How Parents of Children with Autism Spectrum Disorder Make Decisions About Which Intervention Approaches to Access.

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SUMMARY

Autism spectrum disorder (ASD) is a neuro-developmental disorder for which there is no known cure. There is however evidence that intensive early intervention can improve outcomes for children with ASD and their families. There is a vast range of interventions available for ASD, with varying degrees of empirical evidence. For a number of reasons, it is not possible for professionals to make specific recommendations about which intervention approaches families of children with ASD should access. Thus, the responsibility for selecting and accessing interventions lies primarily with parents of children with ASD.

Overall, there is a limited understanding regarding how parents of children with ASD make decisions about which intervention approaches to access, specifically with regard to how decision-making changes over time. The aim of the current study was to explore how parents make decisions regarding which intervention approaches to access for their children with ASD, parents' perceptions of the current supports available for decision-making and how current practices could be improved to support parents making decisions.

A constructivist grounded theory methodology was employed to allow an in-depth exploration of parental decision-making to occur. Data collection was undertaken in two stages. In the first stage, three parents of children with ASD generated questions to be compiled into an interview guide for the subsequent stage of the study. Within the larger second stage, semi-structured interviews were undertaken with 14 parents of children with ASD. As per the conventions of constructivist grounded theory, data collection and analysis occurred concurrently, with open coding being applied to initial interview transcripts, which informed the direction of

subsequent interviews. Constant comparison between the data allowed focused coding and the development of categories to occur. The use of memos allowed comparison between categories to occur and a grounded theory explaining parental decision-making over time to be constructed.

The findings of this study indicated that parental decision-making changes over time, as parents transformed from 'parent' to 'expert'. Six categories of factors were identified as influencing parental decision-making (experience, understanding, needs, information, motivation and logistics). With regards to support for decision-making, parents identified the need for professionals to provide information, guidance and support for decision-making, and a model of collaborative decision-making was established as the ideal model of support from a parent perspective.

The theoretical framework proposed by Giddens (1991) of 'fateful moments' was applied to explain to the process of transformation from 'parent' to 'expert'. Using this framework, a model explaining the transformation of parental decision-making over time was constructed. The findings of this research have implications for future research regarding parental decision-making, with some factors that had not been identified in previous research being identified in this study. Furthermore, the findings indicated that parents of children with ASD require ongoing support for decision-making post-diagnosis, though their support needs may reduce with time. In conclusion, the findings of this study provided a greater understanding of parental decision-making and the supports required by parents, both of which have implications for the delivery of services to families of children with ASD.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: Date:

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CHAPTER 1: INTRODUCTION

Thesis Aims

The purpose of this qualitative study was to explore how parents of children with Autism Spectrum Disorder (ASD) in South Australia make decisions about which intervention approaches to access. Furthermore, the purpose of this study was to explore parental perspectives on the supports available for decision-making. A constructivist grounded theory methodology was implemented to allow a substantive theory explaining parental decision-making to be developed. The theoretical perspective of symbolic interactionism was used to understand how parents construct meaning related to decision-making through their interactions with others and based on their experiences. Ultimately, the aim in conducting this study was to provide professionals working in the field of ASD with a greater understanding of the factors influencing parental decision-making, and the supports that parents require for decision-making. With an ever-increasing number of interventions being marketed to families of children with ASD, it was intended that the findings of this study would provide professionals with information that will allow them to support parental decision-making, so that parents are accessing effective, evidence-based[1] interventions for their children with ASD.

Local Context

This research study was conducted within South Australia (SA). It is important to understand the context in which this study was undertaken, given that there are some differences in diagnostic procedures, service delivery and funding models across the

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[1] "Evidence-based practice refers to clinical decision-making based on the best available evidence and in consultation with those receiving services (Dawes et al., 2005)

different states of Australia. Thus, an overview of services for children with an ASD diagnosis within SA at the time of data collection has been provided.

In SA, assessment for ASD can be accessed through the public health system (the child development units of local hospitals) or through private diagnostic services. Traditionally, there is a lengthy wait time, up to 12 months, for assessment through the public system, which results in delays in accessing early intervention[2] services. However, diagnostic assessment through private services can be expensive, upwards of $750 AUD, which means that it is not an option for some families. In SA, the diagnosic process involves a multi-disciplinary assessment in which at least two qualified professionals (speech-language pathologist, psychologist or pediatrician) determine whether or not the child meets the Diagnostic and Statistical Manual of Mental Disorder, fifth edition (DSM-V; American Psychiatric Association, 2013) criteria for ASD (at the time of data collection within the current study, the DSM-1V, an earlier version of the DSM, was used for assessment). Other assessment tools, for example the Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis & Daly, 1980), are often used in addition to the DSM-V to allow a detailed and thorough assessment to occur.   Children who receive a confirmed ASD diagnosis are subsequently eligible for ASD intervention services.

At the time that this research was being conducted, block grant state government funding provided children with ASD through the state's autism association. For children with ASD aged between 0-5 years, this amounted to a one-off block (five sessions each) of speech-language pathology and occupational therapy, as well as intermittent access to group programs (Autism SA, 2015). At the time of data collection, the funding of disability services had also experienced a recent

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[2] Within the context of this study, early intervention was defined as therapy or intervention received within the early years of life (0 – 7 years) (Roberts & Prior, 2006)

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change. In addition to the State Government funded services, Federal Government funding for ASD had also been established. In 2008, the Australian Federal Government introduced the 'Helping Children with Autism' (HCWA) Initiative. One of the key features of the initiative was $12,000 AUD funding allocated to each child with an ASD diagnosis, able to be spent on therapy and/or therapeutic resources up until the child's seventh birthday (Department of Social Services, 2015). In informing the initiative, Roberts and Prior (2006) conducted a review of interventions to determine the most effective models of practice in early intervention for children with ASD. Based on this review, a selection of interventions eligible for Government funding was generated, which included speech-language pathology, occupational therapy, psychology and ABA therapy (Roberts & Prior, 2006). Consequently, parents were able to select from the range of service providers approved by the former Department of Families, Housing, Community Services and Indigenous Affairs (Department of Social Services, 2015). The HCWA initiative also included the appointment of Autism Advisors, whose role was to provide families with information about the funding and available intervention programs. The responsibility to make decisions regarding which intervention approaches to implement however remained primarily with the parents of children with ASD.

Further to this, at the time of data collection, changes were pending to statewide disability funding, with the imminent introduction of the National Disability Insurance Scheme (NDIS). During the period of data collection, the scheme had not yet been launched, but information had been released to families regarding what the scheme might look like. The NDIS has since been rolled out in South Australia, changing the landscape of disability services once again. The NDIS has in some

aspects expanded concepts behind the HCWA Initiative, whereby parents are able to be in control of all of their child's funding for intervention services.

Research Significance

Overall, there is limited research examining how parents of children with ASD make decisions about which intervention approaches to access. There are several reasons why it is important to gain a greater understanding of parental decision-making. With an increasing prevalence (Centres for Disease Control and Prevention, 2014), ASD is now the most common childhood developmental disability. There is evidence indicating that early intervention can improve the outcomes for children with ASD (Howlin, Magiati, Charman & MacLean, 2009; Roberts & Prior, 2006; Warren et al., 2011), however there is significant heterogeneity within the ASD population, and therefore not all children will respond equally to the same intervention approach. Furthermore, there are some intervention approaches that have little to no empirical evidence supporting their effectiveness, and in fact, there is evidence indicating that some interventions may be ineffective (Jacobson, Mulick & Schwartz, 1995; Sinha, Silove, Wheeler & Williams, 2006) or even harmful (McGuire, Kulkarni & Baden, 2000) for children with ASD. With parents of children with ASD adopting the role of decision-maker as per the HCWA and NDIS funding models, it is important therefore for professionals to understand the factors influencing parental decision-making. Understanding how parents make decisions about which intervention approaches to access will allow professionals to support parents to access evidence-based intervention programs. This is critical, given what is known regarding neuro-plasticity and the potential for sound intervention practices to aid the development of children, particularly within the early years. Furthermore, there have been some cases

where children with ASD have been harmed by being exposed to certain alternative therapies (McGuire, Kulkarni & Baden, 2000). Thus, by providing professionals with an insight into parental decision-making and the supports required by parents for decision-making, the findings of this study will help to ensure that children with ASD are accessing safe, evidence-based intervention programs.

Within the existing research that explores parental decision-making, the focus has primarily been on how parents make initial decisions about which intervention approaches to access. This study aims to add to the literature on parents' perspectives on decision-making regarding the interventions they access for their children with ASD, and how this process develops over time. It is important to explore parental decision-making over time, given that the support needs of parents are likely to change over time, in order for professionals to provide individualised and specific support to families. Furthermore, providing appropriate support to parents of children with ASD is critical given the higher levels of parenting stress that has been reported in this population of parents (Hayes & Watson, 2013). In order to support the health and well-being of both children with ASD and their parents therefore, it is important to understand the support needs of families over time and how professionals can best work with families to reduce parenting stress.

The current study is also timely given the introduction of the NDIS in Australia. South Australia is currently a trial site for the implementation of the NDIS, and within this system as it stands, parents are required to act not only as decision-makers, but also as advocates in order to secure 'reasonable and necessary supports' (National Disability Insurance Scheme, n.d.) for their children with disabilities. Parents are then able to choose from the range of registered service providers to access intervention and support for their child. Given that the role of parents as

decision-makers has been expanded further within this system, which will eventually be implemented across Australia, it is important to understand how parents feel about adopting the decision-making role, and the supports required to achieve the best outcomes for families during this process.

Researcher Position

Given that this study implements a constructivist approach, it is important to acknowledge the position of the researcher in the study. As a speech pathology student during a clinical placement within a special school setting, I became interested in the interventions that the children with ASD were exposed to via their parents. Some of the students were participating in multiple therapy programs, and furthermore, concurrently being involved in therapy programs with conflicting approaches to therapy (e.g. behavioural vs. relationship-based approaches). It was my goal therefore to better understand how parents make decisions, and the supports available for parents in making decisions about which intervention approaches to access. Now as a practicing speech pathologist, I believe that parents should be supported in making decisions regarding intervention approaches, to ensure that children with ASD are able to access evidence-based interventions.

Research Objectives

The purpose of the current study is to:

1. Explore, describe and analyse, using a constructivist grounded theory methodology, the decision-making process regarding selection of intervention approaches by parents of children with ASD.

2. Explore and describe, using thematic analysis, parental perceptions of the supports made available for decision-making, in order to make recommendations about future practice.

Therefore, the objectives of the study are as follows:

1. To explore and describe how parents make decisions regarding intervention approaches, and to identify factors influencing decision-making.

2. To develop a substantive theory explaining the decision-making process underlying the selection of intervention approaches.

3. To explore and describe parents' perceptions of the current supports available for decision-making.

4. To use the substantive theory and parental perceptions of current supports to develop recommendations to improve current practices.

As is detailed further within later chapters, this study employed a constructivist grounded theory methodology. As per the conventions of this methodology, the lines of questioning within semi-structured interviewing can evolve as data emerges, allowing the researcher to pursue topics raised by participants in further detail. Case in point, within the initial interviews in this study, parents spoke of how experiences with interventions had shaped their subsequent decision-making, with interactions with therapists being central to this. Parents also discussed how their understanding of therapy, and specifically the importance of early intervention, had influenced their decision-making. Thus, the decision was made to explore these topics in further detail. In addition, the concept of decision-making changing over time emerged during initial data collection, and was explored in further detail when examining how parents make decisions about which interventions to access.

Consequently, the study was guided by the following five research questions:

1. How do parents of children with an ASD make decisions regarding which intervention approaches to access?

   a) What are the factors influencing parental decision-making?

   b) How does decision-making develop over time?

2. What qualities do parents want in therapists working with children with ASD?

3. What is the impact of the 'early intervention' message on parents of children with ASD?

4. How do parents perceive supports available for decision-making?

5. How can current practices be improved to support families during the decision-making process?

Thesis Structure

This thesis is presented as eight chapters, with this introduction comprising the first chapter. In Chapter Two, a review of the literature relevant to the research questions is presented. Within this chapter, an overview of ASD is provided, including the evolution of the diagnostic criteria for ASD and theories relating to causation. A summary of the interventions available for individuals with ASD is presented, and the literature relating to intervention use by parents of children with ASD is explored. Finally, the existing literature relating to parental decision-making and the supports available for decision-making is examined, which provides the basis for establishing the relevance of the current study.

