yes / No			

8	Yes / No			
9	Yes / No			
10	Yes / No			
SUMMARY	Total Yes – Total No –	List all search terms and words mentioned by parents:	List all search engines mentioned by parents:	List all websites mentioned by parents:

Appendix E - Study 3: Participant Consent Form



Participant Consent Form

Research project title: Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Lay title: Helping parents decide on interventions for their child

Chief investigator:

Nicole Grant
School of Health and Rehabilitation Sciences
The University of Queensland

Co-investigators:

Professor Sylvia Rodger
Head of School
Division of Occupational Therapy
School of Health and Rehabilitation Sciences
The University of Queensland

Dr Tammy Hoffmann
School of Health and Rehabilitation Sciences
The University of Queensland

Thank you for agreeing to participate in this research project. Please sign below to indicate that you have read and understand the requirements for your participation.

I have read the Participant Information Sheet and understand the requirements for my participation in this study.

I understand that my participation is voluntary, and that I may withdraw from this study at any time without penalty.

I understand that information obtained from me during interview will be audiotaped and transcribed, and that all recorded and written information provided by me is confidential and will be de-identified.

I can request further information about the results of this study by submitting my request in writing to the chief investigator.

Participant's Full Name:

Witnesses Full Name:

Signed: _____ Dated: _____

Signed: _____ Dated: _____

Appendix F - Study 3: Information for One-on-One Interview Participants



INFORMATION FOR INTERVIEW PARTICIPANTS

Research project title: Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Lay title: Helping parents decide on interventions for their child

Chief investigator:

Nicole Grant

School of Health and Rehabilitation Sciences

The University of Queensland

Co-investigators:

Professor Sylvia Rodger

Head of School

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

Dr Tammy Hoffmann

School of Health and Rehabilitation Sciences

The University of Queensland

We would like to formally invite you to contribute to this study by participating in a one-on-one interview to review and comment on samples of an intervention or educational resource designed to assist parents of children with autism to understand and interpret the research evidence for autism interventions. The aims of the research project are to investigate:

1. What information do parents use to make decisions about the interventions they access for their children with Autism Spectrum Disorder (ASD)?
2. What decision making processes do parents use in making intervention decisions?
3. What is the quality of the information parents' access in terms of quality of evidence provided, particularly web-based information?
4. Does a purpose-designed workshop on health literacy relevant to ASD change parents' likely intervention decisions and in what ways?

The information gathered from the interview, in addition to review of the literature on this topic, will be used to further develop an intervention or educational resource for parents of children newly diagnosed with autism, to help them better understand and interpret research evidence in order to make decisions about autism interventions.

The interviews will be conducted at the University of Queensland's St Lucia Campus, and will run for approximately 1 hour. Light refreshments will be provided to all participants, in addition to a \$20 gift voucher, to thank you for your time and contribution to this study.

The discussion during the interview will be recorded on audiotape for later transcription. Your privacy while participating in this study will be maintained at all times, and any identifying information removed from records. Strict confidentiality with the study data will at all times be maintained, by ensuring all electronic information is password protected, and any information stored in hard copies will be kept in a locked filing cabinet.

This study has been cleared by The University of Queensland human ethics committee in accordance with the National Health and Medical Research Council's guidelines. If you wish to speak with someone not involved, please contact the UQ ethics officer, Mr Michael Tse on (07) 3365 3924.

You are free to decline from participating in the study or to withdraw from the study at any time without explanation or fear of penalty. Should you have any questions regarding the nature of the research, please feel free to contact the undersigned on the number provided below.

To participate in this study, please complete the consent form attached. Thank you again for considering participation in this project.

Yours sincerely

A handwritten signature in blue ink that reads "ngrant". The signature is written in a cursive style and is positioned on a light blue rectangular background.

Nicole Grant

Doctor of Philosophy Candidate

Ph. 0417 879 461

Email: nicole.grant@uqconnect.edu.au

Appendix G - Study 3: Information for Focus Group Participants



INFORMATION FOR FOCUS GROUP PARTICIPANTS

Research project title: Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Lay title: Helping parents decide on interventions for their child

Chief investigator:

Nicole Grant

School of Health and Rehabilitation Sciences

The University of Queensland

Co-investigators:

Professor Sylvia Rodger

Head of School

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

Dr Tammy Hoffmann

School of Health and Rehabilitation Sciences

The University of Queensland

We would like to formally invite you to contribute to this study by participating in a focus group to discuss your experiences with choosing autism interventions for your child who has been diagnosed with an Autism Spectrum Disorder (ASD). The aims of this study are to investigate:

What information do parents use to make decisions about the interventions they access for their children with Autism Spectrum Disorder (ASD)?

What decision making processes do parents use in making intervention decisions?

What is the quality of the information parents' access in terms of quality of evidence provided, particularly web-based information?

Does a purpose-designed workshop on health literacy relevant to ASD change parents' likely intervention decisions and in what ways?

The information gathered from the focus group, in addition to review of the literature on this topic, will be used to develop an intervention or educational resource for parents of children newly diagnosed with autism, to help them better understand and interpret research evidence in order to make decisions about autism interventions.

The focus group will involve 8-10 parents of children diagnosed with autism, meeting to discuss their experiences with making decisions about treatment options and discussing what information they found most helpful in this process.

The focus group will be conducted at the University of Queensland's St Lucia Campus, and will run for approximately 1 – 2 hours. Light refreshments will be provided to all participants, in addition to a \$20 gift voucher, to thank you for your time and contribution to this study.

Following the focus group, participants will be asked to volunteer to participate in a one-on-one interview to further discuss this topic at a later date. Details regarding this part of the study will be provided at the focus group venue, and a separate Participant Information Sheet issued to interested individuals.

The discussion during the focus group will be recorded on audiotape for later transcription. Your privacy while participating in this study will be maintained at all times, and any identifying information removed from records. Strict confidentiality with the study data will at all times be maintained, by ensuring all electronic information is password protected, and any information stored in hard copies will be kept in a locked filing cabinet.

This study has been cleared by The University of Queensland human ethics committee in accordance with the National Health and Medical Research Council's guidelines. If you wish to speak with someone not involved, please contact the UQ ethics officer, Mr Michael Tse on (07) 3365 3924.

You are free to decline from participating in the study or to withdraw from the study at any time without explanation or fear of penalty. Should you have any questions regarding the nature of the research, please feel free to contact the undersigned on the number provided below.

To participate in this study, please complete the consent form attached. Thank you again for considering participation in this project.

Yours sincerely

A handwritten signature in blue ink that reads "ngrant". The signature is written in a cursive style and is positioned on a light blue rectangular background.

Nicole Grant

Doctor of Philosophy Candidate

Ph. 0417 879 461

Email: Nicole.grant@uqconnect.edu.au

Appendix H - Study 3: Summary sent to participants for member checking

Summary of Parent interviews and Focus Groups

Between October 2011 and January 2012, 23 parents of children with autism were interviewed to find out more about their decision making processes post autism diagnosis – specifically sources of information used and information preferences.

The following is a brief summary of the findings following analysis of the interview and focus group transcripts. Participants are asked to provide comment on whether or not they feel this summary accurately reflects the views and opinions of those who participated in this study. I appreciate it was a while ago now, so I have just provided a brief summary of the key messages.

Parents with children diagnosed with autism described a journey from the point of diagnosis that involves seeking information on autism treatments from a number of sources, and a 'trial and error' approach to choosing and trialling a range of autism interventions.

Many of you described the trust you have in health professionals to provide you with intervention recommendations. The more trusted professionals were likely to be therapists that you were already working with, or who are well known to the family. Parents also relied on other parents of children diagnosed with autism for information about treatment options/decisions. These parents were often accessed via workshop attendance and online forums, such as those found on Facebook.

As a group you described preferring information about autism interventions to be presented in a variety of formats, and preferably tailored to your individual child and circumstances. The timing of information provision was also considered important, for example information should be relevant to the time of diagnosis, or how much time had passed since the diagnosis, the child's life stage (preschool, primary school, adolescence) and developmental stage. Some parents preferred a lot of information, while others

wanted brief brochures, handouts and lists as these were considered less overwhelming than a greater amount of information to sift through.

Many of you had attended workshops to obtain information, and generally found these to be useful, however time and travel constraints, as well as work and other family commitments all impact on your ability to attend. While many parents enjoyed the social aspect of workshops, and enjoyed hearing about other parents' experiences with autism and specific interventions. You also often found at times that the information provided at some workshops was irrelevant to your particular child's needs. The opportunity to ask questions of the presenter was seen as a positive aspect of attending workshops and many mentioned that engaging and interesting presenters were more effective in conveying useful information than those who were not.

Many of you frequently searched the Internet for information. Internet searches range from random 'googling' to searching specific sites. Popular sites included Autism QLD and the Raising Children Network website. Positive aspects of using the Internet for information included having 24-hour access and being able to find information specific to your child's needs from the convenience of your own home. The Internet also helped you to find a lot of information in a short amount of time. While the Internet was a preferred source of information for many, there were some characteristics of websites that were considered undesirable. These included too much information that was confusing and overwhelming, and the lack of information on interventions specific to the Australian context (i.e. what was available locally/nationally). Many parents described conducting Internet searches found themselves on international sites.

When discussing evidence behind interventions and whether research evidence was considered when making intervention decisions, your responses were very mixed. Some parents stated that they read articles about studies undertaken but most of you believed that mainstream therapies must be evidence-based if they are readily available and have reportedly worked for others.

Many of you reported that your confidence improved as you became more familiar with your individual child's diagnosis and needs, and once you had an opportunity to speak to a number of people about your child's diagnosis. You wished to view autism information in a range of formats (Internet, written hard copy, podcast, workshops). It was often easy to be

overwhelmed by the sheer volume of information that is available, and many suggested that less information at the beginning (point of diagnosis) would be better. The information most wanted immediately post-diagnosis included lists of useful contacts and providers. Many commented that the contacts they were provided were often out-dated and no longer available. The need for constantly updated and relevant information was highlighted.

In summary, intervention decision making was considered a complex and ongoing concern for parents of children with autism. Decisions were made based on the availability of providers, funding and the individual needs of your child at different times in their lives. Interventions were chosen based on family fit, and therapists' and other parents' recommendations. Information about autism and autism interventions was sourced from a range of sources including workshops, the Internet, health professionals and therapists, other parents of children with autism and books/ text. Parents preferred to have access to all these different sources and were most likely to be trusting of the advice provided by the health professionals who work with their children.

Appendix I - Parent Focus Group Presentation Slides 13 July 2012



Decision Aid Development

Parent Focus Group
13 July 2012



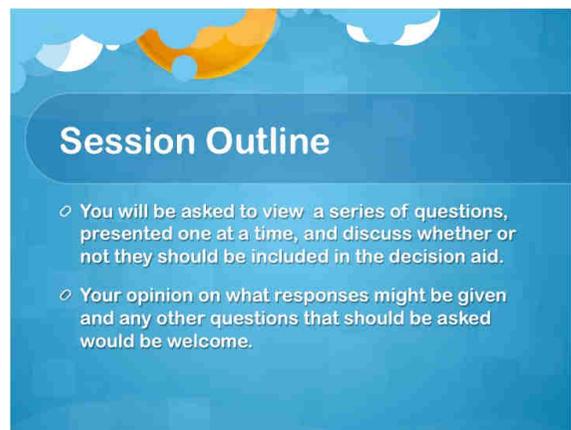
Introduction

The aim of this session is to obtain your feedback regarding an autism decision aid in its early phases of development



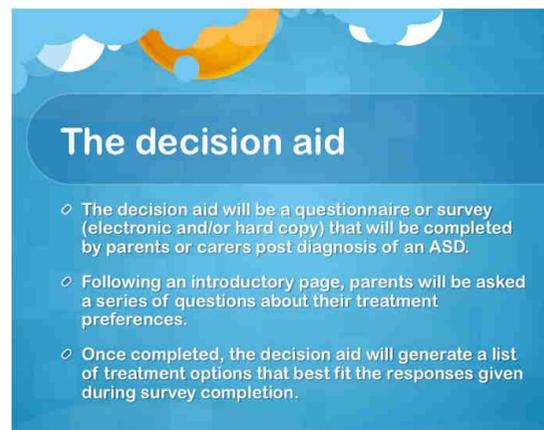
Patient Decision Aids

- Patient Decision options, when there are a number of viable treatment choices.
- There are specific guidelines that should be adhered to that have been proven to more effectively help with the decision-making Aids aim to assist people to make decisions about treatment process.
- Example –
<http://www.mammogram.med.usyd.edu.au/>



Session Outline

- You will be asked to view a series of questions, presented one at a time, and discuss whether or not they should be included in the decision aid.
- Your opinion on what responses might be given and any other questions that should be asked would be welcome.