In Chapter Three, the theoretical assumptions that underpin the methodology for the current study are explored. Crotty's (1998) model is used to explain the relationship between the epistemological paradigm (constructivism), theoretical

perspective (symbolic interactionism), methodology (constructivist grounded theory) and research methods (semi-structured interviewing, questionnaire and field notes) of the current study is provided. Furthermore, a justification for the methodological issues in relation to the specific theoretical assumptions of the study is provided.

Within Chapter Four, the specific methodological processes of data collection and analysis are outlined. This study was conducted in two stages. The first stage involved the construction of the interview guide, and the second stage involved the use of in-depth, semi-structured interviewing as the primary means of data collection to explore parental decision-making. The procedures for each stage of the study are described in detail within this chapter.

The results of the primary research question, relating to how parents of children with ASD make decisions about which intervention approaches to access, are presented in Chapter 5. A model that represents the decision-making journey of parents is presented, and the specific factors influencing decision-making are explored. The theoretical perspective of symbolic interactionism is used to consider the meanings that parents' construct through this journey, specifically relating to self-perception and how this transforms with time.

In Chapter 6, the results for research questions 2 and 3 are presented. These questions are an extension of the data examining parental decision-making, and were originally written as articles for the purposes of publication in peer-reviewed scholarly journals. The original articles are included as Appendices, however the results sections from these articles are included within Chapter 6. The results for Question 2 detail the specific qualities that parents want in therapists working with their children with ASD. The results for Question 3 relate to the impact of the 'early intervention' message on parents of children with ASD.

In Chapter 7, the results for Questions 4 and 5 are presented, which relate to support for decision-making. The parents' perceptions of the ideal model of support for decision-making are first presented, and this model is then used to explore how parents perceive the current supports for decision-making (Question 4) and how they believe this ideal model of decision-making should be implemented (Question 5).

In Chapter 8, the results of this study are discussed in depth. Giddens' (1991) theoretical model of 'fateful moments' is used to explore the transformation of parental decision-making following their child's ASD diagnosis, and a theoretical model relating to the transformation of parental decision-making is proposed. The specific factors influencing decision are discussed in relation to the existing literature. The implications relating to specific professional support for decision-making are also discussed, and the role of therapists in supporting parental decision-making is raised. Finally, the limitations of the current study and implications for clinical practice and future research are also explored.

Within the final chapter of this thesis, Chapter 9, the findings of this study are summarized and concluding remarks relating to the significance of this research and potential directions for future research are presented.

CHAPTER 2: LITERATURE REVIEW

Introduction

In this chapter, a review of the literature is undertaken. An overview of Autism Spectrum Disorder (ASD) is first provided, followed by an outline of how the diagnostic criteria of ASD have evolved over the years. This is important to discuss as the changes to the diagnostic criteria reflect how the scientific and societal understanding of ASD has evolved over the years. In addition, this helps to provide context for the current study, given that data collection was undertaken prior to the release of the most recent diagnostic criteria (DSM-V). Next, literature pertaining to causation of ASD is examined, with a particular focus on some of the more controversial and topical theories of causation (e.g. measles/mumps/rubella (MMR) vaccination, presence of heavy metals). Concepts of causation are relevant within the context of this study, because specific interventions have been developed based on theories of causation (e.g. gluten-free, casein-free diets), and decision-making regarding intervention approaches may be influenced by parental theories of causation. Literature examining the impact of ASD on families is also examined, in order to understand some of the challenges faced by parents of children with ASD (e.g. seeking a diagnosis) and to explore how these factors may directly or indirectly influence parental decision-making. In order to understand how parents of children with ASD make decisions about which interventions to access, it is important to first understand the choices that are available in terms of interventions. Therefore, a review of the literature relating to educational, biological and psychodynamic interventions for ASD is presented, and studies examining parental use of therapies are also examined. These studies provide some insight into parental decision-making

by considering the interventions that are being implemented by families of children with ASD. Literature specifically examining parental decision-making regarding interventions is then examined, to allow factors that have been identified by previous studies as influencing decision-making to be identified. Finally, literature relating to support for parental decision-making is examined. At the conclusion of the literature review, a justification for the current study is provided.

Overview of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder, often diagnosed in early childhood. Individuals with ASD exhibit impairments in social communication, and patterns of restricted or repetitive behaviour. Impairments in social communication can affect the ability of individuals with ASD to engage in social interactions, understand non-verbal communicative behaviours and form relationships with other people (American Psychiatric Association, 2013). Restricted and repetitive patterns of behaviour can result in individuals with ASD engaging in stereotyped or repetitive motor movements, insisting on sameness, and having highly specific areas of interest (American Psychiatric Association, 2013). Furthermore, disturbed sensory processing can result in hypersensitivity or hyposensitivity to incoming sensory stimuli (Kern et al., 2006). The presentation of these impairments varies in each individual, resulting in marked heterogeneity within the ASD population. As such, the level of support required by individuals on the autism spectrum also varies greatly. While individuals with mild ASD may only require limited support, individuals with severe impairments will require very substantial support (American Psychiatric Association, 2013).

There are a number of co-morbidities associated with ASD. It is estimated that 70% of individuals with ASD also have some degree of intellectual impairment (La Malfa, Lassi, Bertilli, Salvini & Palcidi, 2004). Furthermore, ASD can be associated with mental health disorders such as anxiety and obsessive-compulsive disorder (Simonoff et al., 2008), and sleep disorders (Richdale, 1999). Attention-deficit hyperactive disorder can also co-occur in individuals with ASD (Simonoff et al., 2008). There can also be significant behavioural challenges associated with ASD. A number of factors may contribute to challenging behaviour in individuals with ASD, including communication breakdown, response to sensory stimuli or difficulty coping with change (Whitaker, Joy, Edwards & Harley, 2001).

In 2014, the prevalence of ASD in the United States of America was reported to be 1 in every 68 children (Centres for Disease Control and Prevention, 2014). In 2007, the prevalence of ASD in Australia was reported to be 1:160 (MacDermott, Williams, Ridley, Glasson & Wray, 2007), while in 2010, a prospective surveillance study of Victorian children reported a prevalence of 1:119 children (Barbaro & Dissanayake, 2010). Data from the 2012 Survey of Disability, Ageing and Carers (Australian Bureau of Statistics, 2014) indicated 0.5% of the Australian population, or 1:200, have an ASD. Consistent across prevalence studies is the finding that males are almost five times more likely to be diagnosed with ASD than females (Barbaro & Dissanayake, 2010; Centres for Disease Control and Prevention, 2014). Furthermore, these studies indicate that the prevalence of ASD has increased over the years. A number of possible explanations have been put forward regarding the increased prevalence of ASD, including changes to the diagnostic criteria, differences in methods used to measure prevalence and an increased awareness and understanding of ASD by the general population (Prior, 2003). Regardless of the cause for the

increasing prevalence, ASD is now the most common childhood developmental disability.

There is currently no cure for ASD, however there is evidence that intervention can improve the outcomes for children with ASD and their families (Eldevik et al., 2009; Roberts & Prior, 2006). There is a range of intervention approaches available with varying degrees of empirical evidence, and there is significant debate regarding which interventions approaches are most effective for individuals with ASD. Advances in science have led to an increased understanding of the cause and course ASD. Consequently over the years the diagnostic criteria of ASD have been updated to reflect this increased understanding.

Diagnostic Criteria of ASD

Leo Kanner first identified ASD in the 1940's. In his early work, Kanner (1943) reported on 11 individuals who presented with a shared cluster of symptoms. Central to his findings was Kanner's observation that individuals, with what was then described as "autistic disturbances in affective contact", found it difficult to relate to other people (Kanner, 1943). As research within the area of ASD continued and understanding of the disorder advanced, the diagnostic criteria for ASD have evolved. Within the fourth edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM-IV-TR; American Psychiatric Association, 2000) ASD was defined as a collection of pervasive developmental disorders, including Autistic Disorder, Aspergers Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specific. According to this definition, the criteria for an ASD diagnosis involved a triad of impairments of: impaired communication, limited social interactions and repetitive and restricted interests.

In 2013, the DSM-V (American Psychiatric Association, 2013) was released and the definition of ASD was once again updated to reflect the most recent research and current understandings of the disorder. For the first time, ASD was defined as a neuro-developmental disorder, reflecting the advances in the field of neurobiology (Stoner et al. 2014), in which differences between the neocortices of individuals with ASD and typically developing individuals were identified. The diagnostic criteria now includes only two core areas of impairment: deficits in social communication and social interaction, and restricted, repetitive patterns of behaviours, interests and activities. Furthermore, the disorders that had previously existed under the umbrella term of ASD (i.e. Autistic Disorder, Aspergers Disorder) were eliminated, and ASD became the all-encompassing term for the disorder.

Causation of Autism Spectrum Disorder

There has been significant debate over the years relating to causation. For many years, the cause of ASD was not well understood and a number of theories relating to causation were proposed. When Kanner (1943) first reported on ASD, he reported a lack of warmth between the individuals with ASD and their mothers. This contributed to the assertion that ASD was caused by poor attachment between children and their mothers, and resulted in the term 'refrigerator mothers' being coined. Though this theory has since been disproven, the impact that this label had on families at the time cannot be underestimated.

Perhaps one of the most infamous claims regarding causation was the reported link between the measles/mumps/rubella (MMR) vaccination and ASD. Wakefield et al. (1998) investigated the development of 12 children, and reported that a regression of skills and onset of behavioral symptoms was associated with the provision of the

MMR vaccination. The authors acknowledged that the sample size was small and called for further investigation into the possible link between the MMR vaccination and ASD. Since the publication of this study, a number of large-scale studies have found no association between the MMR vaccination and ASD (Wilson, Mills, Ross, McGowan & Jadad, 2003). Furthermore, the original article by Wakefield et al. (1998) was found to contain fraudulent information, and was retracted by the publishing journal.

Another theory that has been put forward regarding causation relates to the presence of heavy metals in the bloodstream. This theory arose from comparisons between children with ASD and children poisoned with mercury (Bernard, Enayati, Redwood, Roger & Blinstock, 2001), and can also be linked to the claims that vaccinations containing heavy metals caused ASD (Wakefield et al., 1998). Though the evidence suggests that there is no association between exposure to normal levels of heavy metals and ASD (Hertz-Picciotto et al., 2010), chelation therapy, in which heavy metals are stripped from the body, still exists as an alternative intervention for ASD.

More recently, it has been claimed that individuals with ASD have deficiencies in essential amino acids, which can be managed with dietary restrictions (Arnold, Hyman, Mooney & Kirby, 2003). This theory emerged from a stream of research investigating dietary interventions for schizophrenia. The basic premise of this theory was that exorphins in gluten and casein leak through the gut of individuals with schizophrenia (and ASD), and consequently impair brain functioning. Cade et al. (2000) conducted a study in which a gluten free casein free diet was trialed with 270 participants; 149 of these participants met the DSM-III criteria for autism. Though the results of this study were modest and studies since have not supported the

link between dietary restrictions and improved outcomes (Elder et al., 2006), interest in the role of gluten and casein on the functioning of individuals with ASD quickly developed, which led to the emergence of dietary restrictions as an alternative intervention for ASD.

With much debate surrounding the causation of ASD within the scientific community, it is evident that parental perspectives on causation are likely to be varied. Though the current evidence strongly implicates the role of genetics and neurological development, a review of parental beliefs about the cause of their child's ASD revealed that there are a number of causal beliefs held by parents (Hebert & Koulouglioti, 2010), including genetic and environmental factors. The authors of this study noted several issues regarding parental perceptions of causation that add to the complex nature of ASD. Firstly, when parents' perceived that they had contributed to their child developing ASD, they were more stressed and had heightened feelings of guilt. Furthermore, diverse perspectives on causation have the potential to influence parents' perspectives on their child's outcomes and decisions regarding intervention approaches (Dardennes et al., 2011).   Thus, the concept of causation and the implications of this on families contribute to the complexity of ASD as a disorder.

Impact of ASD on Families

Raising a child with ASD can be challenging and at times emotionally draining for families, even prior to the point of formal diagnosis. Several studies (Goin-Kochel, Mackintosh & Myers, 2006; Howlin & Moore, 1997) have examined the process of seeking a diagnosis for a child with ASD, with results indicating that parents often have concerns about their child's development from an early age, which causes parents to seek out professional support. However, in many cases, parents have to

endure a lengthy and frustrating process before their child receives a formal diagnosis. Howlin and Moore (1997) conducted a study investigating parents' perspectives on the diagnostic process in the United Kingdom. Within this study, 1295 parents of children with ASD completed a survey, which indicated that over 90% of parents had concerns regarding their child's development before their third birthday. On average, the final diagnosis was received when children were approximately six years of age. This is a considerable amount of time between parents' identifying developmental concerns and a diagnosis being confirmed, and consequently, 49% of the parents surveyed indicated that they were not satisfied with the diagnostic process. More recently, Goin-Kochel, Mackintosh & Myers (2006) surveyed parents of children with a pervasive developmental disorder to determine their satisfaction with receiving an ASD diagnosis. Over four hundred parents from five countries responded to this web-based study, which found that parents were more satisfied with the diagnostic process when their children received an earlier diagnosis, and when they had to consult with fewer professionals to receive a diagnosis. The findings of these studies indicate that parents of children with ASD often face a lengthy search before receiving a formal diagnosis for their child, which in turn has the potential to delay children from accessing early intervention services. Valentine, Rajkovic, Dinning & Thompson (2010) interviewed 32 parents and 17 service providers regarding post-diagnosis support for families of children with ASD in Australia. The results of this qualitative study indicated that many parents faced a wait before their child was diagnosed with ASD, which in turn caused distress at the prospect of missing out on opportunities for early intervention. Some parents within this study chose to commence services (e.g. speech-language pathology) while waiting for a formal

diagnosis, however considered that this therapy was not adequate to meet their child's needs.

Though the process of searching for a formal diagnosis can be challenging for parents, receiving a diagnosis of ASD can lead to a period of grieving for parents. Participants in the study by Valentine et al. (2010) indicated that they experienced a sense of grief following their child's ASD diagnosis, but they were also motivated to commence therapy immediately post-diagnosis. Taylor and Warren (2012) examined and compared the presence of symptoms of depression in mothers of children with ASD in the week following diagnosis, and approximately one year later. Seventy-five participants were involved in the study, which found that 78.7% of mothers reported clinically significant symptoms of depression immediately post-diagnosis, and 37.3% continued to report symptoms of depression over a year later. The results of this study highlight the significant grief and distress that can be associated with a child being diagnosed with ASD, and the ongoing stress that parents' face when raising a child with ASD.

Once a formal diagnosis has been received, parents may face a series of unique challenges while raising their child with ASD. A number of qualitative studies have explored the experience of parenting a child with ASD. Woodgate, Ateah and Secco (2008) interviewed 21 parents from 16 family units regarding their experience parenting a child with ASD. Overwhelmingly, the participants in this study described their parenting experience as 'living in a world of our own'. The participants described their sense of isolation, which was informed by the participants' perceptions of lack of professional support from ASD services and institutions. The participants in this study also reflected on a lack of understanding from broader society, and missing out of a normal life, as contributing to their sense

of isolation. Similarly, Altiere and Von Kluge (2009) interviewed 52 parents of children with ASD to explore the challenges of raising a child with ASD. The parents in this study identified the diagnosis of their child with ASD as a life-altering event. There was a sense of grief and loss associated with diagnosis, which had an impact on parents' day to day functioning. Though the families in this study identified numerous challenges in raising a child with ASD, including searching for a diagnosis, understanding the cause of their child's ASD, and making decisions about which interventions to implement, most families also described positive changes that had occurred as a result of their experiences, such as strengthening of the family unit and personal growth and development. Hines, Balandin and Togher (2014) examined the experiences of older parents of adults with ASD. Sixteen parents from 13 family units were interviewed as part of this qualitative study, which reported that parents of adults with ASD actively work to balance the needs of their children, their own individual needs, and needs of the wider family unit. The findings of this study also indicated that for the majority of participants, interactions with formal services had not been overly positive, with parents often feeling as though they had to fight for appropriate and adequate services for their son or daughter with ASD. The concept of parents of children with ASD acting as advocates was also raised in a study by Lutz, Patterson and Klein (2012). Within this study, 16 mothers were interviewed about their experience of parenting a child with ASD. One of the themes that emerged from this study was the concept of taking on multiple roles, including the role of advocate for their child.

Other studies have examined the impact of raising a child with ASD on parenting stress and parental well-being. Hayes and Watson (2013) conducted a meta-analysis of studies examining levels of stress in parents of children with ASD.

Only quantitative studies that used a comprehensive and valid measure of parenting stress were included in the review. The results of the review indicated that parents of children with ASD experience a significantly higher level of stress when compared to both parents of children with other developmental disabilities and typically developing children. Several factors have been identified as contributing to increased stress in parents of children with ASD. Some studies have found an association between challenging behaviour in children with ASD and increased levels of parental stress (Lecavalier, Leone & Wiltz, 2006; McStay, Dissanayake, Scheeren, Koot & Begeer, 2014). The social impairments associated with ASD, namely the lack of affect or interest in other people, may also contribute to increased stress in parents of children with ASD (Duarte, Bordin, Yazigi & Mooney, 2005).

Another challenge for parents of children with ASD is making decisions about which intervention approaches to implement with their children. While there is a range of interventions available for parents to choose from, there is a varying degree of scientific evidence behind each intervention approach, and the heterogeneity of the ASD population dictates that not every intervention will be equally effective for each individual on the spectrum. Furthermore, there are other factors (e.g. availability of interventions, family resources) which mean that it is not possible for a generalized recommendation to be made about which intervention(s) should be implemented with individuals with ASD (Jensen & Spannagel, 2011). Thus, the responsibility of locating and selecting appropriate interventions often falls solely to parents of children with ASD. Though parents have an intimate knowledge of their own children, decision-making with regard to interventions is a significant responsibility to place on parents, given the importance of early intervention in improving the outcomes for children with ASD (Eldevik et al., 2009; Howlin, et al., 2009; Roberts &

Prior, 2006; Warren et al., 2011). Thus, if intervention does not produce the desired outcomes, there is the potential for parents to blame themselves for selecting the chosen interventions (Goin-Kochel, Mackintosh & Myers, 2009). Before considering parental decision-making regarding interventions for ASD, the range of interventions will first be discussed below.

Interventions for Children with ASD

The range of interventions available for children with ASD, as reviewed by Roberts and Prior (2006), is vast. Not all interventions have an equal level of empirical evidence or accessibility, and the philosophies behind each of the different approaches can vary significantly. Mesibov, Adams and Klinger (1997) grouped intervention approaches into the following categories: educational, biological and psychodynamic. The interventions within each of these categories will be discussed below.

  Educational Interventions. Broadly speaking, educational interventions focus on skill development and relationship development of children with ASD (Roberts & Prior, 2006). Educational interventions include the more traditional approaches to intervention, including behavioural interventions. Though educational interventions share a general goal, there are differences in the principles and the strategies associated with each educational approach. Each of the approaches to educational interventions will be outlined below, using the subcategories established by Roberts and Prior (2006).

  Behavioural. Behavioural interventions are generally intensive intervention programs, which teach a range of specific skills through the use of reinforcement. Based on the principles of applied behaviour analysis (ABA), reinforcement is used to

increase the frequency of positive behaviour and reduce the frequency of maladaptive behaviours. Often referred to as ABA or early intensive behavioural intervention (EIBI), behavioural interventions may implement a number of strategies to support skill development, including discrete trial training and pivotal response training (Raising Children Network, 2015). One of the criticisms regarding traditional ABA programs was that the highly structured nature of programs meant that children had difficulty generalising target behaviours outside of the therapy setting. Consequently, more contemporary approaches to ABA employ strategies such as incidental teaching to support naturalistic learning and the generalisation of skills (Mesibov et al. 1997). Behavioural approaches may also target the development of verbal behavioural (communication) using the principles of ABA, known as applied verbal behaviour therapy. It is recommended that behavioural intervention programs are delivered intensively, with some programs, for example the Lovaas program, recommending 40 hours of behavioural intervention per week (Eldervick et al., 2009). There is considered to be good evidence supporting the implementation of intensive, behavioural intervention programs with children with ASD (Eldervick et al., 2009, Howlin et al., 2009; Reichow, 2012; Warren et al., 2011). However, the empirical evidence also indicates that behavioural outcomes will not be equally effective for all children with ASD (Howlin et al., 2009; Reichow, 2012; Warren et al., 2011), with some studies indicating that the initial intelligence quotient of children with ASD is predictive of intervention outcomes (Eldevik, Eikeseth, Jahr & Smith, 2006; Remington et al., 2007).

Developmental. Developmental interventions focus on supporting children with ASD to form positive, meaningful relationships with others (Roberts & Prior, 2006). In general, developmental intervention approaches are child-directed and

focus on fostering engagement and interaction, rather than aiming to develop specific skills. There are several developmental approaches to intervention, including DIR/Floortime® (or 'Floortime') (Greenspan, 1998), Relationship Development Intervention (Gutstein & Sheely, 2002) and Responsive Training (Mahoney & Perales, 2005). Some studies have reported positive outcomes from developmental intervention approaches (Pajareya & Nopmaneejumruslers, 2011; Solomon, Necheles, Ferch & Bruckman, 2007), however further research is required in order for the efficacy of such approaches to be established.

Combined. Combined intervention approaches use elements from both the behavioural and developmental models. These approaches will generally focus not only on the child, but also on managing the environment to support the child's development (Roberts & Prior, 2006). Currently used combined intervention approaches include the SCERTS (Social-Communication, Emotional Regulation and Transactional Support) program (Wetherby & Prizant, 2000) and the TEACCH program (Cumine, Leach, & Stevenson, 2000). Though further research regarding the efficacy of combined intervention approaches is required, small-scale studies (Virues-Ortega, Julio & Pastor-Barriuso, 2013; Welterlin, Turner-Brown, Harris, Mesibov & Delmolino, 2012) investigating the efficacy of these specific programs have indicated positive results.

Therapy Based. Therapy based interventions focus on specific skill development. This can include speech-language pathology, which focuses on communication development, and occupational therapy, which focuses on sensory motor development. Given that these interventions tend to focus on one skill area, they are often implemented in conjunction with other intervention approaches. Within each intervention approach, there are specific strategies that may be

implemented to support skill development. For example, speech-language pathology may include the use of augmentative and alternative communication (AAC), such as Key Word Sign (Key Word Sign Australia, 2015) and Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) to support communication development. Alternatively, occupational therapy may involve the use of Sensory Integration Therapy (Dempsey & Foreman, 2001), to support children with ASD to process sensory information. While there is some evidence supporting the efficacy of implementing AAC with children with ASD (Flippin, Reszka & Watson, 2010; Tan, Trembath, Bloomberg, Iacono & Caithness, 2014), the effectiveness of Sensory Integration Therapy is unsubstantiated (Dawson & Watling, 2000; Sinha et al., 2006).

   Family-Based.   Family-based interventions aim to support families to understand the nature of their child's ASD, in addition to providing families with strategies to support their child's learning (Roberts & Prior, 2006). Family-based interventions include the Hanen 'More Than Words' program (Sussman, 1999) and Family-Centred Positive Behaviour Support (Marshall & Mirenda, 2002).   The premise behind these programs is that providing parents with the strategies to support their child's development is an effective intervention approach, given the amount of time that parents spend with their children, and how well parents know their own child (Roberts & Prior, 2006). Further research is required into the efficacy of specific family-based interventions, however there have been small positive gains reported as a result of such interventions (Carter et al., 2011).

   Other. There are several other intervention approaches that are considered to be educational interventions, but that do not fit into the other subcategories, such as Music Therapy (Jordan, Jones & Murray, 1998), the Son-Rise Program (Cummins, 1988) and the SPELL framework (National Autistic Society, 2015).   These

approaches do not have significant evidence supporting their efficacy, and in many cases, evidence is primarily anecdotal (Roberts & Prior, 2006).