The decision aid

- The decision aid will be a questionnaire or survey (electronic and/or hard copy) that will be completed by parents or carers post diagnosis of an ASD.
- Following an introductory page, parents will be asked a series of questions about their treatment preferences.
- Once completed, the decision aid will generate a list of treatment options that best fit the responses given during survey completion.



The decision aid

- The decision aid introductory page will include information on autism, with a brief explanation of signs and symptoms.
- The decision aid will adhere to the International Patient Decision Aid Standards Collaboration guidelines.

Part A Questions

- The questions in this part are related to the specific behaviours being targeted. These are the symptoms of autism for which treatment is being sought.

Question 1

- Would you consider medication for your child?
- Possible responses include: Yes, No, Maybe
- The information sheet would provide a link to the existing decision aid developed by Autism Speaks for use of medication with children diagnosed with ASD.

Question 2

- It is important that my child's ability to concentrate and attend to tasks improves
- Possible responses include: Yes, No, Maybe

Question 3

- It is important that my child learns self control and minimises impulsive or aggressive behaviour
- Possible responses may include: Yes, No, Maybe

Question 4

- It is important that my child's speech improves
- Possible responses may include: Yes, No, Maybe

Question 5

- It is important that my child sleeps better at night
- Possible responses may include: Yes, No, Maybe

Question 6

- It is important that my child is more compliant, follows instructions, and is able to demonstrate socially appropriate behaviour
- Possible responses include: Yes, No, Maybe

Question 7

- It is important that my child learns age-appropriate self-care skills such as dressing, and feeding him/ herself
- Possible responses include: Yes, No, Maybe

Question 8

- It is important that my child learns to use the toilet by him or herself and is toilet trained
- Possible responses include: Yes, No, Maybe

Question 9

- It is important for my child to manage his or her anxiety
- Possible responses include: Yes, No, Maybe

Question 10

- It is important that my child better manages transitions between tasks and copes with their daily routine
- Possible responses include: Yes, No, Maybe

Question 11

- It is important that my child fits in and makes friends
- Possible responses include: Yes, No, Maybe

Question 12

- It is important that my child controls his or her self-stimulatory behaviour or tics
- Possible responses include: yes, no, Maybe

Question 13

- It is important that my child be given assistance to learn and acquire new information that is considered age appropriate
- Possible responses include: yes, no, maybe

Question 14

- My child has poor speech. It is important that my child learn alternative forms of communication
- Possible responses include: Not relevant, somewhat relevant, very relevant

Question 15

- It is important that my child feels less overwhelmed or affected by sensory stimuli
- Possible response includes: yes, no, maybe

Question 16

- It is important that my child develops good social skills including making eye contact
- Possible responses include: Yes, No, Maybe

Question 17

- It is important that my child plays with toys and participates in games in an age appropriate way
- Possible responses include: Yes, No, Maybe

Question 18

- It is important that my child finds it easier to make friends
- Possible Responses include: yes, No, maybe

Question 19

- It is important that my child demonstrates an understanding of how others feel
- Possible responses include: Yes, No, Maybe

Question 20

- It is important that my child is able to describe how he or she is feeling
- Possible responses include: Yes, No, Maybe

Question 21

- It is important that my child attempts to share experiences and interests with others
- Possible responses include: Yes, No, Maybe

Question 22

- It is important that my child's tone or voice quality is appropriate and/ or not unusual.
- Possible responses include: Yes, No, Maybe

Question 23

- It is important that my child engages in pretend or imaginative play e.g role playing games, dress ups
- Possible responses include: Yes, No, maybe

Question 24

- It is important for my child to develop a range of interests and not just have fixed interests or obsessions
- Possible responses include: Yes, No, Maybe

Question 25

- My child appears to have food intolerances, and it is important that these are addressed
- Possible responses include: Not relevant, somewhat relevant, not at all relevant

Question 26

- It is important that my child learns to enjoy physical contact and demonstrates affectionate behaviour.
- Possible responses include: Somewhat important, neither important or not important, very important

Question 27

- My child enjoys chewing or mouthing objects. It is important that this behaviour is addressed
- Possible responses include: Relevant, Somewhat relevant, not at all relevant

Question 28

- My child likes to play rough and is at risk of hurting him or herself and/ or others. It is important that this behaviour is addressed
- Possible responses include: Relevant, Somewhat relevant, not at all relevant

Question 29

- My child sometimes appears not to hear when he or she is spoken to. It is important that this apparent auditory delay is addressed
- Possible responses include: relevant, somewhat relevant, not at all relevant

Question 30

- It is important that the treatment option we choose has been proven to be effective in a clinical trial
- Possible responses include: Yes, No, maybe

Part B Questions

- The questions in this part relate to your preferences for services and service providers, and your resources to access services.

Question 31

- How much time are you able to commit to therapy activities?
- Possible responses include: 0 – 5 hours/ wk, 5 – 10 hours/ wk etc

Question 32

- How much could you afford to pay for treatment
- Possible responses include: \$0 - \$30 per session or per week, \$30 - \$80 per session or per week, etc

Question 33

- Would you prefer interventions be conducted in-home or centre-based
- Possible responses include: home, centre-based (e.g clinic, school)

Question 34

- Are you interested in undertaking 'home-work' between sessions, or would you prefer the therapist to be solely responsible for treatment?
- Possible responses may include: Prefer therapist led, prefer home-work

Question 35

- Over what period of time would you prefer the intervention be undertaken:
- Possible responses include: 0 – 4 weeks, 1 – 3 months, 3 – 12 mths, 1 – 2 years, 2 years +

Summary

- Based on the responses to these questions, a list of intervention options that best fit the responses will be generated. Links to more information regarding these options will be provided
- It is important that intervention preferences be discussed with your treating health practitioner
- It is important to note that not all intervention options available are listed. Some options not provided may still be worth considering. The information provided is a guide only to assist you to make an informed decision about your child's treatment needs.

Appendix J - Expert Feedback Information Sheet for Interactive Questionnaire Consensus

Autism Decision Aid Questionnaire

An interactive decision aid is in development to help parents make intervention decisions for children when newly diagnosed.

The decision aid includes a questionnaire that parents will answer in order to obtain a list of intervention options that best fit their responses.

Parents will be asked to respond to nine (9) questions about their preferences. For each question, parents will select either very important, important, a little important, not very important, or not at all important.

These responses will be weighted so that for each available intervention, a score will be calculated, and the intervention options scoring the highest (in terms of relevance) will be presented.

Your feedback on which interventions best address the issues in each question is requested.

The spreadsheet attached shows the nine (9) questions in the first column, and lists 25 interventions across the top. For each intervention, indicate if it will address the behaviour or skill area mentioned in each question, by placing a 1 or 0 in each cell. A score of 1 means that the intervention does address the behaviour or skill area. A score of 0 means that the intervention does not address the behaviour or skill area. Each cell should have either a 1 or 0 on completion.

Example:

	Intervention			
Question	A	B	C	D
1.	0	0	1	0
2.	1	0	1	1

A summary of each of the interventions is below for you to refer to if needed.
Thank you very much in advance for your assistance with this.

Nicole Grant

Applied Behaviour Analysis (ABA)/ EIBI - A theoretical basis upon which principles of other therapies are based, breaks down complex skills or behaviours into smaller steps which are taught through learning-based, repetitive instruction and reward. ABA involves an initial assessment of the child's skills and difficulties, which are outlined in attainable goals and objectives that include ongoing measurement and evaluation as needed.

Early Start Denver Model (ESDM) – Play-based teaching designed for preschool and toddlers which is focused on social communication via three different settings (one-on-one, school and home), which emphasises play skills, relationships and language. A program is developed between intervention staff and parents including objectives, goals and activities targeting specific skill development. This model uses play to increase child interest in activities and other people through communication and self-expression.

LEAP - The primary goals of the curriculum are to expose children with autism to typical preschool activities and to adapt the typical curriculum for the children with autism only when necessary. Skill areas focussed on are social and communication skills. Independent play skills are facilitated by using peer models and by prompting, fading, and reinforcing target behaviours. Services include parent involvement and training. The program does not provide one-to-one intervention; instead, services consist of 15 hours per week of classroom instruction provided by a teacher and an assistant who implement the program with 10 typically developing children and 3 to 4 children with autism.

TEACCH - The approach looks at the skills and strengths a person already has, and aims to build on these skills to promote development. The program is used to promote learning and development – in particular, communication and social skills, independence, coping skills and skills for daily life (for example, dressing, washing, cleaning teeth and so on). For children with autism, TEACCH offers an intensive intervention program that supports children by creating a very structured learning environment. The environment includes physical boundaries between different tasks and clear schedules of daily activities. This

helps children understand how daily life works so that they can become more independent.

SCERTS – social communication, emotional regulation and transactional support - A model of service provision combining techniques to create individualised programs aimed at regulating emotions and communication. Focuses on 3 key areas: social communication, emotional regulation and transactional support and incorporating therapies in an individualised program designed by parents and therapists together.

DIR/ Floortime approach - Promotes development and interaction through play in sensory and motor skills, emotional and cognitive development and communication. This therapy uses large amounts of play time between adult and child on the floor, problem solving interactions and other specialised activities.

Developmental social-pragmatic model (DSP) - Developmental therapy that uses techniques from ABA, DIR/Floortime, More Than Words to provide children with ASD who have basic communication skills to initiate and engage in spontaneous communication. This model aims to improve social skills necessary to this such as turn taking. All communication attempts and efforts are rewarded to encourage further attempts.

RDI – Relationships Development Intervention - Developmental therapy promoting learning, social skills and relationship development. This parent led approach for high functioning autism focuses on building and improving close two-way relationships.

The P.L.A.Y project – Play and Language for Autistic Youngsters - Based on the DIR theory, this approach emphasises the importance of helping parents to provide intensive interventions in their own home to help their young children with autism reach full potential.

SERVAM - Integrates therapy and education in family, incorporating 6 elements and providing a flexible framework to create an ideal learning environment for home, school and in public. SERVAM is used as an aid in addition to professional therapy services.
Autism Specific Long Day Care – e.g. AEIOU

Hanen – More Than Words - Family based intervention focused on training parents of children with autism less than 6 years of age to help develop communication skills in daily life. Centre-based group sessions also provide social support networks for parents. Preschoolers with autism – manualised parent training program.

Triple P – Stepping Stones Adaptation - Stepping Stones Triple P has been developed for parents of children with a developmental disability to help manage problem behaviour and developmental issues common in children with disabilities. Available in primary care, individual or group settings, it is based on Triple P's parenting strategies.

Speech Generating Devices (SGD) and other Augmentative & Alternative Communication (AAC) - Speech generating devices offer people with autism a way to communicate through an electronic device that allows the user to speak words, sentences and phrases electronically.

PECS - Based on the principles of ABA, this method incorporates the use of images and cards to facilitate and provide an alternative means of communication for those who experience problems with spoken communication.

Signing and Makaton - Makaton uses speech with signs (gestures) and symbols (pictures), facial expression, eye contact and body language to accurately communicate. Signs and symbols can provide additional information which can be seen and easily interpreted. Makaton is regularly used in mainstream school as an alternative to spoken communication.

Alert Program for self-regulation - Program using an "engine" analogy, which is easily identifiable and relatable for children, for them to acknowledge their "engine" and enhance their inner experience of self-regulation.

Social Stories - A therapy based and highly structured intervention that uses stories to explain social situations to children with autism. They also help children learn socially appropriate behaviours and responses. Developed as a way for children to learn how they should behave in social settings by explicitly pointing out details about the setting and what typically happens in that setting. These details help children pick up on cues they

would normally overlook. Social Stories™ aim to increase social understanding by answering the 'who', 'what', 'where', 'how', and 'why' questions.

Aquatic OT programs – autism specific - Aquatic Occupational Therapy incorporates water-based play activities in order to develop motor, communication and play skills as well as social relationships. It also helps regulate sensory responses.

Sleepwise - A manual called Sleepwise was developed to provide allied health workers with information and resources to educate families of children with a disability on identifying and treating sleep disturbances.

PALS Social Skills program – Ten-session program, aimed at children aged 3 to 6, to develop social skills in groups of 6 to 8. Parent information sheets available. Strategies include role-playing and singing.

Toilet Time - Toilet training packages for girls (Emily) and boys (Tom) designed for parents of children with developmental delay who are teaching their children how to use the toilet independently.

Music Therapy - Music therapy uses music and the interaction between teacher and child to teach specific skills and may improve social and communication skills in subjects with Autism. There are many different types of music therapy. These activities promote interaction, expression and social skills such as taking turns. Sessions are conducted with a Registered Music Therapist who will assess individual need before creating goals and activities with ongoing evaluation.

Circles of Support - inclusion program encouraging other children to help the child affected with ASD to participate in activities.