Biological Interventions. Biological interventions aim to address impairment at the biological level (Mesibov et al., 1997). There are two general approaches with regard to biological interventions. The first is based on the theory that there is an underlying biological cause for ASD, and with treatment, ASD can be cured. The second approach to biological interventions is to treat a specific medical, developmental or psychological need of the individual with ASD.

Medication. Specific medications can be used to treat co-morbid disorders. For example, stimulants may be used to manage inattention and hyperactivity in children with ASD (Roberts & Prior, 2006). While there is evidence that some medications can be effective in minimizing co-morbid behaviours associated with ASD (Aman, Farmer, Hollway & Arnold, 2008), there is also the risk of potential side effects and misuse.

Complementary and Alternative Medicine. Complementary and alternative medicine is broadly considered to be any alternative to mainstream therapies, including biological interventions such as exclusion diets, chelation and vitamin/dietary supplements. There is minimal evidence for the efficacy of these interventions (Levy & Hyman, 2008), and there is evidence that some interventions (e.g. chelation) have the potential to cause harm (McGuire, Kulkarni & Baden, 2000).

Psychodynamic Interventions. Psychodynamic interventions are based on the assumption that ASD is caused as a result of emotional damage to the child (Mesibov et al., 1997). Examples of psychodynamic interventions including holding therapy (Tinbergen & Tinbergen, 1983), where the child is held tightly by the parent to teach the child to accept comfort, and Pheraplay (DesLauriers, 1978), where highly

stimulating experiences are provided to the child with ASD, with the aim of overcoming sensory impairments (Roberts & Prior, 2006). These interventions are now rarely used, as there is strong evidence that ASD is a neuro-developmental disorder, not an emotional disorder.

Use of Interventions

In recent years, a number of studies have investigated which interventions parents choose to implement with their children with ASD. Green et al. (2006) recruited 552 participants to complete an Internet survey to identify the treatments used by parents of children with ASD. The survey listed 111 treatment options, including educational and behavioural approaches, dietary modifications, pharmacological interventions and augmentative and alternative communication. The results of this study found that parents of children with ASD were implementing an average of seven approaches simultaneously, and were accessing approaches both with and without empirical evidence. This study reported that parents of children with severe autism were implementing more interventions than parents of children with mild autism or Aspergers syndrome. However, this finding must be interpreted with caution, given that severity rating was based on parental report, as indicated by the child being non-verbal.

Goin-Kochel, Myers and Mackintosh (2007) conducted an Internet study investigating the number and type of interventions that parents of children with ASD were currently implementing, and had implemented in the past. A total of 479 participants responded to this study, with the results indicating that parents were currently implementing between four and six therapies, and had tried between seven and nine therapies in the past. The results of this study identified that differences in

sub-diagnosis (which existed under the DSM-lV at the time) influenced the number and type of interventions being implemented, whereby children with autism and PDD-NOS were using more therapies on average than children with Aspergers, and children with Aspergers had trialled more pharmacological interventions than children with autism and PDD-NOS. It was also reported in this study that parents of younger children were more likely to use behavioural, educational and alternative interventions, whereas parents of older children used a higher frequency of pharmacological interventions, indicating that parental decision-making may change over time. The advantage of these Internet-based studies is that large and broad-ranging samples of parents could be recruited into the studies providing a large pool of data. However, the disadvantage is that a representative sample cannot be guaranteed, given that participant recruitment relies on self-selection, and that families who do not have Internet access are automatically excluded from participating.

There are several studies that have used other methods to gather information regarding intervention use. Carter et al. (2011) examined the type of interventions selected by the families of Australian preschool children with ASD, and the influence of the child's developmental status on the number of interventions implemented. Eighty-four participants were recruited from the waiting list for an early intervention service in New South Wales, and were interviewed three times over the course of a year. The results of this study indicated that on average, parents were employing between two and three intervention approaches, in addition to the service for which they were on the waiting list. The most frequently implemented interventions were speech-language pathology, preschool and childcare, generic early intervention and occupational therapy. There was found to be no significant relationship between

developmental status and the number of interventions that parents chose to implement, which was in contrast to the findings of Green et al. (2006). While the study by Carter et al. (2011) provided useful information regarding the interventions selected by Australian parents, the participants were only recruited from one geographic region, which had an above average social economic status, and from the waiting list of one service provider. Therefore, the results of this study may not account for the influence of cost and accessibility on the interventions that parents choose to implement.

Regehr and Feldman (2009) interviewed 23 parents who were participating in a larger study examining at-risk infants. The participants in this study already had a child diagnosed with ASD, and therefore their younger child was being monitored due to being at an increased genetic risk of developing ASD. The results of this study indicated that parents implemented interventions both with and without empirical evidence, though parents also indicated that they were more satisfied with applied behaviour analysis (ABA) therapy and perceived this to be a more effective intervention than alternative therapies. Though this study had a relatively small sample size, the findings replicated the results of previous studies. However, the sample was drawn from a specific population (families who have one child with a confirmed ASD diagnosis, and one child 'at risk' of developing ASD) and therefore the degree to which the family situation influences the use of specific interventions is unknown.

In 2014, a review of the literature regarding the interventions used by parents of children with ASD was conducted (Carlon, Stephenson & Carter, 2014). This review focused on quantitative studies, and included 41 articles, describing the results of 42 studies. One of the challenges reported in reviewing this literature was the

different way in which the interventions were labelled and grouped across the various studies, and the authors acknowledged this as a limitation of the review. Furthermore, not all of the studies included in the review were specifically designed to collect data relating to the interventions used by parents of children with ASD. Nonetheless, the results of this review, as well as the studies examined earlier in more detail, reveal two overarching patterns with regards to parental use of interventions. Firstly, parents of children with ASD frequently choose to implement a number of interventions concurrently. The decision by parents to implement multiple interventions is understandable, given that children with ASD often have impairments in more than one area of development. However, the implementation of concurrent interventions makes it difficult for parents to determine which intervention, if any, is responsible for the child's developmental progress. The second pattern that is evident with regards to intervention use is that parents often choose to implement interventions both with and without empirical evidence. The results of these studies do not examine in depth the rationale for decision-making, however given the range of interventions selected, it is reasonable to conclude that empirical evidence is not the sole factor that parents consider in making decisions.

In summary, studies examining parental use of interventions for ASD provided useful information regarding the number and type of interventions that parents of children with ASD implement, and patterns of use can be established on the basis of these findings. However, in most of these studies, there was a call for further investigation into the factors influencing parental decision-making, so that the patterns of intervention use could be better understood.

Parental Decision-Making Regarding ASD Interventions

Overall, parental decision-making with regards to ASD interventions is not well understood. A few studies have employed quantitative methods to examine the impact of a specific factor on parental decision-making. One study examined the role of parental perceptions of ASD on intervention decisions (Al Anbar, Dardennes, Prado-Netto, Kaye & Contejean, 2010). Eighty-nine participants completed a modified version of an illness perception questionnaire, the results of which were compared to parents' reported intervention choices. There were several significant associations found in this study, specifically; parents who had perceptions of ASD as a serious disorder were more likely to implement education-based interventions (e.g. ABA), and parents who perceived ASD as an unpredictable disorder were more likely to use medication to manage symptoms.

Dardennes et al. (2011) recruited 78 participants to complete a questionnaire relating to parental beliefs about the cause of their child's ASD to examine choices of intervention. The results of this study indicated some significant associations between parental perceptions of cause and interventions choices. For example, parents who believed in food allergies as contributing to the development of ASD symptoms were more likely to use detoxification, diet modification and vitamins. These findings also supported the earlier work of Mandell and Novak (2005), who suggested that the cultural beliefs of the family unit might influence decision-making with regard to ASD intervention approaches.

Another factor thought to influence parental decision-making is information gathered from various sources. Green (2007) conducted a quantitative study examining parental experience with ASD interventions, as a follow-up to the study conducted by Green et al. (2006). Nineteen parents who had originally participated in

the 2006 study were interviewed via telephone about their experience with three interventions (ABA, sensory integration and vitamins (B6 and magnesium)), and asked to comment on sources of information, how easy the intervention was to implement and the effectiveness of the interventions. The author reported that these factors had influenced parental decision-making, and in particular influenced parents in deciding to continue with interventions that had limited empirical evidence. The small sample size of this study however means that the results must be interpreted with caution.

A larger study by Miller, Schreck, Mulick and Butter (2012) surveyed 400 parents of children with ASD to determine which sources of information influenced their decision-making. The participants in this study indicated that multiple sources of information influenced their decision-making, with information from non-medical professionals (e.g. speech-language pathologists), books and recommendations from other parents being the most frequently used. By comparing the sources of information to the interventions that parents had chosen to implement, the authors of this study concluded that parents are more likely to be influenced by recommendations from other people than from empirical evidence. The results of this study also suggested that the interventions recommended by professionals had varying degrees of empirical evidence, that is, professionals were not necessarily recommending interventions with a high level of empirical evidence.

A few quantitative studies have also used internet-based questionnaires to examine parental perceptions of their child's progress as a result of intervention and priorities for intervention, and the subsequent implications this has for parental decision-making. Goin-Kochel, Mackintosh and Myers (2009) recruited 479 participants to complete an online questionnaire rating the efficacy of ASD

interventions. The results of this study indicated that the participants in this study perceived that most interventions had produced some level of improvement for their child, regardless of the level of empirical evidence. The authors therefore suggested that parental perceptions of change are more influential than empirical evidence in shaping their decision-making.

A study in 2010 attempted to replicate the findings of the study by Goin-Kochel, Mackintosh and Myers (2009), while also aiming to gain further information about which areas of functioning improved due to intervention, and examine the reasons parents choose to discontinue interventions (Bowker, D'Angelo, Hicks & Wells, 2010). The results of this study indicated that behavioural and linguistic (communication) areas of development were perceived by parents to be most improved following intervention. The most common reason for discontinuing intervention as identified by the participants in this study was due to lack of progress or improvement in the child's functioning, reinforcing the suggestion that parental decision-making is informed by their perceptions of progress, rather than empirical evidence. Equally though, the majority of participants who discontinued ABA intervention in this study did so because it was no longer available to them. Therefore, accessibility to interventions appears to also impact on parental decision-making.

Another Internet survey examined the intervention priorities for parents of children with ASD (Pituch et al., 2010). A total of 90 participants completed the survey, which listed 54 skills (e.g. responds appropriately to questions, reading, self-injury) and behaviours across 10 domains (e.g. communication, academic, behaviour). The participants were required to rate each skill in terms of current level of ability and priority for intervention. The results of this study indicated that parents' intervention

priorities reflected a needs-based model, that is, parents' priorities for intervention were for developmental areas in which they perceived there to be the greatest deficits. Though this study had a relevantly small sample size, the results indicate that decision-making with regard to intervention is informed by parental perceptions of their child's current skills and ongoing needs.

In summary, studies employing quantitative methods have a number of factors have been identified as potentially influencing parental decision-making, including: parental understanding of ASD (cause and manifestation), sources of information, perceptions of the child's needs and progress as a result of intervention, and the accessibility of the intervention. Though quantitative studies provide an importance insight into the influence of specific factors on parental decision-making, in most cases by nature of the methods used, the rationale for decision-making could not be explored in great detail. Furthermore, most quantitative studies explored a single factor of decision-making, when in reality, there is likely to be more than one factor influencing the choice of intervention. For example, a parent may choose to trial diet modification because of perceptions of cause, and also because it is an inexpensive intervention option. Consequently, in order to gain a deeper understanding of parental decision-making, some studies have employed qualitative methods.

Valentine (2010) explored the experience of parents of children with ASD making decisions regarding interventions, with a specific focus on the effects of choice on the participants. Semi-structured interviews were undertaken with 49 participants, and data relating to the effects of choice making on parents were analysed. The participants in this study reported feeling that they had to make decisions without having enough information, and found the process of making decisions to be overwhelming. However, some participants responded to the

challenge of making decisions, becoming experts in the research literature and ASD interventions. With regards to choosing interventions to implement, a number of the participants in this study perceived ABA as being the only option for intervention, based on the significant empirical evidence supporting ABA. This finding is in contrast to a number of other studies (Goin-Kochel, Mackintosh & Myers, 2009; Miller et al., 2012), where empirical evidence was reported to not significantly influence parental decision-making.

Shyu, Tsai and Tsai (2010) explored how parental explanatory models of ASD (how parents understand and explain their child's ASD) influenced their decision-making. In-depth interviewing was undertaken with 13 families in Taiwan. The parents in this study often provided both biomedical and supernatural explanations of their child's ASD. Some of the parents in this study had consulted with a fortune-teller in an attempt to gain an understanding of their child's ASD, which reflected the cultural and religious beliefs of those involved. The participants in this study implemented both therapy-based interventions (e.g. speech-language pathology) and biomedical interventions (e.g. vitamins), and identified a number of factors as influencing their decision-making, including: attribution of cause, effect of the intervention, child's preference/resistance to intervention, relationship with therapist, accessibility and affordability. Thus, the findings of this study indicated that although a number of factors influence parental decision-making, parents' understanding of ASD and specifically causal attribution, have an overarching influence.

Hebert (2014) interviewed 23 parents to understand the factors influencing their decision-making regarding interventions for their children with ASD, as well as choosing a preschool program. The focus of this study was parents' initial decision-making. Data analysis resulted in the development of three themes relating to

decision-making; parental attributes (e.g. personal experience, perception of ASD), child attributes (age and developmental level, child's needs) and program attributes (e.g. cost, intensity). The author reported that the influence of each of these factors varied according to the values of different family units.

Overall, qualitative studies have provided a deeper understanding of parental decision-making, with multiple factors being identified as influencing decision-making. Moreover, qualitative studies provide an insight into the influence of one factor over a number of others, for example, the role of culture in influencing parental understanding of ASD and attribution of cause. However, a limitation of qualitative research is that by nature of the methods used, the findings of these studies often cannot be generalized outside of the participants involved.

Though research into parental decision-making is relatively limited, there have been attempts to summarize the findings in order to better understand the influence and relevance of the specific factors on decision-making. In 2013, a review of the declared factors influencing parental decision-making was compiled (Carlon, Carter & Stephenson, 2013). Sixteen studies were reviewed, which included studies focusing on decision-making in general, studies focusing on individual interventions and studies examining decision-making related to complementary and alternative medicine. Both quantitative and qualitative studies were included in the review, which focused on factors explicitly declared by parents. The authors grouped the factors most frequently identified across all 16 studies into four categories; recommendations (from professionals and other parents), pragmatic issues (availability/accessibility of interventions, cost/funding, specific needs of the child, time constraints, and the compatibility of the intervention with other interventions used), effectiveness of interventions (parental satisfaction with an intervention, the

use and perceived effectiveness of other interventions, side effects, and the child's resistance to/preference for the intervention) and research evidence. Additional factors were identified in fewer than three studies that were not included (e.g. impact of intervention on family). However, it is possible that these factors were not identified more broadly in other studies because they were not explicitly asked (e.g. on a questionnaire). Therefore, certain factors may have been excluded because of limitations within the existing research, rather than actually not influencing decision-making. Overall, this study provides a useful summary of the declared factors influencing parental decision-making. The limitations with this review result predominately from the general lack of research in the area. Examination of parental decision-making with regard to interventions for children with ASD is a relatively new area of study, and therefore conclusions drawn from a review of these studies must be interpreted with caution. For example, the influence of recommendations was the most frequently reported factor, however not all factors were explored in every study. Similarly, factors that were identified in less than three studies may be more significant in influencing decision-making but have not been explored within previous studies.

In summary, research investigating into parental decision-making with regards to ASD interventions has identified a range of factors in recent years. Table 1 provides a recap of the factors identified by the studies discussed above. Overall, understanding of parental decision-making is still developing. Though some factors have been identified, further research is required in order to understand decision-making across different cultures, regions and service provision frameworks. Within the current literature, there has also been very limited consideration of changes in decision-making changes over time, with initial decision-making the predominant

focus of existing studies. The existing literature highlights the complexity of decision-making, and yet the responsibility for decision-making rests almost entirely with parents. Thus, it is reasonable to conclude that support is needed for decision-making. This topic will now be explored in further detail.

Table 1. Factors that can influence parental decision-making.

Category: Factors related to…	Specific factors
Parent/child	Understanding of ASD (cause and course)
	Cultural beliefs
	Family values
	Intervention priorities
	Child's needs
	Child's preferences
Experience	Perception of progress / effectiveness
	Personal experience
	Side effects
	Relationship with therapists
Logistics	Availability
	Accessibility
	Cost
	Program requirements
Information	Sources of information
	Empirical evidence

Support for Parental Decision-Making

The literature relating to support for parental decision-making is also limited. In recent years, some strategies have been explored with regard to providing parents with support for decision-making, namely: the provision of information, parent education programs and support form professionals. The first strategy relates to the provision of information. With regard to the provision of information, Mackintosh,

Myers & Goin-Kochel (2006) investigated the sources of information and support used by families of children with ASD. A total of 498 participants from a range of countries completed an online questionnaire, regarding sources of information and support for their child's ASD. The results of this study indicated that among professional and personal relationships, other parents of children with ASD were the most frequent source of information and support. Written sources of information were also frequently used, with books being used by 88% of the participants and online information being accessed by 86% of participants. Only 57% of participants considered allied health professionals to be a source of information, and 46% a source of support.

With regards to the provision of information, given that parents are frequently using online resources as a source of information and support, there is the need to evaluate the content that is presented. Stephenson, Carter and Kemp (2012) evaluated the information related to educational interventions that is provided on the websites of the national autism associations in a number of countries. The information on the websites was rated according to the empirical and anecdotal evidence that was provided, as well as whether there were endorsements for specific interventions and links to specific service providers. The results of this research indicated that the websites provided limited information regarding the empirical evidence for interventions, thus making it difficult for parents to make judgements about the efficacy of interventions and consequently make informed decisions about which interventions to implement.

Similarly, O'Reilly, Karim & Lester (2015) investigated the information needs and current sources of information for parents of children with ASD. Three focus groups were undertaken over the span of six months with the same 13 stakeholders

who had a professional and/or personal interest in ASD, including medical, allied health and research professionals as well as parents and siblings of individuals with ASD. The participants in this study commented on the accessibility and trustworthiness of the current information available, and raised concerns in particular about the validity on the information presented online. The participants in this study also highlighted the vulnerability of parents post-diagnosis, and the potential for harm due to inaccurate information at this stage.

The results of the studies by Stephenson et al. (2012) and O'Reilly et al. (2015) therefore indicate that information presented online may not necessarily meet the needs of parents with regard to support for decision-making. Furthermore, support for decision-making must be accessible to all families, and therefore needs to be made available across a number of forms.

Another strategy to support parents to make decisions is to provide education to parents about evaluating interventions. Given the individual differences between children with ASD, it is important for parents to be able to evaluate the efficacy of interventions, as even interventions with empirical support will not necessarily be equally effective for all children on the autism spectrum. Berquist and Charlop (2014) conducted a study investigating the efficacy of a parent education program, in which parents were taught to evaluate the effectiveness of interventions for their children with ASD. The authors in this study argued that as parents are making the final decision with regard to interventions, it is important for parents to be taught how to scientifically evaluate interventions in order to make informed decisions. Twelve participants were involved in the study, six each in the experimental and control groups. The parents in the experimental group participated in education sessions and were provided with training materials. The participants' ability to evaluate the

efficacy of their child's intervention was measured at multiple points throughout the study. The findings of this study indicated that the participants in the experimental group had significantly increased in their ability to evaluate the efficacy of their children's intervention program. The parent education program also influenced the decision-making of the participants in the experimental group, with participants indicating that they used empirical data to measure intervention efficacy, whereas prior to the program, they relied on non-empirical data. Thus, the findings of this research suggest that parental education can support parents to use empirical evidence in their decision-making with regards to interventions.

Similarly, Murphy, Trembath, Arciuli and Roberts (2011) implemented and evaluated the effectiveness of a parent education program. Within this study, parents of children with ASD participated in an interactive workshop regarding evidence-based practice in speech-language pathology, in addition to being provided with written information on the same topics. Twelve participants completed the pre- and post-intervention measures, which collected both quantitative and qualitative data. As per the findings of Miller et al. (2012), the participants in this study also indicated that professionals were the most valued source of information. At the conclusion of the parent education program, the participants were found to have an increased knowledge of evidence-based practice. Though the sample size in this pilot study was small, the results indicate a positive relationship between educating parents with regards to evidence-based practice, which acts to support parental decision-making.

The final avenue that has been explored with regards to support for decision-making relates to the role of the professional. Though differences have been identified in the value parents place on support from professionals, the role of professionals in supporting decision-making is arguably an important one. Medical

and allied health professionals are often in the unique position of being able to evaluate interventions objectively, as well as acting as trusted advisors and being in regular contact with families. Golnik, Maccabee-Ryaboy, Scal, Wey and Gaillard (2012) examined parental perceptions of shared decision-making with medical professionals with regard to health care decisions for children with ASD. A total of 128 participants completed a survey that allowed perceptions of shared decision-making to be compared to degree of satisfaction with health care. The results of this study indicated that perception of shared decision-making was associated with parents' feeling increasingly satisfied with their child's health care. Furthermore, shared decision-making resulted in parents feeling as though they had received better guidance with regards to the intervention options and controversial issues related to ASD. The results of this study highlight the potential for professional support to positively influence parental decision-making as well as increase parental satisfaction with the services provided.

Robert, Leblanc and Boyer (2014) examined the parents' perceptions of services for their children with developmental disabilities. Though not specifically related to support for decision-making regarding ASD interventions, one of the themes to emerge was the concept of support. Fifteen parents, seven of whom had a child with an ASD diagnosis, were interviewed about their experiences with professional services. The participants in this study were satisfied with the support received from professionals when it resulted in an increased understanding of their child's needs, but were less satisfied when their expertise relating to their own child was not acknowledged. The results of this study can be interpreted as demonstrating the need for professional support for decision-making to be collaborative, and for

professionals to support parents to use their own knowledge to inform their decision-making.

One study has specifically examined parental perspectives of professional support for decision-making following an ASD diagnosis. Valentine et al. (2010) conducted a review of post-diagnosis support for children with ASD and their families. Interviews were conducted with 32 families and 17 clinicians from the eastern states of Australia. Parents and clinicians expressed different perspectives on the level of information and support provided post-diagnosis. At this point of diagnosis, clinicians believed that it was important not to overwhelm parents with information, acknowledging that parents were grieving and in a state of shock. Clinicians reported feeling limited in being able to provide specific recommendations (e.g. recommending one service provider over another). Some clinicians felt comfortable recommending a particular intervention approach, while medical professionals were reluctant to do so. The parents who participated in this study reported feeling abandoned post-diagnosis. Parents wanted clinicians to provide specific recommendations, and then to be able to commence therapy immediately, and were surprised to find that this was often not what happened in reality. Parents who took part in this study reported feeling concerned about making decisions with regard to intervention, and the consequences of making the wrong decision. Furthermore, the parents in this study perceived the role of Autism Advisors, a role created by the Australia Government to support parents in accessing services, as an administrative one. Consequently, the parents in this study requested increased support for decision-making, and support in general. Parents expressed a preference for case management to be introduced, a role that would support parents to develop a course of action for intervention.

In summary, the literature examining support for parental decision-making is limited. Several strategies have been explored with regards to support, including the provision of information, parent education programs and professional support. A number of factors, including the service provision framework, will influence the means by which support for decision-making is provided. Further research is required into parental perspectives regarding support for decision-making.

Summary

In this chapter, an overview of ASD and some of the critical issues related to ASD were presented. Within the literature, the complexity of ASD was highlighted, both in terms of the evolving understanding of the cause and course of the disorder, and the potential impact on families. Parents often had to endure a lengthy process to receive diagnosis of ASD, which in turn raised feelings of shock and grief as parents processed the diagnosis. If parents perceived that they have caused their children's ASD, they were more likely to express feelings of guilt (Hebert & Koulouglioti, 2010). Parents' theories of causation were also thought to influence their choice of intervention approaches (Dardennes et al., 2011).