Appendix K - Screenshot of home page of www.autismdecisionaid.com.au

The screenshot shows the homepage of the Autism Early Intervention Decision Aid website. At the top, the title "Autism Early Intervention Decision Aid" is displayed next to a search bar. A navigation menu includes "HOME", "ABOUT", "QUESTIONNAIRE" (highlighted), and "CONTACT". A large banner image features a young boy hugging a golden retriever, with the text "AUTISM INTERVENTIONS" and a partial sentence "What is an Intervention? Intervention is a word used to describe specific...". Below the banner are four columns of text: "What is Autism Spectrum Disorder?", "Autism Interventions", "Questions to ask your health/ early intervention provider", and "Additional Information, Resources and Links". A second row contains "About", "Questionnaire", and "Contact" sections. The footer includes logos for The University of Queensland, Olga Tennison Autism Research Centre, Gateway Therapies, and Springfree, along with a testimonial quote and a copyright notice.

Autism Early Intervention Decision Aid

HOME ABOUT **QUESTIONNAIRE** CONTACT

AUTISM INTERVENTIONS
What is an Intervention? Intervention is a word used to describe specific...

What is Autism Spectrum Disorder?
Autism Spectrum Disorder (ASD) or autism, is the term given to the group of...

Autism Interventions
What is an Intervention? Intervention is a word used to describe specific...

Questions to ask your health/ early intervention provider
The Early Intervention for Children with Autism Spectrum Disorders:...

Additional Information, Resources and Links
Autism Resources Helping Children With Autism (FaHCSIA) Raising Children...

About
This website has been created to provide you, the parent or carer of a child under 7 years of age with autism (or Autism Spectrum Disorder (ASD)), to make informed decisions about interventions. This includes children with Asperger's Disorder, and Pervasive Developmental Disorder or PDD-NOS.

Questionnaire
How important is it that your child better understand and appropriately react to their own feelings and the feelings of others e.g anger, frustration? (Social-emotional development)

Contact
Do you have a question or any feedback regarding this website?
Nicole Grant
PO Box 536
Cannon Hill QLD 4170
Phone: 0417 879 461
Email: nicole@uqconnect.edu.au

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

Olga Tennison AUTISM RESEARCH CENTRE AUSTRALIA

GATEWAY THERAPIES

springfree TEAMFOLKE

“ If a recent autism diagnosis has left you confused about treatment options for your child, this website is designed for you. ”

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Appendix L - Hard Copy (Printable) Version of the Autism Early Intervention Decision Aid

Autism Patient Decision Aid Questionnaire

PART A

Circle the answer that best fits your response to each question in the table below

1. How important is it that your child better understand and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	Very Important	Important	A Little Important	Not Very Important	Not at all important
2. How important is it that your child receives assistance developing relationships?	Very Important	Important	A Little Important	Not Very Important	Not at all important
3. How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	Very Important	Important	A Little Important	Not Very Important	Not at all important
4. Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	Very Important	Important	A Little Important	Not Very Important	Not at all important
5. How important is it that your child receives assistance with learning and to develop academic skills?	Very Important	Important	A Little Important	Not Very Important	Not at all important

6. How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	Very Important	Important	A Little Important	Not Very Important	Not at all important
7. How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	Very Important	Important	A Little Important	Not Very Important	Not at all important
8. How important is it that your child better manage his/ her sensory processing e.g. tolerance to noise/ light etc.?	Very Important	Important	A Little Important	Not Very Important	Not at all important

PART B
SCORING

For each Intervention, shade or circle the number that corresponds with the answers provided above.

Add up the scores in each column for the circled or shaded numbers only (see example below).

On the final page, record all your scores for each intervention.

The intervention that scores the highest is the best fit for your child based on your responses.

EXAMPLE	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	0	0	0	0	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
6. How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care	4	3	2	1	0

(toileting, dressing), play or recreational activities.					
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
How important is it that your child better manage his/ her sensory processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL	8	3	0	0	0
SCORE	14				

Early Intensive Behavioural Intervention	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	0	0	0	0	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
How important is it that your child better manage his/ her sensory processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Early Start Denver Model	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Learning Experiences – An Alternative Program for Pre-schoolers and Parents (LEAP)	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	4	3	2	1	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Treatment and Education of Autistic and related Communications-handicapped Children (TEACCH)	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	4	3	2	1	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
8. How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	4	3	2	1	0
SUB TOTAL					
SCORE					

Social Communication, Emotional Regulation and Transactional Support (SCERTS)	Very Important	Important	A Little Important	Not Very Important	Not at all important
1. How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
2. How important is it that your child receives assistance developing relationships?	4	3	2	1	0
3. How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
4. Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
5. How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
6. How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
7. How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
8. How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	4	3	2	1	0
SUB TOTAL					
SCORE					

DIR/ Floortime Approach	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
8. How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	4	3	2	1	0
SUB TOTAL					
SCORE					

RDI/ Relationships Development Intervention	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

The P.L.A.Y project – Play and Language for Autistic Youngsters	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Sensory Considerations, Environmental Management, Routines and Planned Change, Visual Supports, Autism Friendly Communication, Motivation (SERVAM)	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	4	3	2	1	0
SUB TOTAL					
SCORE					

Hanen 'More Than Words'	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Pre-schoolers with Autism – Manualised Parent Training Program	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	4	3	2	1	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Triple P – Stepping Stones Adaptation	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	0	0	0	0	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Speech Generating Devices (SCD) and other Augmentative & Alternative Communication (AAC)	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Picture Exchange Communication System (PECS)	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Signing and Makaton	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Alert Program for Self-Regulation	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	0	0	0	0	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	0	0	0	0	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	4	3	2	1	0
SUB TOTAL					
SCORE					

Social Stories™	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	4	3	2	1	0
SUB TOTAL					
SCORE					

PALS Social Skills Program	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Toilet Time	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	0	0	0	0	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	0	0	0	0	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	4	3	2	1	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Music Therapy	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	0	0	0	0	0
How important is it that your child receives assistance developing relationships?	0	0	0	0	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	0	0	0	0	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

Circles of Support	Very Important	Important	A Little Important	Not Very Important	Not at all important
How important is it that your child better understands and appropriately react to their own feelings and the feelings of others e.g. anger, frustration? (Social-emotional development)	4	3	2	1	0
How important is it that your child receives assistance developing relationships?	4	3	2	1	0
How important is it that your child develops better social skills? E.g. turn taking, sharing, active listening	4	3	2	1	0
Is it important that your child develop better communication skills? E.g. asking for things, answering yes/ no etc.	4	3	2	1	0
How important is it that your child receives assistance with learning and to develop academic skills?	0	0	0	0	0
How important is it that your child receives assistance to develop his/ her ability to undertake daily living tasks and be independent? E.g. self care (toileting, dressing), play or recreational activities.	0	0	0	0	0
How important is it that your child improve his/ her fine motor skills? E.g. holding a pencil, using cutlery etc.	0	0	0	0	0
How important is it that your child better manage his/ her sensory How important is it that your child processing e.g. tolerance to noise/ light etc.?	0	0	0	0	0
SUB TOTAL					
SCORE					

PART C

Insert your total scores below next to the relevant intervention

Intervention	Score	Intervention	Score	Intervention	Score
Hanen 'More Than Words'		Toilet Time		Early Start Denver Model (ESDM)	
Preschoolers With Autism – manualised parent training program		Music Therapy		LEAP	
Triple P – Stepping Stones Adaptation		Alert Program for Self Regulation		TEACCH	
Speech Generating Devices and other Augmentative & Alternative Communication		Social Stories™		SCERTS	
Signing and Makaton		Circles of Support		DIR/ Floortime approach	
PECS – Picture Exchange Communication System		SERVAM – Sensory Considerations, environmental management, routines and planned change, visual supports, autism friendly communication, motivation		RDI – Relationships Developmental Intervention	
PALS Social Skills Program		Early Intensive Behavioural Intervention (EIBI)		The P.L.A.Y Project – Paly and Language for Autistic Youngsters	

Which 5 interventions are you leaning towards?

1. _____
2. _____
3. _____
4. _____
5. _____

For more information on each intervention, go to www.autismdecisionaid.com.au

Need more information to make a decision? Answer the questions below about your preferences for time, cost and typical environment for interventions.

PART D

The following questions refer to cost, time and preferred environment for interventions to occur, which may help you further to decide which interventions best suit your needs.

How many hours are you able to commit to therapy each week?	
Under 20 hours per week	20 + hours per week
SERVAM Preschoolers With Autism Parent Training Triple P – Stepping Stones Adaptation ALERT program Social Stories Toilet Time Music Therapy Circles of Support PALS Social Skills Program	Early Intensive Behavioural Intervention (EIBI) Early Start Denver Model (ESDM) SCERTS DIR/ Floortime RDI P.L.A.Y Project Hanen More Than Words Speech Generating Devices and AAC Signing and Makaton PECS LEAP TEAACH

What is your budget for intervention per week?				
\$0 - \$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Early Start Denver Model (ESDM) Social Stories Circles of Support	P.L.A.Y Project Triple P – Stepping Stones Adaptation Music Therapy	Nil	Toilet Time	Early Intensive Behavioural Intervention (EIBI) LEAP TEACCH SCERTS DIR/ Floortime RDI SERVAM Hanen More Than Words Preschoolers With Autism Speech Generating Devices and AAC PECS Signing and Makaton Alert Program PALS social Skills program

Where would you prefer intervention to occur?		
Home	Clinic	Home, Clinic or Both?
P.L.A.Y Project SERVAM Circles of Support	LEAP TEACCH PALS Social Skills Program	Early Intensive Behavioural Intervention (EIBI) Early Start Denver Model (ESDM) SCERTS DIR/ Floortime RDI Hanen More Than Words Preschoolers With Autism Triple P Stepping Stones Adaptation Speech Generating Devices and AAC PECS Signing and Makaton Alert Program Social Stories Toilet Time Music Therapy

Based on this additional information, which intervention or interventions are you considering for your child?

1. _____
2. _____
3. _____

Appendix M - Autism Early Intervention Decision Aid Website Copy

WEBSITE CONTENT

Pages

Homepage

About This Project

Contact the Author

What is Autism Spectrum Disorder?

Autism Interventions (Introduction and including links to 21 Intervention pages)

Questions to ask your Health/ Early Intervention Provider

Additional Information Resources and Links

HOMEPAGE

(INTRO – Above Questionnaire)

If a recent autism diagnosis has left you confused about treatment options for your child, this website is designed for you.

Why does this website exist?

This website has been created to provide you, the parent or carer of a child under 7 years of age with autism (or Autism Spectrum Disorder (ASD)), to make informed decisions about interventions. This includes children with Asperger's Disorder, and Pervasive Developmental Disorder or PDD-NOS.

We know from research in Australia and overseas that from the point of diagnosis, many parents turn to the Internet for information about autism. The Internet contains a massive volume of pages available on the subject. It has information about a large number of intervention choices for managing symptoms of autism.

This website aims to help parents of children recently diagnosed with autism to understand the intervention options for their child's needs. The interventions mentioned on this website have been chosen because evidence from research studies suggest that these interventions can help children with autism.

The aim of this website is to:

1. Help you to better understand intervention options available for your child
2. Provide you with a list of options that 'best fit' your child's needs and your goals for him or her
3. Help to better understand the likely outcomes for available interventions, and
4. Find out more about the risks and benefits of different options, including what will happen if you choose no intervention for your child.

This information does not replace advice and recommendations made by a qualified health/education professional. It is important that you discuss all your options with your

treating doctor or health/education professional. [Click here for questions to ask your health/ early intervention provider \(hyperlink\).](#)

Does this website have all the answers?

Autism is complex. Each child will have different needs and respond differently to interventions. While the interventions mentioned on this site are supported by research evidence, this does not guarantee that your child will respond in the same way as any children previously tested in the research studies. For some children there may be less benefit from the interventions. For others, there may be more; and for others, no benefit at all.

This website does not include all possible options for helping a child with autism. The interventions chosen for this website are based on those recommended in the 2012 Guidelines for Good Practice. These guidelines were commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

Where can I find more information?

In the sidebar, you will find links to more information about autism services in Australia. If your child has not been diagnosed with autism but you have concerns about them, contact your state-based agency or GP who may then refer you to a developmental paediatrician.

What do I do now?

Are you ready to read some information to help you make some decisions? Complete the questionnaire below to obtain a list of interventions that you can explore further. To see the full list of interventions, [click here \(hyperlink to interventions page\).](#)

(Beneath Lower Menu)

References:

Prior, M & Roberts, J. (2012), Early Intervention for Children With Autism Spectrum Disorders: "Guidelines for Good Practice" 2012.

http://www.fahcsia.gov.au/sites/default/files/documents/11_2012/early_intervention_practice_guidelines.pdf

Prior, M., Roberts, J. M.A., Rodger, S., Williams, K. & Sutherland, R. (2011). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia.

http://www.fahcsia.gov.au/sites/default/files/documents/09_2012/review_of_the_research_report_2011_0.pdf

Roberts, J. M. A. & Prior, M. (2006) A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders, Australian Government Department of Health and Ageing, Australia.