There is a range of interventions available for individuals with ASD. The review of the literature indicated that psychodynamic interventions are rarely used in the present day, due to the recognition of ASD as a neuro-developmental disorder, not an emotional disorder. Educational interventions are used most commonly, though the scope of the interventions covered within this category is sizeable, and the level of evidence for the different educational approaches can vary significantly. Medical approaches also have varying degrees of empirical evidence. There are specific medications that have been found to be effective in managing some of the co-

morbidities associated with ASD (Aman et al., 2008). The literature examining the use of ASD interventions indicated that parents often used multiple interventions concurrently, and implemented interventions both with and without scientific backing, thus indicating that empirical evidence must not be the only factor influencing parental decision-making (Carter et al., 2011; Green et al., 2006). Though using multiple interventions concurrently seemed to be the dominant approach favored by parents, it does raise the question of how parents are able to evaluate the effectiveness of each intervention in order to determine which intervention, if any, is resulting in positive outcomes. There have been a number of strategies proposed to support parental decision-making (Berquist & Charlop, 2014; Murphy et al., 2011; O'Reilly et al., 2015; Stephenson et al., 2012), however a standard practice has not been implemented across the board.

A number of factors have been identified as influencing parental decision-making. Quantitative approaches to examining parental decision-making have often used Internet-based questionnaires or surveys to examine the impact of a specific factor on the decision-making of a large sample of participants. Such studies have reported that factors such as parental causal beliefs, illness perceptions and sources of information influence parental decision-making (Al Anbar et al., 2010; Dardennnes et al., 2011; Miller et al., 2012). Qualitative studies have also examined parental decision-making, typically exploring decision-making more in-depth but with a smaller sample of participants. These studies report multiple factors that influence decision-making, including attribution of cause, effectiveness of the intervention, accessibility and affordability (Hebert, 2014; Shyu, Tsai & Tsai, 2010). It is recognized within these studies that the influence of each of these factors varied according to the dynamics of each family unit. Overall, it can be concluded that an

understanding of parental decision-making is still developing, and changes in decision-making over time in particular has not been widely examined. Similarly, while several strategies for supporting parental decision-making, including provision of information, parent education programs and professional support, have been explored, further research into parental perspectives on support for decision-making is required.

It is the aim of the current study to examine parental decision-making and parents' perceptions of the supports available for decision-making, to provide a greater understanding and insight into these topics. In order to do so, a qualitative methodology was deemed most appropriate, as it would allow parental decision-making to be explored in depth, and allow for the multiple factors influencing decision-making to be identified. The foundations for the methodology will be outlined in the next chapter.

CHAPTER 3: FOUNDATIONS FOR METHODOLOGY

Introduction

In this chapter, the theoretical assumptions that underpin the current study will be explored. Due to the nature of the phenomenon under examination in this study, a qualitative approach was deemed most appropriate. The justification for the choice of methodology will be provided as each of the underpinnings for this study is described.

Within the field of qualitative research, the terminology regarding methodological issues is often used interchangeably. For the purposes of this study, the model proposed by Crotty (1998) will be used to represent the relationship between the epistemological paradigm, theoretical perspective, methodology and research methods. A visual representation of this model, and the frameworks used within this study, is depicted in Figure 1. Each of these elements will be discussed further below, specifically in relation to the approach selected and the implications for the current study.
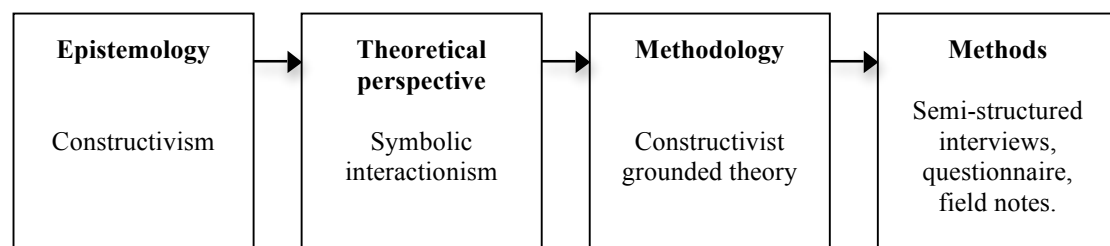

Figure 1. Relationship between epistemology, theoretical perspective, methodology and methods of data collection (Crotty, 1998).

Epistemology

Epistemology refers to theories of knowledge, and provides a framework for understanding what kinds of knowledge are legitimate (Crotty, 1998; Gray, 2014). There is more than one epistemological paradigm, each representing a different

position on human knowledge. It is important to understand the epistemological perspective adopted within a study, as it will inform the research design and interpretation of data (Easterby-Smith et al., 2002).

The current study is positioned primarily within the constructivist research paradigm. Constructivism is based on the view that individuals construct knowledge based on interactions with other individuals and the world around them (Crotty, 1998). Within the constructivist paradigm, reality is considered to be a social construction of the mind, and individuals may construct different meanings in relation to the same phenomenon based on their own experiences and interactions (Mills, Bonner & Francis, 2006). Research within the constructivist paradigm, therefore, is based on the assumption that knowledge is co-constructed. Constructivist researchers acknowledge both the role of the participants and the researcher in contributing to the research outcomes (Mills et al., 2006). Furthermore, given the focus on the construction of meaning within the constructivist paradigm, researchers must examine not just what meanings exist, but also how meaning has been constructed.

The current study fits within the constructivist paradigm given that the purpose is not to uncover a universal approach, but rather to explore and describe the decision-making experience of parents of children with ASD. Furthermore, the current study aims to acknowledge and understand the influence of different experiences on parents' approaches to decision-making. Adopting a constructivist paradigm has implications for how theory is constructed from the data, for example, acknowledging the different parental perceptions of ASD and therefore different approaches to decision-making.

Theoretical Perspective

The theoretical perspective of a study is the philosophical position that informs the methodology, and offers a framework for understanding the specific processes and methods chosen (Crotty, 1998). Adopting a theoretical perspective provides a framework through which research findings can be explained and positioned (Charmaz, 2006), thus transforming sets of data into meaningful theories. There exists a range of theoretical perspectives, and researchers must adopt a theoretical perspective in line with their epistemological view, in order to inform decision-making regarding methodology (Gray, 2014).

The theoretical perspective adopted within this study is symbolic interactionism. Symbolic interactionism is an interpretivist perspective, which focuses on the construction of meaning through interaction (Gray, 2014). Symbolic interactionism fits within the constructivist paradigm, given that it is based on the notions that individuals construct meanings through interaction and there is not a universal truth or reality.

Symbolic interactionism is based on three central assumptions related to the construction of meaning and knowledge. Firstly, it is assumed that individuals interpret the meaning of objects and actions, and the act upon these interpretations. According to Snow (2002), this interpretative process of creating meaning becomes explicit when people's meanings or actions become problematic, or their situations change. The second assumption underlying symbolic interactionism is that meaning is derived from social interaction. Finally, it is assumed that individuals use an interpretative process to direct and modify meanings when they encounter different situations (Annells, 1996; Blumer, 1969; Crotty, 1998). Thus, within the symbolic interactionism framework, it is assumed that meanings are not fixed, but rather will

change with experience (Gray, 2014). These meanings can include the perceptions of self and of others. Also central to symbolic interactionism is the concept of symbols, in which social life is expressed in symbols, for example, language (Charmaz, 1980).

Symbolic interactionism is an appropriate framework within which to consider parental decision-making for a number of reasons. Firstly, the role of parental perceptions of the cause and course of ASD has been reported to influence parental decision-making with regard to ASD (Al Anbar et al., 2010; Dardennes et al., 2011). In other words, parents have acted on the meanings that they have created. Furthermore, the focus within this perspective on creating meaning through social interaction lends itself to the current study, given that the influence of recommendations from other individuals have been established as influencing parental decision-making. Finally, symbolic interactionism provides fluidity, and acknowledges that the meanings that individuals create are modified based on experience. This is a particularly important assumption within the context of the current study, given that one of the research objectives is to explore how parental decision-making changes over time.

Symbolic interactionism requires the researcher to consider constructions of meaning from the perspectives of the participants. In order to do so, a method that allows the researcher to gain an insight into the lives and experiences of participants is necessary. There are several methodologies that provide this insight, shaped by the symbolic interactionism perspective, including grounded theory.

Methodology

The methodology of a study provides a theory relating to how research should proceed to answer the research question, and the justification for the methods of data

collection (Gray, 2014). Within the current study, the methodology that has been selected is a specific approach to grounded theory known as constructivist grounded theory. Grounded theory is a qualitative research methodology, which provides researchers with a framework of processes and principles to facilitate their understanding of common social life patterns (Charmaz, 2006). The ultimate goal of grounded theory research is to offer a substantive theory generated from the lived experience of participants (Ponterotto, 2010). Developed from the work of Glaser and Strauss (1967), grounded theory was originally established as a means of generating abstract, conceptual understandings of complex social phenomena. Glaser and Strauss (1967) challenged the perception that qualitative research lacked rigor by providing a systematic framework by which valid theories regarding social phenomena could be developed (Charmaz, 2006). Early grounded theory studies were very much influenced by the post-positivism research paradigm, whereby it was intended that the theoretical categories produced would serve as variables, and context-free statements would allow the application of one theory to different research situations (Skeat & Perry, 2008).

Since this initial work, approaches to grounded theory have diversified significantly, through the influence of various epistemological and theoretical perspectives. While 'Glasserian' grounded theory remains positioned squarely within the post-positivist paradigm, Strauss and Corbin (1998), though still influenced by post-positivist teachings, present a more interpretive perspective. Under the interpretive perspective, theories are developed within the context of the data, and the role of the researcher in providing the interpretation of the phenomenon is recognized (Crotty, 1998). Chamaz (2006) built on the interpretative perspective by introducing the constructivist approach to grounded theory.

A constructivist approach to grounded theory (CGT) places priority on the phenomena of study, and views both data generation and data analysis as an outcome of the researcher's shared experiences and relationships with the participants (Charmaz, 2006). In opposition to traditional post-positivist approaches to grounded theory, which state that theories are discovered, Charmaz (2006) argues, "Data do not provide a window of reality. Rather, "the 'discovered' reality arises from the interactive process and its temporal, cultural, and structural contexts" (Charmaz, 2000, p. 524). That is, theory is constructed through interaction between the participants, the researcher and the phenomenon of study. In order to achieve this, constructivist grounded theory prescribes an iterative research process, in which initial data collection and analysis shapes subsequent data collection and analysis (Charmaz, 2006). Thus, the researcher does not collect data to test a hypothesis, but rather is open to the ideas and experiences of the participants relating to the phenomenon under investigation. Constructivist grounded theory analysis involves the coding of research data, in which short labels or definitions are applied to segments of data (Charmaz, 2006). Initial coding evolves into focused coding, whereby the researcher reviews which codes are most frequently occurring or significant, and makes decisions about which data to pursue in subsequent interviews and how data are going to be categorized. At this stage, potential categories and concepts begin to emerge from the data. The relationships between concepts are constructed using a method of data analysis known as the constant comparative method, which involves the comparison of "data with data, data with category, category with category and category with concept" (Charmaz, 2006, p. 187) in order to generate increasingly more abstract concept and theories. Throughout the process of data coding, the researcher engages in a process known as memo-writing. Memo-

writing is considered to be a critical method by which to compare data, generate categories and construct theories (Charmaz, 2006). Once the data have reached a more abstract level of analysis, theoretical sampling occurs, in which further data are collected for the purposes of further informing or defining theoretical concepts. This process continues until no new theoretical insights are garnered. It is at this point that data collection ceases and theoretical saturation has been achieved.

Constructivist grounded theory was deemed to be the most appropriate methodology to facilitate the exploration of parental decision-making for two primary reasons. The methods of data collection adopted within the constructivist grounded theory allow for a focus on participants' experiences with decision-making. The aim of this study was to develop an in-depth understanding of decision-making, rather than to focus on the influence of one specific factor. Furthermore, constructivist grounded theory provides a framework by which to produce a substantive theory, rather than just describe patterns of data. This is important because one of the research objectives of this study was to produce a theory explaining parental decision-making.

Methods of Data Collection

In order to enhance the credibility of this study, multiple methods of data collection were implemented to allow triangulation to occur. Each method of data collection will be detailed below.