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Page updated on (date) by (name)

ABOUT THIS PROJECT

This website has been developed as part of research being conducted by Nicole Grant, an Occupational Therapist and doctoral (PhD) student in the School of Health and Rehabilitation Sciences, at The University of Queensland, Australia. This project is being supervised by Professor Sylvia Rodger (BOccThy., MEdSt., PhD, FAOTA) and Associate Professor Tammy Hoffmann (BOccThyHons, PhD). The project is aimed at helping parents of children newly diagnosed with autism to make intervention decisions. The project is due for completion in late 2013.

This website was created to comply with The International Patient Decision Aid Standards (<http://iPtDAs.ohri.ca/>) and the DISCERN evaluation tool for consumer health information (http://www.discern.org.uk/discern_instrument.php). It's currently in its trial phase. Your feedback and suggestions are very welcome (link to contact page).

Any questions regarding the project can be directed to nicole.grant@uqconnect.edu.au or s.rodger@uq.edu.au.

How was the questionnaire developed and scored?

The decision aid starts with a list of 9 questions for parents about their preferences for features of interventions. For each question, parents have a choice of 5 response options: very important, important, a little important, not very important, or not at all important. Their answers result in a list of intervention options that 'best fit' their responses being provided. Responses to each question are weighted. For each intervention, a score is calculated, and the 5 intervention options scoring the highest (in terms of relevance to parent's preferences) will be presented.

These results are both displayed on the screen, with links to more information, and also emailed to parents where an email address is provided.

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<http://www.latrobe.edu.au/otarc/>

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Website developed by Website Design City

www.websitedesigncity.com.au.

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References:

Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., Coulter, A., Thomson, R., Barratt, A., Barry, M., Bernstein, S., Butow, P., Clarke, A., Entwistle, V., Feldman-Stewart, D., Holmes-Rovner, M., Llewellyn-Thomas, H., Moumjid, N., Mulley, A., Ruland, C., Sepucha, K., Sykes, A., & Whelan, T., on behalf of the International Patient Decision Aids Standards (IPDAS) Collaboration. [Developing a quality criteria framework for patient decision aids: online international Delphi consensus process.](#) BMJ 2006 Aug 26;333(7565):417.

Charnock, D., Shepperd, S., Needham, G. & Gann, R. (1999) DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. J Epidemiol Community Health, 53:2 105-111.

CONTACT THE AUTHOR

Do you have a question or any feedback regarding this website?

Please complete the form below and we will respond as soon as possible. Alternatively, email Nicole at nicole.grant@uqconnect.edu.au.

Queries regarding autism services should be directed to your state-based autism support agency. Links to each of these agencies can be found in the menu below (Link to Additional information)

<create contact form>

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Page updated on (date) by (name)

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) or autism, is the term given to the group of neurodevelopmental disorders that are characterised by:

1. Difficulty with social interaction
2. Poor communication skills, and
3. Observed restricted repetitive and stereotyped patterns of behaviour, interests, and activities.

There is no known cause and no known cure. However there are many interventions that focus on improving quality of life.

How is autism diagnosed?

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV and DSM-5 from May 2013) or the International Classification of Diseases (ICD-10) can be used by health professionals to diagnose autism.

Various assessment tools are used by health professionals, child psychiatrists and paediatricians to screen for and diagnose autism. In addition to using diagnostic tools, interviews with primary carers, observations of the child and ruling out other possible explanations also takes place. The information that comes from doing this helps health/early intervention professionals work with parents to plan intervention goals.

How common is autism?

In Australia and around the world, an increasing number of children are being diagnosed with autism. An Australian study in 2007 found that 1 in every 160 (1:160) children in Australia aged between 6 and 12 years had been diagnosed with autism. A 2010 report suggested this figure could be as high as 1:100.

What can be done to help children with autism and their families?

There are hundreds of interventions that claim to help children with autism. Some interventions even claim to be able to cure autism. There is currently no cure for autism.

Having so much information available, some of it even misleading, is a problem. It makes it confusing for parents when making decisions about which interventions they should try with their child.

It is not easy to understand which information should be believed and which shouldn't.

Some questions to think about are:

1. Has any research tested this intervention?
2. You should be very cautious and reluctant to try any intervention with your child that has not been tested in a research study.

What did the research find?

If the research found that children who got the intervention did not improve, then this intervention should not be considered any further for now. This may change if future research finds different results though. If the research found that children who got the intervention improved, then you should ask yourself the question below. You should also look at what the children in the study improved on (e.g. behaviour) and if this is an area where you would like to see an improvement in your child.

Was the research of good quality?

Unfortunately not all research studies are of good quality. Badly done studies can lead to the wrong conclusion – such as concluding that an intervention is effective (that is, it works), when in fact, it may not. Worse still, it may even cause harm. Telling good quality research from poor quality research is tricky.

It is important that you discuss any intervention you might be considering with your child's health/ early intervention provider. If you are unsure what questions you should be asking, [click here](#). (link to questions to ask your health/ early intervention provider). Likewise, for any intervention that is recommended to you by a health/early intervention provider, ask about the research evidence supporting the intervention.

What if no treatment is chosen?

There is no reliable information available about what happens if no treatment is sought. As autism affects children in different ways, it is difficult to know what possible outcomes may occur for all the different intervention options available. What we do know from the existing evidence is that sometimes there is a need to try a number of interventions before any progress can be seen.

Autism Treatment and Research

The [Raising Children Network](#) (link) is an Australian website which was collaboratively developed by a consortium of Australia's leading early childhood agencies (Smart Population Foundation, Parenting Research Centre and Centre for Community Child Health) and the Australian Government. Its aim is to provide parents with useful, up to date, and accurate information on a range of issues affecting children. The Raising Children Network has collected extensive information on autism, including autism interventions. A rating system based on the National Standards Project (National Autism Center, 2009) was adopted by the Raising Children Network website authors to rate interventions based on whether the research has shown positive effects or is considered ineffective based on lack of evidence or potential to be harmful.

A summary of the most effective interventions are provided on this site (link to Interventions)

References:

Australian Advisory Board on Autism Spectrum Disorders, Education and Autism Spectrum Disorders in Australia, The provision of appropriate educational services for school-age students with Autism Spectrum Disorders in Australia, Position Paper, Launched Autism Month Australia, April 2010

First, M., 1994, Quick Reference to the Diagnostic Criteria from DSM-IV, American Psychiatric Association, Washington, DC

- First, M., 2008, Autism and Other Pervasive Developmental Disorders Conference (February 3-5, 2008), accessed online 11 September 2010.
- Green, V., Pituch, K., Itchon, J., Choi, A., O'Reilly, M., @ Sigafos, J., 2006, Internet survey of treatments used by parents of children with autism, *Research in Developmental Disabilities*, 27,1.
- MacDermott, S., Williams, K., Ridley, G., Glasson, E., & Wray, J. (2007). The prevalence of autism in Australia. Can it be established from existing data? Report for the Australian Advisory Board on Autism Spectrum Disorders.
- Mesibov, G., & Shea, V. 2010, Evidence-Based Practices and Autism, *Autism*, published online 27 September 2010.
- National Autism Center, 2009, The National Autism Center's National Standards Report <http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf>
- O'Reilly, B. & Smith, S., 2008, *Australian Autism Handbook: The essential resource guide for autism spectrum disorders*, Jane Curry Publishing, Edgecliff, NSW.
- Prior, M. & Roberts, J. (2012), *Early Intervention for Children With Autism Spectrum Disorders: "Guidelines for Good Practice" 2012*. (Link <http://www.latrobe.edu.au/otarc/otarc-documents/Margot-EI-guidelines-revised.pdf>)
- Szatmari, P., 2011, New recommendations on autism spectrum disorder, *BMJ*, 342:d2456
- Valentine, K., 2010, A consideration of medicalisation: choice, engagement and other responsibilities of parents of children with autism spectrum disorder, *Social Science & Medicine*, 71, 5.
- Valentine, K., Rajkovic, M., Dinning, B., & Thompson, D., 2010, Occasional Paper No. 35 Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers, social Policy Research Centre, University of New South Wales.

Warren, Z., McPheeters, M., Sathe, N., Foss-Feig, J., Glasser, A., & Veenstra-VanderWeele, J., 2011, A systematic review of early intensive intervention for Autism Spectrum Disorders, *Pediatrics*, 127,5.

Warren, Z., Veenstra-VanderWeele, J., Stone, W., Bruzek, J., Nahmias, A., Foss-Feig J., Jerome, R., Krishnaswami, S., Sathe, N., Glasser, A., Surawicz, T., & McPheeters, M., 2011, Therapies for children with autism spectrum disorders. Comparative Effectiveness Review No. 26. (Prepared by the Vanderbilt Evidence-based practice centre under contract no. 290-2007-10065-1) AHRQ Publication No. 11-EHC029-EF.
http://www.effectivehealthcare.ahrq.gov/ehc/products/106/656/CER26_Autism_Report_04-14-2011.pdf)

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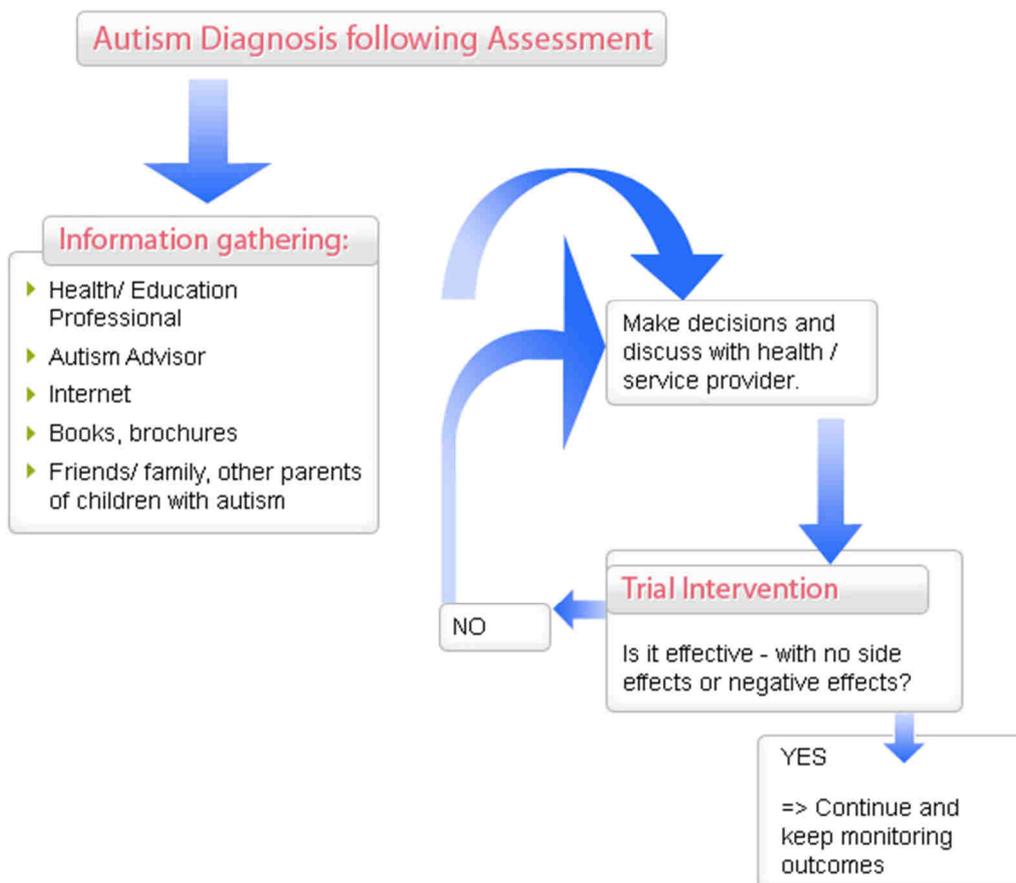
INTERVENTIONS

What is an Intervention?

Intervention is a word used to describe specific strategies or therapy activities undertaken to improve or manage those characteristics of autism that impact on a child's ability to function well in their daily lives.

Autism is a life-long, neurodevelopmental condition that cannot be cured. Interventions exist, however that can impact on how well a child with autism functions or manages within the constraints of the condition.

Interventions are typically accessed following assessment to confirm an autism diagnosis. The following diagram explains the process of determining diagnosis and then choosing and trialling an intervention.



Who provides autism interventions?

Autism Interventions can be provided by speech therapists, occupational therapists, psychologists and sometimes special needs educators or other related and specially trained health professionals.

An intervention may involve parents and carers undergoing training to use a strategy or tool, or it may be regular contact with a therapist. Therapy usually requires regular visits to a clinic, or your therapist may conduct a home or school visit. They mostly occur frequently, for example every day, week or fortnight. Less frequent therapist contact usually requires parents, carers and other people in close contact with the child to practice and reinforce strategies at home and in other settings.

Evidence suggests that some therapies are more effective when undertaken for at least 15-20 hours per week.

Click on each intervention to find out more about what each intervention offers and useful information about each service including time commitment required, cost of services, typical settings, and positive and negative features of each.

For more information on interventions and understanding research evidence, click here (hyperlink to What can be done to help children with autism and their families?)

Autism Interventions in Australia

The interventions below are evidence-based, meaning that research has proven them to be effective for some children in certain settings. The interventions below are also known to be available in Australia. Check with your state-based autism support agency to see if your preferred intervention is available in your area. Consider contacting approved providers directly and ask them about their services (hyperlink to questions to ask health/early intervention providers). They are listed on FaHCSIA's list of approved service providers (<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/helping-children-with-autism/providers>).

Approved autism service providers typically have undergraduate education/training as occupational therapists, speech therapists, psychologists, social workers or special needs educators. Ask if they are specifically trained in one or more of the interventions listed here. They may use different elements of one or a number of interventions, and tailor their service according to your child's needs. It's always best to ask them some questions so that you can be sure that you understand the interventions, their risks, benefits, and what is involved ([hyperlink to questions to ask your healthcare provider](#)).

The interventions below are categorised as per the Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Good Practice (Roberts & Prior, 2012). These categories attempt to describe the type of intervention on offer, for example, whether the intervention involves parent training or involves the child attending therapy, or whether the intervention addresses all characteristics of autism or just a few.

Family-based including parent training

Hanen 'More Than Words'

Pre-schoolers with autism – manualised parent training program

Triple P – stepping stones adaptation

Therapy-based Interventions

Speech Generating Devices (SGD) and other Augmentative & Alternative Communication (AAC)

Signing and Makaton

PECS – Picture Exchange Communication System

Single element components addressing one aspect of autism

PALS Social Skills Program

Toilet Time

Music Therapy

Alert Program for Self Regulation

Social Stories

Therapies not specific to autism, but which may benefit children with autism

Circles of Support

Service based treatments specific to autism

SERVAM – Sensory Considerations, environmental management, routines and planned change, visual supports, autism friendly communication, Motivation

Comprehensive programs, combined approaches and developmental approaches

Early Intensive Behavioural Intervention (EIBI)

Early Start Denver Model (ESDM)

LEAP

TEACCH

SCERTS – social communication, emotional regulation and transactional support

DIR/ Floortime approach

RDI – Relationships Developmental Intervention

The P.L.A.Y project – Play and Language for Autistic youngsters

What happens if I choose not to treat my child or not access intervention services?

As autism affects children differently, it is not possible to say whether your child will regress (go backwards), stay the same, or continue to gradually improve without intervention. What we do know is that early intervention may help your child develop necessary skills for living, including playing, interacting with family and friends, undertaking hygiene and self care tasks, and participating in school or preschool activities with their peers. There is no physical or psychological risk to not choosing an intervention, however the benefits of trialling interventions that are evidence-based and tailored to your child's needs are worth taking into account.

(Link) [Click here to return to the questionnaire for help making decisions about interventions for your child.](#)

References:

First, M., 1994, Quick Reference to the Diagnostic Criteria from DSM-IV, American Psychiatric Association, Washington, DC

First, M., 2008, Autism and Other Pervasive Developmental Disorders Conference (February 3-5, 2008), accessed online 11 September 2010.

- Green, V., Pituch, K., Itchon, J., Choi, A., O'Reilly, M., @ Sigafos, J., 2006, Internet survey of treatments used by parents of children with autism, *Research in Developmental Disabilities*, 27,1.
- Mesibov, G., & Shea, V. 2010, Evidence-Based Practices and Autism, *Autism*, published online 27 September 2010.
- National Autism Center, 2009, The National Autism Center's National Standards Report <http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf>
- O'Reilly, B. & Smith, S., 2008, *Australian Autism Handbook: The essential resource guide for autism spectrum disorders*, Jane Curry Publishing, Edgecliff, NSW.
- Prior, M. & Roberts, J. (2012), Early Intervention for Children With Autism Spectrum Disorders: "Guidelines for Good Practice" 2012. (Link <http://www.latrobe.edu.au/otarc/otarc-documents/Margot-EI-guidelines-revised.pdf>)
- Szatmari, P., 2011, New recommendations on autism spectrum disorder, *BMJ*, 342:d2456
- Valentine, K., 2010, A consideration of medicalisation: choice, engagement and other responsibilities of parents of children with autism spectrum disorder, *Social Science & Medicine*, 71, 5.
- Valentine, K., Rajkovic, M., Dinning, B., & Thompson, D., 2010, Occasional Paper No. 35 Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers, social Policy Research Centre, University of New South Wales.
- Warren, Z., McPheeters, M., Sathe, N., Foss-Feig, J., Glasser, A., & Veenstra-VanderWeele, J., 2011, A systematic review of early intensive intervention for Autism Spectrum Disorders, *Pediatrics*, 127,5.
- Warren, Z., Veenstra-VanderWeele, J., Stone, W., Bruzek, J., Nahmias, A., Foss-Feig J., Jerome, R., Krishnaswami, S., Sathe, N., Glasser, A., Surawicz, T., & McPheeters, M., 2011, Therapies for children with autism spectrum disorders. Comparative Effectiveness Review No. 26.

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SUBPAGES

21 pages – one per intervention – Questionnaire results will provide five most relevant interventions and then link to these.

(See spreadsheet)

Early Intensive Behavioural Intervention (EIBI)

Early Intensive Behavioural Intervention is a therapy approach that is based on Applied Behaviour Analysis and includes The Lovaas Method. This approach aims to break down complex skills or behaviours into smaller components (little steps). These are then taught through repetitive instructions and rewards. The use of repetitive instruction and reward is known as Discrete Trial Training.

This intervention targets the following skills and behaviours:

Reducing self-stimulatory (“stimming”) behaviours and replacing them with more socially acceptable behaviours.

- Teaching play skills such as using toys in their correct manner
- Teaching expressive and abstract language skills
- Improving social skills and emotional expression
- Teaching pre-academic skills, such as reading, writing and maths.

For therapy to be effective, it usually requires the child to participate in 35 – 40 hours per week of therapist and trained teacher intervention.

Supporting Evidence/ Likely treatment success

Generally acknowledged as being the most effective approach, due to research studies demonstrating improvement in various areas of functioning including cognitive, language, adaptive behaviour, social, and academic skills, in some children with autism receiving this intervention.

Link to more information

www.abia.net.au/parents_and_carers

http://www.autismawareness.com.au/information/early_intervention/behavioural_interventions

http://en.wikipedia.org/wiki/Early_intensive_behavioral_intervention

Video of health professional explaining aspects of EIBI therapy:

<http://www.youtube.com/watch?v=n3zTqcmfKqc>

References

www.raisingchildren.net.au

www.abia.net.au/parents_and_carers www.autism.about.com/od/allaboutaba

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Number of participation hours required each week	
Under 15	15+
Notes: Best results usually achieved when EIBI therapy is undertaken for between 35 and 40 hours per week.	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: Programs can cost \$35,000 to \$40,000 per year in some circumstances.				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Can be beneficial for children with mild, moderate and severe symptoms of autism.</p> <p>Relevant for all settings (home, school, community).</p> <p>Strategies can be incorporated easily into daily interactions.</p> <p>Parents can play an active role in</p>	<p>Very time intensive</p> <p>Expensive</p> <p>There may be perceived pressure on the family to incorporate strategies into every day living.</p>

EIBI programs. This can reduce therapy costs.	
---	--

Early Start Denver Model (ESDM)

Early Start Denver Model is a play-based therapy, designed for pre-schoolers and toddlers. This therapy focuses on helping children with autism to develop social communication and interpersonal skills across different settings, including one-on-one, at home and in school/ preschool. A program is developed by therapists in collaboration with parents.

Supporting Evidence/ Likely treatment success

Promising results have been reported from some research studies, but more high quality investigations are required. Best results are achieved when therapy is undertaken for at least 20 hours per week.

Link to more information

www.raisingchildren.net.au/articles/denver_model_th.html

Video of therapist using ESDM theory to engage a child in therapy:

<http://www.youtube.com/watch?v=9idgYB9CdPw>

References

www.raisingchildren.net.au/articles/denver_model_th.html

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Number of participation hours required each week	
Under 15	15+
Notes: Once appropriately trained, parents are asked to provide therapy at home with intermittent support from a therapist. Therapist input may be 1 hour per week, however parents are required to provide therapy for at least 20 hours per week for program to be	

successful.

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes:				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Can improve social, communication and academic skills.	More research into this model is needed. High level of parent involvement is required to reinforce strategies at home and other settings. Limited service availability in some areas.

Learn Experiences – An Alternative Program for Pre-schoolers and Parents (LEAP)

LEAP combines a variety of strategies, including elements from Applied Behaviour Analysis (See EIBI), peer-mediated instruction (working alongside children of a similar age), incidental teaching, self-management training, prompting strategies, and systematic parent training. The primary goals of the program are to expose children with autism to typical preschool activities and to adapt the typical curriculum for these children only when necessary. Independent play skills are learnt from other typically developing children and reinforced using strategies such as age-appropriate rewards and praise for demonstrating correct actions and behaviours.

Supporting Evidence/ Likely treatment success

Promising results have been obtained from some research, however more investigations are required due to the small number (and therefore insignificant) number of children who have been studied.

Link to more information

<http://www.autism-help.org/intervention-LEAP.htm>,

http://researchautism.net/autism_treatments_therapies_intervention.ikml?ra=20

Video presentation by expert explaining components of a LEAP preschool program:

<http://www.youtube.com/watch?v=vVI08IHZdZA>.

References

<http://www.autism-help.org/intervention-LEAP.htm>

<http://www.health.gov.au/Internet/publications/publishing.nsf/Content/mental-child-autrev-toc~mental-child-autrev-comb~mental-child-autrev-comb-lea>

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Number of participation hours required each week	
Under 15	15+
Notes: 15 hours per week of classroom	

participation is required. Intervention not available one-to-one.

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: No information available				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes: Program is set in a classroom environment.		

Possible pros of this intervention	Possible cons of this intervention
Can improve social and communication skills.	More research is required to gauge effectiveness of therapy. Therapy is not available one-on-one. Adverse results are possible if LEAP is applied without following the relatively strict guidance, specifically if it is confused with putting children into mainstream schools with little or no support.

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Treatment and Education of Autistic and Communication related handicapped Children (TEACCH)

The TEACCH program is used to help children with autism to develop communication and social skills, independence, coping skills and other skills for daily living (for example, dressing, washing, cleaning teeth). This program can be used in conjunction with other therapies. TEACCH offers an intensive intervention program that supports children by creating a very structured learning environment. The environment includes physical boundaries between different tasks, workstations and clear schedules of daily activities. While pure TEACCH programs are not always available, many therapists and interventions use principles of TEACCH in their programs.

Supporting Evidence/ Likely treatment success

Current studies show that TEACCH could potentially help children improve aspects of their behaviour and communication skills, however more studies are required using control groups, larger sample sizes, and other high standard research techniques to demonstrate the effectiveness of this method.

Link to more information

http://raisingchildren.net.au/articles/teacch_th.html/context/908

Video by Autism Speaks explaining components of this intervention:

<http://www.youtube.com/watch?v=ddGLJ2r4rcw>

References

http://raisingchildren.net.au/articles/teacch_th.html/context/908

<http://teacch.com/>

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Number of participation hours required each week	
Under 15	15+

Notes: The program is more likely to be effective with increased frequency of sessions.

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: Varies upon individual assessment of needs, and therapist fee schedule.				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Promotes a range of different daily living skills.</p> <p>Can be used in conjunction with other therapies.</p>	<p>Program can be time consuming.</p> <p>Program not widely available in 'true' form.</p>

SCERTS – Social Communication, Emotional Regulation and Transactional Support

SCERTS is an intervention model that combines techniques from a number of interventions to create individualised programs for children with autism. Techniques may be drawn from established interventions such as LEAP, TEACCH, DIR@/Floortime™, RDI, Hanen, and Social Stories™ (link to each). Parents and therapists design individualised programs collaboratively. Therapists are specifically trained to provide this service and to learn which elements of the other interventions to use.

Supporting Evidence/ Likely treatment success

Individual techniques used in treatment have been validated by research, but overall effect of using this intervention method has not been rated.