Semi-structured interviews. The primary method of data collection within this study was in-depth interviewing. Qualitative interviewing allows the researcher to understand the meaning of participants' experiences (Kvale, 1996). Interviewing provides the researcher with an insight into phenomena that can often not be

observed, such as thoughts and feelings (Patton, 2002). By nature of this method, the researcher is able to deeply explore a specific phenomenon, of which the participants have significant experience (Charmaz, 2006). Consequently, in-depth interviewing was selected as the primary method of data collection for this study, as this method would allow the exploration of parental decision-making, a phenomenon that cannot be directly observed.

As a method of data collection, interviewing fits well with the grounded theory methodology. Both grounded theory and in-depth interviewing are "open-ended yet directed, shaped but emergent, and paced yet unrestricted" (Charmaz, 2006, p. 28) approaches. Grounded theory interviewing however, requires the researcher to narrow the range of interview topics as data emerges from initial interviews, to allow theoretical categories to be developed. Consequently, the questions asked within constructivist grounded theory studies will evolve with time.

Given the dynamic nature of qualitative interviewing, the role of the interviewer in enabling the participants to express and reflect on their experiences is central to the richness of the data that are generated. How the interviewer elicits the experiences of the interviewee will vary according to the structure of the interview. Grbich (1998) identifies three approaches for qualitative interviewing: unstructured, semi-structured and structured. A point of difference between the three interview approaches is the level of flexibility that each approach allows the interviewer. Semi-structured interviewing involves the use of an interview guide to ensure that the same basic lines of questioning are pursued with each participant, but the interviewer is able to be flexible with the wording of questions, follow up on topics raised by the interviewee and establish a conversational style of interview (Patton, 2002). Semi-

structured interviewing was selected as the specific method of in-depth interviewing in this study to provide structure but flexibility with the interview.

The interview guide used within semi-structured interviews becomes an important instrument in the research process. For the purpose of semi-structured interviewing, Grbich (1998) defines an interview guide as a set of broad ranging questions derived from theory, the literature and the researcher's intuition. However, within constructivist grounded theory studies, there is an argument for increased preparation and analysis in constructing the interview guide (Krauss et al., 2009). Krauss at el. (2009) argue that significant background analysis and preparation is required to develop an effective interview guide. Charmaz (2006) asserts that within constructivist grounded theory studies, the questions must explore the interviewer's topic, and fit the participants' experience. In order to ensure that the interview guide generated for semi-structured interviews truly reflects the experiences of the research participants, several studies have involved participants in the process of developing the interview guide. Krauss et al. (2009) used a focus group to explore and understand the experiences and values of their participants. This enabled an interview guide to be developed that more accurately represented the values and experiences of the subsequent interviewees. Similarly, Newman, MacDougall & Baum (2009) conducted a focus group prior to conducting semi-structured interviews with children who had experienced parental job losses. Within this study, participants were involved in the study design, whereby the participant focus group generated the interview questions to be asked in the subsequent stage of the research (Newman et al, 2009).

Involving participants in the generation of the interview guide can overcome one of the potential disadvantages of implementing a semi-structured interview

method, which is that the questions may not accurately reflect the experiences the interviewees. By engaging participants with similar experiences and backgrounds in the generation of an interview guide, the resulting questions are more likely to elicit insightful responses from the participants. Furthermore, involving participants in the construction of the interview guide supports the credibility of a study, whereby the experiences of the participants are incorporated from the outset, with the implication that the findings are more likely to be considered credible by the research participants. Consequently, the first stage of the current study involved participants contributing to the construction of the interview guide.

Questionnaire. In order to support the analysis of the data collected via semi-structured interviews, it was determined that the participants would be asked to complete a questionnaire. Questionnaires provide a means by which participants can share relevant information that they may not feel comfortable discussing during a face-to-face conversation (e.g. family's annual income) (Patton, 2002). The use of a questionnaire fits well within constructivist grounded theory studies, as the information provided adds to the researcher's ability to understand the phenomenon under investigation and consider multiple perspectives when constructing a theory (Charmaz, 2006). Within the constructivist paradigm, data collected via questionnaire is not necessarily considered to be objective fact. Rather, there is an acknowledgement that the information that participants provide is influenced by context (Charmaz, 2006).

Researcher Field Notes. The final method of data collection in this study was use of field notes and memos. Field notes involve the researcher recording observations and reflections relating to phenomenon under investigation (Patton, 2002). In relation to constructivist grounded theory studies, the researcher can record

reflections about interactions with participants, paying particular attention to information that is not explicitly stated (e.g. body language of the participant, location of the interview) (Charmaz, 2006). The theoretical perspective that is adopted within the study will influence the content of field notes. When reflecting on an intervention from a symbolic interactionism perspective, the researcher might pay particular attention to the language that participants use to describe their experiences and how participants define the concepts under discussion (Charmaz. 2006).

Summary

This study was positioned within the constructivist paradigm, and symbolic interactionism was selected as the theoretical perspective. A constructivist grounded theory methodology was implemented, with semi-structured interviewing used as the primary method of data collection. Data were also collected via the use of a questionnaire and researcher field notes. Having considered the epistemological paradigm and theoretical perspective of this study, and justifying the methodology and research methods, the specific processes regarding the implementation of this study will now be discussed.

CHAPTER 4: METHODS

Introduction

Having established the theoretical assumptions and justified the selection of methodology and research methods within this previous chapter, the procedures for undertaking the current study will now be explored. The current study was conducted in two stages. The first stage resulted in the development of an interview guide. The second stage involved in-depth interviews with participants to generate data to develop a grounded theory related to parental decision-making, and to understand parental perspectives of the supports required for decision-making. Within this chapter, the procedures for each stage of the study will be explored. Figure 2 provides an overview of the research process, including how the methods of data collection and analysis fit together.

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┌─────────────────────────┐
│   Interview guide        │
│   construction:          │
│   3 participants         │
└─────────────────────────┘
             │
             ▼
┌─────────────────────────┐
│   CGT Matrix Study:      │
│   14 participants         │
│   (including             │
│   lamination interview)  │
└─────────────────────────┘
      │              │
      ▼              ▼
┌──────────┐  ┌──────────────┐        ┌──────────────────────┐
│ Data Set:│  │ Data Set: How│───────▶│ Data Subset: Early   │
│ Supports │  │ Parents      │        │ Intervention Message │
│ for      │  │ Make         │        │ Thematic Analysis    │
│ Decision-│  │ Decisions    │        └──────────────────────┘
│ Making   │  │ CGT Analysis │        ┌──────────────────────┐
│ Thematic │  │              │───────▶│ Data Subset: What    │
│ Analysis │  │              │        │ Parents Want From    │
└──────────┘  └──────────────┘        │ Therapists           │
                                      │ Thematic Analysis    │
                                      └──────────────────────┘
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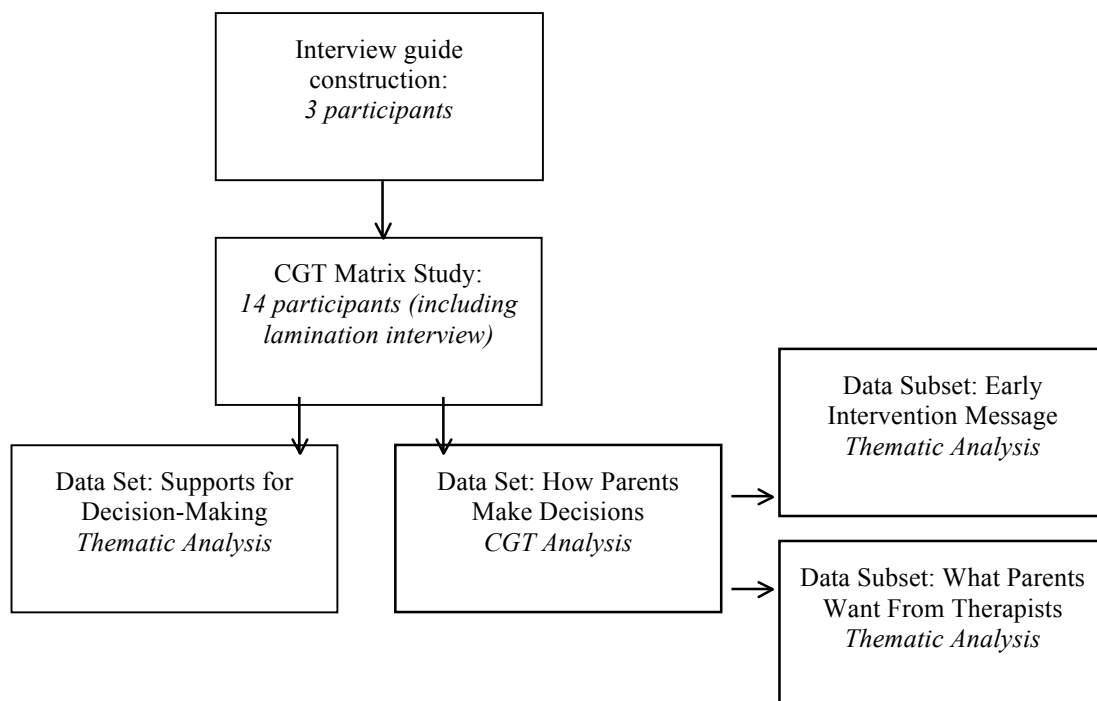
Figure 2. Research process.

Ethical Considerations

Prior to commencing participant recruitment, ethics approval was granted from the Southern Adelaide Clinical Human Research Ethics Committee. This covered recruitment through the child assessment team of a local hospital and a private practice specialising in the assessment of ASD. In addition, approval was granted from the ethics committee of the state's autism association, as well as the ethics committee of a HCWA approved service provider in South Australia, to allow recruitment through these agencies.

Participants

      Eligibility criteria. To be included in the study, participants needed to meet the following criteria:

- Parent of a child with a confirmed diagnosis of autism (as per DSM-IV diagnostic criteria), and;

- The child was 0-5 years post-diagnosis at the time of recruitment.

Ethics approval and initial participant recruitment was undertaken prior to the release of the DSM-V, and thus at this time, autism existed as a sub-diagnosis under the diagnosis of ASD. The decision was made to focus specifically on the decision-making on parents of children with autism, given the already significant heterogeneity within the autism population, and because it was anticipated that the needs of parents of children with autism were likely to differ from the needs of parents of children with, for example, PDD-NOS.

      Exclusion criteria for this study were established in order to ensure that the wellbeing of the participants recruited into the study was maintained and that

informed consent regarding participation was ensured. Parents who met the following

criteria were excluded from participating in the study:

- Parents with a confirmed ASD diagnosis

- Parents with known mental health issues

Sampling.   It was determined that convenience sampling would be

implemented in this study.   Convenience sampling is a sampling method in which

participants who meet the eligibility criteria are recruited into a study based on their

availability, and therefore attempts are not made to balance the participant sample for

gender, age or any other demographic attributes (Marshall, 1996).   The decision to

implement convenience sampling was influenced primarily by the relatively small

population under investigation.

Recruitment.   Participants were recruited from both public and private

agencies serving children with ASD in South Australia to ensure a range of

experiences were encapsulated within the data. Participants were also recruited from

services specializing in the diagnosis of ASD, as well as intervention providers, to

ensure that parents who were not currently accessing intervention services were still

given the opportunity to participate in the study.

Participants for the first stage of the study were recruited from the child

development unit from a Southern Adelaide hospital and a centrally located private

practice specializing in assessment of ASD. A speech pathologist involved with both

services provided potential participants with an introductory letter and expression of

interest form. The researcher contacted individuals who returned the expression of

interest form.

Larger scale recruitment was undertaken for the second stage of the study.

Participants were once again recruited through the child development unit and the

diagnosis service. Information was also sent to potential participants through a large HCWA-approved provider delivering services in the Southern and Northern regions of South Australia. In addition, the state's autism association placed an advertisement on their website, with links to an information sheet and consent form, as well as the researcher's contact details. Studies included on the website were also advertised to subscribers via email, and included in newsletters produced by autism support groups in South Australia (e.g. Adelaide Autism Adventures).