Link to more information

http://raisingchildren.net.au/articles/scerts_th.html?context=19

<http://products.brookespublishing.com/SCERTS-C1073.aspx>

Video presentation by Dr Barry Prizant, co-developer of the SCERTS program, explaining the program in detail: <http://www.youtube.com/watch?v=srJ2BnR-Qp8>

References

<http://raisingchildren.net.au/search.aspx?q=scertssingchildren.net.au>

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Number of participation hours required each week	
Under 15	15+
Notes: May vary depending on individual assessment of needs, however it is likely that strategies incorporated into the program will need to be regularly monitored and reinforced	

each week in order to be effective.

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
<p>Notes:</p> <p>Varies upon individual assessment of needs, however costs will include therapist fees during the initial assessment phase.</p>				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
<p>Notes: Therapy environment will be dependant upon strategies chosen.</p>		

Possible pros of this intervention	Possible cons of this intervention
<p>Parents are involved in initial assessment, goal setting and therapy activities.</p> <p>Can use the most effective and relevant elements of a number of autism interventions.</p>	<p>Requires the coordination and collaboration of different professionals (speech therapist, OT, psychologist) familiar with this model and the different interventions, which may be incorporated.</p>

DIR ® / Floortime ™ approach

DIR ® / Floortime ™ aims to help improve children's social interaction and communication skills through play. This therapy approach involves lots of playtime between adult and child on the floor. Parents and carers are specifically trained to continue therapy activities each day in the home environment.

Supporting Evidence/ Likely treatment success

Positive and promising research results have been found for this intervention, however more high quality studies are needed e.g. study to include greater number of participants and use of blinding.

Link to more information

<http://www.icdl.com/dirFloortime/overview/index.shtml>

http://raisingchildren.net.au/articles/dir_model_th.html/context/907

Video interview with DIR/ Floortime developer, Dr Stanley Greenspan explaining principles of DIR/ Floortime: <http://www.youtube.com/watch?v=EPHjLe7MVYE>

Video example of Floortime ™ therapy session:

<http://www.youtube.com/watch?v=h3gcpNcq29M>

References

http://raisingchildren.net.au/articles/dir_model_th.html/context/907

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Number of participation hours required each week	
Under 15	15+
Notes: Parents to be trained to undertake sessions 2 to 5 hours per day / 3 to 4 times per week plus sessions with a therapist where required.	

Cost of intervention per week				
	\$30 -	\$80 -	\$100 -	
\$0-\$30	\$80	\$100	\$120	\$120 +
Notes: Fees include therapist consultations and parent training expenses.				

Home, Clinic, or both?		
	Clinic or	Both or it
Home-based	centre-based	doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Increased parent involvement can reduce therapy visits and cost.</p> <p>Claims to promote social, emotional, and intellectual development.</p>	<p>Specific training is required for therapists.</p> <p>High demand and time requirement on parents.</p> <p>High cost involved undergoing training in this method.</p>

Relationships Development Intervention (RDI) ®

Relationships Development Intervention® is an intervention aimed at improving a child's ability to learn social skills and develop relationships with others. Therapists train parents, who then work with their child using strategies taught by the therapist. This parent-led approach is most suited to children with high functioning autism. Strategies include looking for opportunities to practice communication, encouraging the sharing of feelings, and focussing on speed/ pace of conversations.

Supporting Evidence/ Likely treatment success

Promising results from some research, however more high quality research studies are required.

Link to more information

<http://www.rdiconnect.com/pages/our-programs.aspx>

http://raisingchildren.net.au/articles/rdi_th.html/context/907

Video case-study of child learning communication skills through RDI:

<http://www.youtube.com/watch?v=6J4lvnUCwdA>

References

<http://www.rdiconnect.com/pages/our-programs.aspx>

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Number of participation hours required	
Under 15	15+
Notes: Requires ongoing practice and reinforcement of skills learned in the home environment in order to be effective.	

Cost of intervention per week				
	\$30 -	\$80 -	\$100 -	
\$0-\$30	\$80	\$100	\$120	\$120 +
Notes: Fees include training, manuals and ongoing therapist support.				

Home, Clinic, or both?		
	Clinic or	Both or it
Home-based	centre-based	doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Learnt skills such as:</p> <p>Sharing feelings, memories, plans and ideas</p> <p>Understand that sharing is a good thing, and recognise when other people share</p> <p>Solving problems in creative and flexible ways</p> <p>Reflecting on past experiences and thinking about what might happen in the future</p> <p>Cope with uncertainty and setbacks when these happen.</p> <p>These learnt skills are all transferrable to daily interactions.</p>	<p>High level of cost for assessment and ongoing monthly support over a period of time.</p>

The P.L.A.Y project – Play and Language for Autistic Youngsters

The P.L.A.Y project has origins in the DIR/ Floortime™ approach (hyperlink) and involves helping parents to provide intensive interventions in their own home. Specially trained consultants provide training and support to parents, in an effort to minimise the need for ongoing therapy appointments.

Supporting Evidence/ Likely treatment success

Promising results from initial research, although further investigations are required. More recent research undertaken by the developers reportedly demonstrates that P.L.A.Y may improve language and interactional skills in children with autism.

Link to more information

www.playproject.org

Video Introduction of the P.L.A.Y project featuring developer, Dr Richard Soloman:

<http://www.youtube.com/watch?v=TWPFjSqM5FI>

Series of videos about the P.L.A.Y project:

<http://www.youtube.com/user/ThePLAYProjectHQ>

References

www.playproject.org

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Number of participation hours required	
Under 15	15+
Notes:	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +

Notes:

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Provides cost effective intervention by educating parents to deliver intervention at home.	High time demand on parents.

Sensory considerations, Environmental management, Routines and planned change, Visual supports, Autism friendly communication, Motivation (SERVAM)

SERVAM is a handbook for parents that teaches them strategies to develop their child's intellectual, emotional, social, physical and creative skills in daily family life.

The authors of the handbook are from allied health professions including occupational therapy, speech therapy and special needs education. The SERVAM handbook claims that that this model provides a flexible framework that enables parents to balance their child's specific learning needs with family life.

SERVAM borrows techniques from Special Education, Speech Therapy and Occupational Therapy. This model does not replace the input of professionals, but aims to explain how research-based, practical strategies from these disciplines may be used to assist children with autism in everyday situations.

Supporting Evidence/ Likely treatment success

Some evidence exists to support some of the concepts in the handbook and the use of parents in therapy provision, however no studies have been undertaken to test the effectiveness of employing the strategies taught to parents in the handbook in the context of a therapy intervention.

Link to more information

www.servam.com.au

References

www.servam.com.au

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Number of participation hours required	
Under 15	15+
Notes:	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: The costs involved pertain to purchasing the handbook (\$18/ chapter) or there are training sessions available (up to \$1500 per training session – both online and face-to-face).				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Claims to provide a flexible framework for parents to balance their child's specific learning needs with other family commitments.</p> <p>Combines a range of strategies from a number of disciplines.</p>	<p>Does not replace the input of professionals or provide exclusive strategies for working with children with autism.</p>

Hanen – More Than Words™

Hanen More Than Words™ is a family-based intervention focused on training parents of children with autism to help them develop communication skills in daily life. Centre-based group sessions also provide social support networks for parents.

The intervention is provided by parents who are trained by speech pathologists, typically in a group setting. Parents are taught to take advantage of opportunities in every day life to improve their child's communication skills.

The three goals of this program are:

1. Improved social skills
2. The ability to engage in back-and-forth interactions
3. Improved understanding of language

Supporting Evidence/ Likely treatment success

No studies have yet been undertaken to test the effectiveness of this intervention. This program does however, apply best practice principles.

Link to more information

www.hanen.org/Hanen-Programs/Programs-For-Parents.aspx

Video example of therapist home visit: <http://www.youtube.com/watch?v=Yo8UwhCOHM4>

References

www.raisingchildren.net.au

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Number of participation hours required each week	
Under 15	15+

Notes:
 20+ hours per week home based and 8-10 weekly group sessions (2.5 hrs per session)

Cost of intervention per week				
	\$30 -	\$80 -	\$100 -	
\$0-\$30	\$80	\$100	\$120	\$120 +
Notes: \$30-\$120 per session / item / week				

Home, Clinic, or both?		
	Clinic or	Both or it
Home-based	centre-based	doesn't matter.
Notes: Parent training is usually undertaken in a clinic, with therapy activities then undertaken in the home and other frequently accessed settings.		

Possible pros of this intervention	Possible cons of this intervention
Emphasis is on parent education and empowerment. Group sessions and feedback offer support and ongoing training.	Limited by regional access. Sessions can only be delivered by speech therapists / pathologists trained in this technique. Additional expenses are incurred, as parent guidebook should also be purchased.

Pre-schoolers with Autism – manualised parent training program

Pre-schoolers with Autism is a 20-week parent education program that provides them with an understanding of autism and its effect on their child's development, skills and abilities.

There are 10 parent group sessions (90 mins per week) and 10 individual sessions (60 mins per week). These sessions focus on topics such as managing difficult behaviours, coping with stress, and how to encourage communication.

Supporting Evidence/ Likely treatment success

Research has shown that a 20-week parent education and skills training program for parents of young children newly diagnosed with autism provides significant improvements in parental mental health and adjustment, justifying its addition to early intervention programs.

Link to more information

<http://www.med.monash.edu.au/spppm/research/devpsych/actnow/presch-autism.html>

References

<http://www.med.monash.edu.au/spppm/research/devpsych/actnow/presch-autism.html>

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Number of participation hours required per week	
Under 15	15+
Notes: 20 week program involving 10 group sessions (90 mins) and 10 individual sessions (60 mins)	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes:				

Up to \$4000 to participate in the program
(includes copy of parent manual book)

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>The authors' view is that families do better when parents/carers have the opportunity to work in partnership with professionals.</p> <p>Meeting with other parents whose children have autism to share feelings and experiences is also important.</p>	<p>Limited by regional access.</p> <p>Sessions can only be delivered by clinicians experienced in counselling, child development and autism specific family supports.</p> <p>An additional parent guidebook is required to be purchased.</p>

Triple P – Stepping Stones Adaptation

Triple P – Stepping Stones Adaptation is a parent-training program that has been developed for parents of children with a disability to help with difficult behaviour and managing issues common in children with disabilities. Available in individual or group settings, it is based on Triple P's parenting strategies and is appropriate for parents of children diagnosed with autism who are experiencing challenging behaviours.

Supporting Evidence/ Likely treatment success

Research suggests that when parents change their approach to problem behaviours, children are more receptive to making a change in behaviour patterns. This gives parents greater confidence in their ability to deal with daily challenges.

Link to more information

http://raisingchildren.net.au/articles/autism_spectrum_disorder_interventions.html

Link to podcast – Assoc. Prof Kate Sofronoff of The University of Queensland explaining Triple P in relation to helping children with autism:

<http://www.abc.net.au/local/stories/2012/05/15/3503444.htm>

References

<http://www.pfsc.uq.edu.au/research/evidence/>

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Number of participation hours required each week	
Under 15	15+
Notes: Time commitment varies. Can be 9-16 hours over 10 sessions, or longer individual sessions if needed.	

Cost of intervention per week				
	\$30 -	\$80 -	\$100 -	
\$0-\$30	\$80	\$100	\$120	\$120 +
<p>Notes: A group program will cost approx. \$550, usually to be paid in full before the commencement of the course. This equates to \$35 an hour. Individual sessions would most likely be higher.</p> <p>A parent workbook can also be purchased for an additional \$15.</p>				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Educates and empowers parents of children with autism to effectively resolve daily behavioural difficulties.	Therapy is directed towards assisting parents manage their child's behaviour. There is little or no interaction between the therapist and child in this intervention.

Speech Generating Devices (SGD) and other Augmentative & Alternative Communication (AAC)

Speech Generating Devices and other Augmentative and Alternative Communication includes electronic devices that convert text or pictures to a recorded voice, enabling the user to speak. These devices include Dynavox machines and iPads, amongst others. They offer people with little or no ability to speak the opportunity to communicate. These devices are particularly useful for children who are non-verbal. They can be used to support participation in other therapies. Some devices may rely on words being typed on a keyboard, or words/ pictures being tapped on a screen to generate speech.

Supporting Evidence/ Likely treatment success

The impact of using SGD and AAC with this client group has not been studied, however the obvious benefits of providing children with autism with a means to communicate, justifies the inclusion of this technology as an appropriate intervention for some children diagnosed with autism.

Link to more information

<http://www.spectronicsinoz.com/catalogue/communication-tools>

Video example of child with autism using SGD:

<http://www.youtube.com/watch?v=1QhuWMuWRqw>

Video example of child learning to use an iPad for speech:

<http://www.youtube.com/watch?v=AP7YJ4zUcWk>

References

raisingchildren.net.au/articles/speech-generating_devices_th.html/context/932

Page created on (date) by Nicole Grant.

Page updated on (date) by (name)

Number of participation hours required	
Under 15	15+

Notes:
Daily constant use is required to acquire skills for communication.

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: Initial equipment purchase can be thousands of dollars, however newer technology is more cost effective.				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>These devices offer a communication solution for children with limited or no verbal skills.</p> <p>Use of these devices can encourage verbal communication.</p>	<p>Some devices are very expensive.</p> <p>Therapy sessions are usually required to educate children and their families in the use of these devices.</p>

Picture Exchange Communication System (PECS)

PECS is a strategy that incorporates the use of visual images and pictures on cards to facilitate and provide an alternative means of communication for those who experience problems with spoken communication. It is often used in conjunction with other therapies, such as EIBI (link to EIBI). The child using PECS learns to associate pictures as visual representations of real life objects and then learns to use the cards to communicate needs/desires etc. For example, a child may be learning to request juice. The child learns that by providing their parent with the juice picture card, they will most likely be given a glass of juice. PECS can also be used to teach choice making. For example a parent might present the picture cards for juice and milk, and then ask which one they would prefer.

Supporting Evidence/ Likely treatment success

Current evidence is promising, however further investigations involving more rigorous trials are needed.

Link to more information

<http://www.pecsaustralia.com/>

<http://autismspectrum.illinoisstate.edu/resources/factsheets/pictureexchange.shtml>

http://raisingchildren.net.au/articles/pecs_th.html/context/905

http://en.wikipedia.org/wiki/Early_intensive_behavioral_intervention

Video demonstrating use of PECS for motivation:

<http://www.youtube.com/watch?v=c9ywf0WDoj0>

Video demonstrating use of PECS for communication:

<http://www.youtube.com/watch?v=eTzedhezar8>

References

http://raisingchildren.net.au/articles/pecs_th.html/context/905

http://en.wikipedia.org/wiki/Early_intensive_behavioral_intervention

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Number of participation hours required	
Under 15	15+
Notes: Being a method of communication, this requires daily use and reinforcement.	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: Initial training costs and materials can be high.				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Positive reinforcement for desired behaviours may encourage further communication.</p> <p>Ongoing costs may be lower than other intervention options.</p>	<p>Initial training cost can be high.</p> <p>Parents should to expand card library as required.</p>

Signing and Makaton

Makaton uses speech with signs (gestures) and symbols (pictures), facial expression, eye contact and body language to help the child to communicate with those around him/her. Signs and symbols can provide additional information and cues, which can be seen and easily interpreted by children with autism. It may also be an alternative for language, while for others it may be used as a bridge to developing language /communication skills. Makaton can be used in conjunction with other therapies.

Supporting Evidence/ Likely treatment success

Current evidence is promising, however more rigorous studies are needed. This intervention strategy is best used in combination with other intervention methods.

Link to more information

<http://www.makaton.org/aboutMakaton/>

Video of child learning Makaton: <http://www.youtube.com/watch?v=-DqruTfsnfU>

Video explaining use of Makaton: http://www.youtube.com/watch?v=MASkfzYf_9w

References

http://raisingchildren.net.au/articles/manual_signing_th.html

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Number of participation hours required each week	
Under 15	15+
Notes: Skills need to be practiced daily and integrated into daily activities.	

Cost of intervention per week				
	\$30 -	\$80 -	\$100 -	
\$0-\$30	\$80	\$100	\$120	\$120 +
<p>Notes:</p> <p>Costs may vary depending on training and support needs, and can range from \$30 - \$120 per session.</p>				

Home, Clinic, or both?		
	Clinic or	Both or it
Home-based	centre-based	doesn't matter.
<p>Notes:</p>		

Possible pros of this intervention	Possible cons of this intervention
<p>Makaton can improve communication skills and impact on behaviours due to reduced anxiety and frustration caused by inability to articulate wants and needs.</p> <p>Best used in conjunction with other therapy approaches.</p>	<p>There can be a requirement for the whole family and extended friends and carers to learn.</p> <p>Not universally used or recognised.</p>

Alert Program for Self-Regulation

Alert is a program aimed at helping children to recognise their emotions and feelings. Children are taught this by using an "engine" analogy, which is easily identifiable for children, and helps them to acknowledge their "engine" (whether it is running slow, fast or just right). For example, the child learns that he /she needs to do something physical like jump up and down before settling to do speech therapy/reading, or that he/she needs to use a fidget toy e.g. squeeze a stress ball when they are feeling restless.

Supporting Evidence/ Likely treatment success

No evidence currently exists to support the use of this program with children with autism, however the underlying principles of the program are based on sound and well-accepted theories.

Link to more information

www.alertprogram.com

Video presentation explaining aspects of the Alert Program by developers Sherry Shellenberger and Mary Sue William: http://www.youtube.com/watch?v=NPEwwzAT_Ic

References

http://raisingchildren.net.au/articles/sensory_integration_th.html

Page created on (date) by Nicole Grant.

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Number of participation hours required	
Under 15	15+
Notes: 0 to 10 hours per week depending service provider's method of training.	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes:				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
<p>Program helps children with autism to identify their emotions and feelings and self regulate accordingly.</p> <p>Educates parents and educators in how to read and respond to different emotional states in the child.</p>	<p>Requirement for ongoing reinforcement.</p>

Social Stories™

Social Stories™ are specifically written stories that follow a prescribed format that are used to explain social situations to children with autism. They help children learn socially appropriate behaviours and responses. They are developed as a way for children to learn how they should behave in social settings by explicitly pointing out details about the setting and what typically happens in that setting (e.g. sitting and listening at story time at kindergarten, or standing in line to wait to go to the toilet). These details help children pick up on cues they often overlook. Social Stories™ aim to increase social understanding by answering the 'who', 'what', 'where', 'how', and 'why' questions.

These stories are a strategy used to support and enhance other interventions or therapies and are rarely used in isolation. Therapists and educators often incorporate social stories/methods into their interventions.

Supporting Evidence/ Likely treatment success

Established results - research shows positive effects

Link to more information

<http://www.autismnetwork.org/modules/social/sstory/index.html>

References

http://raisingchildren.net.au/articles/social_stories_th.html/context/905

Page created on (date) by Nicole Grant.

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Number of participation hours required	
Under 15	15+
Notes:	

Cost of intervention per week

\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes:				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Uses real life scenarios to assist in developing socially acceptable responses.	May be less effective in children with poor comprehension skills.

PALS Social Skills program

PALS Social Skills program is a ten-session program, aimed at children aged 3 to 6, to develop social skills in groups of 6 to 8 participants. Parent information sheets are available. Strategies include role-playing and singing.

Supporting Evidence/ Likely treatment success

Research findings indicate PALS significantly reduces perceived problem behaviour and increases social skills

Link to more information

<http://www.palsprogram.com.au/>

References

<http://www.palsprogram.com.au/>

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Page updated on (date) by (name)

Number of participation hours required each week	
Under 15	15+
Notes: 10 sessions each, 20-30 minutes in duration	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: Program resource kit purchase price \$375				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Skills at each session build on the previous session to achieve competent social interactions	Works best in a group environment (6-8) or entire class when adapted, not by individual cases

Toilet Time

Toilet Time is a toilet training package for girls (Emily) and boys (Tom), designed for parents of children with developmental delay (including autism) who are teaching their children how to use the toilet independently.

Supporting Evidence/ Likely treatment success

Further study needed to confirm effectiveness of this intervention strategy for children with autism

Link to more information

http://shop.service.sa.gov.au/site/page.cfm?content=search_results.cfm&mode=single&product_id=5338

References

http://www.downsyndromevictoria.org.au/DSAV/Information/Online_information_library/Toilet_training/DSAV/Families/Toilet_training.aspx#.URJNcKVvPK0

Page created on (date) by Nicole Grant.

Page updated on (date) by (name)

Number of participation hours required	
Under 15	15+
Notes: 0-10 hours per week, more time intensive at first stages	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: \$100 for resources available for purchase				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Offers parents access to cue cards, strategies for teaching independent toilet use	Intensive home element

Music Therapy

Music therapy uses music and the interaction between the teacher/therapist and child to teach specific skills and may improve social and communication skills in children with autism. There are many different types of music therapy. Therapy activities promote interaction, expression and social skills such as taking turns. Sessions are conducted with a Registered Music Therapist who will assess individual need before creating goals and activities with ongoing evaluation.

Supporting Evidence/ Likely treatment success

Some evidence exists supporting this intervention, however more high-quality studies are needed.

Link to more information

<http://www.austmta.org.au/contact-us/find-a-music-therapist/>

Video presentation on benefits of Music Therapy – one on one session:

<http://www.youtube.com/watch?v=8sgb9DrkVeE>

Video showing group music therapy session:

<http://www.youtube.com/watch?v=YIH3MESWFZg>

References

http://raisingchildren.net.au/articles/music_therapy_th.html

Page created on (date) by Nicole Grant.

Page updated on (date) by (name)

Number of participation hours required per week	
Under 15	15+
Notes: Sessions are typically 20 to 50 minutes per week	

Cost of intervention per week				
	\$30 -	\$80 -	\$100 -	
\$0-\$30	\$80	\$100	\$120	\$120 +
Notes: \$30 to \$100 per session each week				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Promotes a range of skills. Suitable for all ages.	Registered Therapists might not be experienced in working specifically with people with autism.

Circles of Support

Circles of Support is an inclusion program encouraging other families with typically developing children to form a support network around families with a child or children with autism. Support may take place in the form of organised group activities or other social activities, with an aim to provide families with the opportunity to discuss goals and aspirations for their child, issues around caring for a child with a disability, and other aspects of family life. The circle is centered around, and is focused on the family whose child has been diagnosed with autism.

Supporting Evidence/ Likely treatment success

This intervention is a support tool, and only to be used in conjunction with existing evidence-based interventions.

More information

http://www.resourcingfamilies.org.au/images/stories/PDFs/entiredoc-circles_%20of_%20support.pdf

References

http://www.resourcingfamilies.org.au/images/stories/PDFs/entiredoc-circles_%20of_%20support.pdf

Page created on (date) by Nicole Grant.

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Number of participation hours required each week	
Under 15	15+
Notes: Regular meetings typically held every 6 - 8 weeks, usually about 2 hours in duration.	

Cost of intervention per week				
\$0-\$30	\$30 - \$80	\$80 - \$100	\$100 - \$120	\$120 +
Notes: Community based facilitator, relies on funding sources. No fixed cost.				

Home, Clinic, or both?		
Home-based	Clinic or centre-based	Both or it doesn't matter.
Notes:		

Possible pros of this intervention	Possible cons of this intervention
Ability to nurture and develop friendships and relationships, with a view to long-term support for people with disabilities, particularly for respite and progression into independent living.	Program not available in all areas.

QUESTIONS TO ASK YOUR HEALTH/ EARLY INTERVENTION PROVIDER

The Early Intervention for Children with Autism Spectrum Disorders: “Guidelines for Good Practice” page 10, 2012 recommend that parents ask the following questions of their healthcare provider:

Questions Parents Should Ask

1. What are the specific aims of the program?
2. Are there any medical or physical risks
3. What assessments of individual children are carried out prior to the intervention?
4. What is the evidence base for this intervention?
5. What evaluation methods have been used to assess the outcome of intervention?
6. Do the proponents of the treatment program have a financial stake in its adoption?
7. What is known about the long-term effects of this treatment?
8. How much does it cost?
9. How much time will be involved?

Reference:

Prior, M. & Roberts, J. (2012), Early Intervention for Children With Autism Spectrum Disorders: “Guidelines for Good Practice” page 10, 2012.
<http://www.latrobe.edu.au/otarc/otarc-documents/Margot-EI-guidelines-revised.pdf>

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Page updated on (date) by (name)

(Link to print this page)

ADDITIONAL INFORMATION, RESOURCES AND LINKS

Autism Resources

[Helping Children With Autism \(FaHCSIA\)](#)

[Raising Children Network](#)

[The Olga Tennison Autism Research Centre](#)

State Based Organisations

[Autism Asperger ACT](#)

[Autism Northern Territory](#)

[Autism Queensland](#)

[Autism South Australia](#)

[Autism Spectrum Australia \(Aspect\)](#)

[Autism Victoria \(Amaze\)](#)

[Autism Western Australia](#)

Treatment and Intervention Information

[Medication Decision Aid](#)

[Research Autism – Autism Treatments and Therapies](#)

Further Reading

Testing treatments 2nd edition (free at the website) - <http://www.testingtreatments.org/tt-main-text/>

Smart Health Choices (also has a free website) -

<http://sensiblehealthadvice.org/uncategorized/smart-health-choices-is-now-free/>

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Appendix N - Study 5: RCT Participant Information Sheet



INFORMATION FOR RESEARCH PROJECT PARTICIPANTS

Research project title:

Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Lay title: Helping parents decide on treatment options for their child

Chief investigator:

Nicole Grant

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

Co-investigators:

Professor Sylvia Rodger

Head of School

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

Dr Tammy Hoffmann

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

and

Centre for Research in Evidence-Based Practice (CREBP)

Faculty of Health Sciences and Medicine

Bond University

We would like to invite you to contribute to this study, by participating in a trial of a decision aid designed to help you choose autism interventions for your child, who has recently been diagnosed with an Autism Spectrum Disorder (ASD). The aims of this study are to:

1. Develop an understanding of the information parents are currently using to make decisions.
2. Develop an understanding of parents' decision making processes.
3. Evaluate the most commonly accessed information by parents, particularly web-based information in terms of the quality of information available.
4. Review intervention taxonomies and help parents to understand what interventions are available and how they are classified.
5. Evaluate the effectiveness of a decision aid for parents of children with Autism Spectrum Disorder.

Participation Requirements

This stage of the research project is a Randomised Controlled Trial (RCT), designed to test the effectiveness of a purpose-designed decision aid. Participants will be randomly allocated to either a Treatment or Control group. If you are selected for the Treatment Group, you will be given access to the decision aid, which is currently an interactive website containing information on autism and autism treatment options. If you do not have Internet access, the information will be posted to you.

Participants allocated to the Control group, will not be given access to the decision aid, but will be contacted twice in three (3) months, to discuss decision making processes used while accessing the information and support typically available to parents upon receiving a diagnosis of autism for their child.

All participants, that is both the Treatment and Control groups, will be interviewed via telephone upon commencing the trial and then again approximately three (3) months later. During this time, participants in the treatment group, will be expected to have accessed the web-based decision aid. After completion of the trial, participants allocated to the Control group will also be offered access to the decision aid.

Eligibility

To be eligible for participation, participants must meet the following requirements:

Be a parent or guardian of a child under the age of seven (7), who has been diagnosed with an autism spectrum disorder within the past 12 months.

Reside within an Australian State or Territory

Additional Information

This study has been approved by The University of Queensland human ethics committee in accordance with the National Health and Medical Research Council's guidelines. If you wish to speak with someone not involved directly with this study, please contact the UQ ethics officer, Mr Michael Tse on (07) 3365 3924.

You are free to decline from participating in the study or to withdraw from the study at any time without explanation or fear of penalty. Should you have any questions regarding the nature of the research, please feel free to contact the undersigned on the number provided below.

No incentive is offered for participation in this trial, however your involvement will contribute to the development of better quality information for parents of children diagnosed with autism in the future. It is anticipated that information regarding this resource, if proven effective in improving parents' ability to make informed decisions, will be distributed by the health professional or health care teams involved in supporting parents of children who are diagnosed with autism. The resource would also be made available freely online.

To participate in this study, please complete the consent form attached. Thank you again for considering participation in this project.

Yours sincerely

A handwritten signature in blue ink that reads "ngrant". The signature is written in a cursive style and is set against a light blue, textured background.

Nicole Grant

Doctor of Philosophy Candidate

Ph. 0417 879 461

Email: Nicole.grant@uqconnect.edu.au

Appendix O - Study 5: RCT Participant Consent Form



Participant Consent Form for Participation in a Randomised Controlled Trial (RCT)

Research project title:

Assisting parents of children with autism to make intervention decisions by improving their health literacy about evidence.

Lay title: Helping parents decide on interventions for their child

Chief investigator:

Nicole Grant

School of Health and Rehabilitation Sciences

The University of Queensland

Co-investigators:

Professor Sylvia Rodger

Head of School

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

Dr Tammy Hoffmann

Division of Occupational Therapy

School of Health and Rehabilitation Sciences

The University of Queensland

and

Centre for Research in Evidence-Based Practice (CREBP)

Faculty of Health Sciences and Medicine

Bond University

Thank you for agreeing to participate in this trial. Please sign below to indicate that you have read and understand the requirements for your participation.

- I have read the Participant Information Sheet and understand the requirements for my participation in this trial.
- I understand that my participation is voluntary, and that I may withdraw from this study at any time without penalty.
- The risks and benefits of participating in the trial have been explained to me and I understand them.
- I understand that information obtained from me during interviews may be audiotaped and transcribed, and that all recorded and written information provided by me is confidential and will be de-identified.
- I understand that I will be asked to complete a short questionnaire about decision making and confidence levels, and that some demographic data will be recorded.
- I understand that I will be allocated to one of two groups A or B and that if allocated to group B I will be able to access the web-based resource after a period of 3 months.
- I can request further information about the results of this study by submitting my request in writing to the chief investigator.

Participant Consent Form

Please return to:

Nicole Grant

PO Box 536

Cannon Hill QLD 4170

or nicole.grant@uqconnect.edu.au

or Fax No. (07) 3843 4084

Signed: _____ Dated: _____

Participant's Full Name: _____

Address _____

Telephone Number: _____

Email Address: _____

Appendix P - Study 5: REALM Health Literacy Screen

REALM Scoring Sheet and Administration Instructions

REALM Scoring Sheet

fat _____	fatigue _____	allergic _____
flu _____	pelvic _____	menstrual _____
pill _____	jaundice _____	testicle _____
dose _____	infection _____	colitis _____
eye _____	exercise _____	emergency _____
stress _____	behaviour _____	medication _____
smear _____	prescription _____	occupation _____
nerves _____	notify _____	sexually _____
germs _____	gallbladder _____	alcoholism _____
meals _____	calories _____	irritation _____
disease _____	depression _____	constipation _____
cancer _____	miscarriage _____	gonorrhoea _____
caffeine _____	pregnancy _____	inflammatory _____
attack _____	arthritis _____	diabetes _____
kidney _____	nutrition _____	hepatitis _____
hormones _____	menopause _____	antibiotics _____
herpes _____	appendix _____	diagnosis _____
seizure _____	abnormal _____	potassium _____
bowel _____	syphilis _____	anaemia _____
asthma _____	haemorrhoids _____	obesity _____
rectal _____	nausea _____	osteoporosis _____
incest _____	directed _____	impetigo _____

Score

List 1 _____

List 2 _____

List 3 _____

Raw Score _____

Scoring + = right
 - = not attempted
 x = pronounced wrong

Grade Range Estimates

REALM raw score	Grade range estimate
0-18	Third grade and below
19-44	Fourth to Sixth grade
45-60	Seventh to Eighth grade
61-66	Ninth grade and above

Instructions for Administration of the REALM

Participants are given the enlarged copy of the words in the REALM test and asked to read aloud as many words as they can, beginning with the first word on the first test sheet. If participants encounter a word that they cannot read, they are asked to do the best they can or say “blank” and go onto the next word. There is no time limit. If participants stop, they are asked to look down the list of words and pronounce as many of the remaining words as they can. Testing is stopped when participants are unable to pronounce any additional words correctly.

The examiner keeps score on a separate scoring sheet. Each word is marked with a plus for correct, a cross for incorrect, or a minus for any word that is not attempted. Dictionary pronunciation is the scoring standard. The raw score is determined by adding the number of correctly pronounced words.

From: Murphy, P., Davis, T., Long, S., Jackson, R., & Decker, B. (1993). Rapid Estimate of Adult Literacy in Medicine (REALM): A quick reading test for patients. *Journal of Reading*, 37, 124-130.

REALM Sheets Shown To Participants

fat
flu
pill
dose
eye
stress
smear
nerves
germs
meals
disease
cancer
caffeine
attack
kidney
hormones
herpes
seizure
bowel
asthma
rectal
incest
fatigue
pelvic
jaundice
infection
exercise

behaviour
prescription
notify
gallbladder
calories
depression
miscarriage
pregnancy
arthritis
nutrition
menopause
appendix
abnormal
syphilis
haemorrhoids
nausea
directed
allergic
menstrual
testicle
colitis
emergency
medication
occupation
sexually
alcoholism
irritation
constipation
gonorrhoea
inflammatory

diabetes
hepatitis
antibiotics
diagnosis
potassium
anaemia
obesity
osteoporosis
impetigo

Appendix Q - Study 5: Decisional Conflict Scale (DCS) Data Collection Sheet

B. Considering the option you prefer, please answer the following questions:

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
	[0]	[1]	[2]	[3]	[4]
1. I know which options are available to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I know the benefits of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I know the risks and side effects of each option.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I am clear about which benefits matter most to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I am clear about which risks and side effects matter most to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I am clear about which is more important to me (the benefits or the risks and side effects).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I have enough support from others to make a choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I am choosing without pressure from others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I have enough advice to make a choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I am clear about the best choice for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I feel sure about what to choose.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. This decision is easy for me to make.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I feel I have made an informed choice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. My decision shows what is important to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I expect to stick with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I am satisfied with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Appendix R - Study 5: Parenting Sense of Competency Scale (PSOC)
Data Collection Sheet**

Being a Parent

Name:

Date:

We would like to understand your experience of being a parent.

Please indicate the degree to which you agree with the following questions in relation to parenting your child with autism.

	Strongly Agree	Agree	Mildly Agree	Mildly Disagree	Disagree	Strongly Disagree
The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.	1	2	3	4	5	6
Even though being a parent could be rewarding, I am frustrated now while my child is at her/his present age.	1	2	3	4	5	6
I go to bed the same way I wake up in the morning, feeling that I have not accomplished a whole lot.	1	2	3	4	5	6
I do not know why it is, but sometimes when I am supposed to be in control, I feel more like the one being manipulated.	1	2	3	4	5	6
My mother/father was better prepared to be a good parent than I am.	1	2	3	4	5	6
I would make a fine model for a new mother/father to follow in order to learn what she/he would need to know to be	1	2	3	4	5	6

a good parent.						
	Strongly Agree	Agree	Mildly Agree	Mildly Disagree	Disagree	Strongly Disagree
Being a parent is manageable, and any problems are easily solved.	1	2	3	4	5	6
A difficult problem in being a parent is no knowing whether you're doing a good job or a bad one.	1	2	3	4	5	6
Sometimes I feel like I'm not getting anything done.	1	2	3	4	5	6
I meet my own personal expectations of expertise in caring for my child.	1	2	3	4	5	6
If anyone can find the answer to what is troubling my child, I am the one.	1	2	3	4	5	6
My talents and interests are in other areas not in being a parent.	1	2	3	4	5	6
Considering how long I've been a mother/father, I feel thoroughly familiar with this role.	1	2	3	4	5	6
If being a mother/father were only more interesting, I would be motivated to do a better job as a parent.	1	2	3	4	5	6
I honestly believe I have all the skills necessary to be a good mother/father to my child.	1	2	3	4	5	6
Being a parent makes me tense and anxious.	1	2	3	4	5	6

Appendix S - Study 5: Demographic Questionnaire for RCT



**THE UNIVERSITY
OF QUEENSLAND**
A U S T R A L I A

Demographic Questionnaire

1.	Are you a mother, father, or carer/ guardian of a child with AUTISM? (Please tick one)	<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Carer/ Guardian (Male) <input type="checkbox"/> Carer/ Guardian (Female)
2.	What is your postcode?	
3.	a) Is English your first language? (Please circle) b) If English is your second language, what other languages do you speak?	Yes/ No _____
4.	What is your current living/household situation?	<input type="checkbox"/> Married <input type="checkbox"/> De Facto <input type="checkbox"/> Divorced (Separated) <input type="checkbox"/> Never Married/ Single
5.	What is your current age (in years)?	
6.	What is your highest level of education? (Please tick)	<input type="checkbox"/> Year 8 <input type="checkbox"/> Year 10 <input type="checkbox"/> Year 12 <input type="checkbox"/> Certificate or Diploma <input type="checkbox"/> Undergraduate Degree <input type="checkbox"/> Postgraduate Degree
7.	What is your usual area of employment? (Please tick)	<input type="checkbox"/> Manager or Administrator <input type="checkbox"/> Professional <input type="checkbox"/> Associate Professional <input type="checkbox"/> Tradesperson <input type="checkbox"/> Clerical, Sales or Service Worker <input type="checkbox"/> Labourer

8.	For each of your children, please provide information about their age, gender, whether they have received a diagnosis of autism, and when they were diagnosed. (If you have more than 4 children, please provide additional information on the reverse side of this page).		Child 1	Child 2	Child 3
		a) Age (in years)			
		b) Gender (M/F)			
		c) Diagnosed with autism? (Y/N)			
		d) Year of Diagnosis (if relevant)			
9.	Please list which interventions you have used so far.				
10.	What sources of information have you used so far to find out about autism interventions?				
11.	<p>On a 10-point scale, how confident do you currently feel making decisions about autism interventions for your child? (Circle)</p> <p>(Not at all confident) 1 2 3 4 5 6 7 8 9 10 (Extremely confident)</p>				

Additional Comments:

END