Despite pursuing participant recruitment through a number of avenues, participant numbers were small, and recruitment was slow, especially during the first stage of the study. There are a number of potential explanations for this. One factor that is thought to have significantly impacted on recruitment is the time pressures on parents of children with ASD, given that children with ASD are often involved in intensive intervention programs and may have high care needs. Furthermore, parents may have been interested in the study but did not meet the inclusion criteria, or may not have held strong opinions about the topics under investigation, and therefore may not have been motivated to participate.

A total of 17 participants were recruited into this study. Three participants participated in the first stage, and 14 participants from 12 family units participated in the second stage. All the participants had male children with autism, with ages ranging from two to 11 years, 3 months. One participant could not recall the age of her child at the point of diagnosis, and five participants did not have information relating to their child's Childhood Autism Rating Scale (CARS; Schopler et al., 1980) score at the time of diagnosis. A summary of the key participant demographic information is provided in Tables 2 and 3.

Table 2. Key participant demographic information for Stage 1 participants.

Participant Pseudonyms	Highest level of completed education (mother)	Child's sex	Child's age at diagnosis	CARS[a] score at diagnosis
Jane	University degree	Male	2;3	43
Marjorie	Secondary school	Male	4;0	N/A
Rachael	University degree	Male	5;2	30.5

Table 3. Key participant demographic information for Stage 2 participants.

Participant Pseudonyms	Highest level of completed education (father)	Highest level of completed education (mother)	Child's sex	Child's age at diagnosis	CARS[a] score at diagnosis
Elka	Trade qualification	Trade qualification	Male	3;6	46
Adriana	Trade qualification	Diploma	Male	2;10	39
Michelle	Trade qualification	Diploma	Male	8;10	39.5
Ellen & David	Research higher degree	University degree	Male	1;8	34.5
Nicola	Trade qualification	Diploma	Male	N/A	N/A
Debra	University degree	University degree	Male	1;8	32
Hannah	University post graduate diploma	University post graduate diploma	Male	1;10	33
Fiona	Diploma	University degree	Male	4;6	N/A
Deepak	Research higher degree	University degree	Male	5;3	45.5
Sophie	Trade qualification	Secondary school	Male	3;0	31.5
Alice	Diploma	Diploma	Male	8;5	N/A
Joanna & Russell	Trade qualification	University degree	Male	3;6	N/A

[a] Childhood Autism Rating Scale (Schopler et al., 1980)

Stage 1: Constructing the Interview Guide

Data Collection. In order to gather data to inform the interview guide, individual meetings with three participants were undertaken. It was determined that a focus group was not necessary in order to collect the data and that individual meetings would be sufficient. The researcher met with participants at a location of their choosing; two participants chose to meet at their respective homes, and the third participant chose to meet at a local cafe. At the beginning of each meeting, the participants were provided with an overview of the research project, and the rationale for seeking the participants' knowledge to inform the researcher's perspective was explained. The participants were asked to generate questions, based on their own experiences, which would allow other parents to share their stories. Once the participants had generated all the questions they felt were relevant, probing questions were used to explore other topics that had been raised by the participant (but not directly stated as questions). At this point, the researcher also raised any preconceived topics that had not already been addressed, to determine whether these topics should also be included in the interview guide.

Upon conclusion of the discussion, the researcher asked participants to complete a brief questionnaire to provide demographic information to aid with data interpretation (Appendix 4). Following the meeting, the researcher immediately reflected on the discussion. These reflections and observations were compiled, along with a transcript of questions and significant comments made by the participant. In order to ensure that the data collected had accurately reflected the participants' meanings, the first author sent an individual summary transcript, containing the questions generated and significant quotes, to each participant for review. None of the participants requested changes to the data.

Data Analysis. Within each interview transcript, questions generated both directly and indirectly during that meeting were highlighted. The questions from all the interviews were compiled into topics including: diagnostic experience, experience with autism interventions (positive and negative), factors influencing decision-making, confidence in decision-making, interactions with professionals and sources of information. Questions that had been generated more than once, as well as questions generated directly by the participants, were highlighted to indicate the significance of exploring these topics.

The order and structure of the interview guide was informed by the strategies outlined by Minichiello, Aroni, Timewell, & Alexander (1990). Specifically, Minichiello et al. (1990) suggest the use of descriptive questioning initially, and using follow up probing questions to prompt for more information. Furthermore, a final question was included to allow participants to share anything that may not have been covered during the interview. A copy of the original interview guide is included within the appendices (Appendix 2).

One of the conventions of constructivist grounded theory is the evolving nature of the interview guide. As categories of data emerge, the interview guide is updated to explore new topics raised by participants, or to explore certain topics in further detail. This process enables theoretical saturation of the data to occur. Thus, the original interview guide evolved as data collection proceeded. The process of updating the interview guide will be described in further detail when discussing the interview process.

Stage 2: Data Collection

In-depth Interviewing. In-depth interviewing was undertaken with the 14 participants involved in the second stage of this study. Just over half of the participants chose to meet with the researcher at their home; three participants chose to meet at Flinders University, two participants chose a local café and one participant chose a private office at her workplace. Before starting the interview, the researcher provided an outline of the study and explained how the interview guide had been developed. At this point, subtle changes in body language indicated that the participants had relaxed slightly. This may have been due to the statement regarding how the interview guide was constructed, or may just have reflected the participants becoming more comfortable with the interviewer. The researcher reviewed the consent form with the participants, highlighting that information would be treated confidentially and that participation in the study was voluntary.

Interviews were recorded on a Phillips digital voice recorder. The interview guide was used to direct the interviews, however a degree of flexibility within the interviews was employed, whereby the researcher would gauge from the conversation whether or not probing questions needed to be used, and was flexible with regard the specific topics discussed. On average, the interviews ran for 60 minutes, though interviews where two parents were involved naturally ran longer. The first interview was treated as a lamination interview (Agar, 1986; Simmons-Mackie & Damico, 1999), whereby the participant was asked for feedback regarding the interview guide and the order of questions. The first participant did not suggest any changes to the interview guide.

At the conclusion of the interview, the researcher explained that the interview transcript would be sent to the participants for review, to ensure that the transcript was

an accurate reflection of the interview and that they were happy with the content. Participants were also provided with a notepad, for recording any further thoughts or comments that they may have wanted to include but did not raise during the interview. None of the participants returned the notebooks with additional thoughts or comments. Only one participant requested that some information (not central to the topic under investigation) be removed from a transcript, and this was completed before the transcript was added to the data pool.

As data collection continued, the interview guide was updated to explore certain topics in further detail, in order to develop a deeper understanding of the concepts being raised by participants and to explore the theoretical concepts being constructed. For example, questions in the original interview guide focused on decision-making more broadly, and did not list any specific factors. The following statement from the first participant led to the addition of a question regarding the cost of interventions.

> *"But it's also an expense thing as well, you know, it's, it's huge, I mean we've got private health[3], but that only covers you for so much, you know."*

The interview guide was updated following each interview, and colour coding was used so that the interview questions could be traced back to each interview. Data collection via semi-structured interviewing continued until theoretical saturation had been achieved (outlined in 'Stage 2: Data Analysis'.) A copy of the final interview guide is included as an appendix (Appendix 3).

Questionnaire. At the completion of the interview, participants were asked to complete a questionnaire that had been developed by the researcher, to collect demographic information, as well as information about the interventions that

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[3] Within Australia, private health insurance ("private health") covers some of the costs of healthcare as a private patient. Private health insurance may not cover the entire cost of private healthcare, and therefore individuals may be left with some out-of-pocket expenses.

participants had implemented with their child. The questionnaire (Appendix 4) was developed for specific use in this study, after an earlier search of the literature for an existing questionnaire that met the brief for the current study was unsuccessful. In developing the questionnaire for this study, the focus was on gaining information to support the interpretation of data relating to parental decision-making. Thus, it was important to gather information relating to factors that had been identified within previous studies. For example, cost is a factor that is considered to influence parental decision-making (Hebert, 2014), and therefore a question relating to the family's annual income was included in the questionnaire. The questionnaire was divided into three sections; information relating the parent, information relating to the child and information about interventions, reflecting the broad categories of factors identified from the previous literature (refer Table 1, page 47). With regard to specific interventions, within the questionnaire participants were asked to provide a timeframe and to rate each intervention in terms of effectiveness, affordability and feasibility on three-point Likert scales. A three-point Likert scale, though not as strong statistically as a five-point Likert scale, was considered adequate for this study, given that the purpose of this measure was to provide further insight into parents' perspectives on interventions, not for statistical analysis.

Researcher field notes. Following each interview, the researcher recorded field notes, with relevant observations and reflections relating to the interview. The field notes were used to support data interpretation and as method of ensuring that the researcher attended to both verbal and non-verbal communication of the participants, which is especially important within the context of constructivist grounded theory and symbolic interactionism. An extract of a field note is included below as an example:

Motivated to participate in the study because her experience with services had been so poor. Explained to her daughter that she was talking to the researcher because the researcher was trying to help other families like theirs. Became upset at times when talking about her experiences – when upset, would restate the need for services and supports to improve.

Stage 2: Data Analysis.

Following each interview, the audio recordings were transcribed verbatim using Microsoft Word. Pseudonyms were allocated to participants and family members, and names of organisations and professionals were substituted for broader terms (e.g. the acronym for speech-language pathologists (SLP) replaced names of speech-language pathologists). The transcripts were then reviewed and data analysis was undertaken. Within qualitative research, there is the scope for different methods of data analysis to be implemented according to the research question and the theoretical perspective adopted. As has been established, a constructivist grounded theory approach to data analysis was the most appropriate approach to address the central research question (Question 1), relating to parental decision-making. However, it was decided that thematic analysis was the most appropriate method of data analysis to address the remaining research questions, given that the aim was not to produce a substantive theory relating to these topics. Both methods of data analysis will be outlined below.

Constructivist Grounded Theory. Initial line-by-line coding was applied to the first three transcripts in this study using NVivo9. Line-by-line coding is a detailed, thorough approach to coding, in which a code is applied to each line of the interview transcript. The decision was made to implement line-by-line coding initially to ensure that data were not overlooked based on the researcher's

preconceptions and that subtle nuances within the data were captured. Samples of line-by-line coding were reviewed with the research supervisors, and in addition, one of the research supervisors independently coded the first three interview transcripts. Given that constructivist grounded theory acknowledges the perspectives of both the researcher and the participants in constructing theory, the purpose of these checking processes was not to calculate a level of agreement with regard to coding, given that each person will bring a slightly different perspective to a set of data (Charmaz, 2006). However, there is a need to ensure that careful coding has been applied to the data. The research supervisors agreed that that coding had been applied logically and was representative of the data.

The researcher engaged in memo-writing in order to reflect on the initial codes and to develop tentative categories at this stage of data analysis. From the initial line-by-line coding, nine potential categories were raised with regard to factors influencing decision-making, as shown in Table 4.

Table 4. Potential factors identified through initial data coding.

Initial Categories	Potential Factors (identified through initial coding)
Decision-making	Risks vs. benefits (to child, to family, financially) Confidence to trust decisions Gut instinct Experience with decision-making
What parents' know	Identifying child's needs – matching to therapy approach Setting therapy goals Knowledge of available therapies Therapy priorities
Perceptions of therapy	Intensity Early intervention / timing Past experience with therapy (i.e. siblings, prior to diagnosis) Expectations of therapy

	Attitude to therapy
	Importance of therapy
	Perceived need for specific therapy (i.e. OT)
	Perceptions about therapy approaches (i.e. mainstream vs alternative)
	Expectations of service providers
	Ability to offer consistency (service providers)
Perceptions of ASD	Acceptance of ASD/disability
	Understanding of ASD (e.g. learning style, where strengths/weaknesses lie)
	Perceptions of ASD/disability
Motivation for therapy	Need to do something (motivation to persist)
	Schooling
	Coping with diagnosis
	Valuing therapy outcomes (motivation to persist)
Information	Recommendations from (trusted) professionals
	Experience/recommendations from other parents
	Own research (online, reading)
	Clinical research
	Reputation/word of mouth
	Perceptions about service providers
	Media
	Information provided during advisory process
Logistics	Cost/funding (funded providers, free services)
	Ease of access
	Location
	Availability (waiting lists)
	Flexibility of providers (i.e. home/school visits)
	Timing/other commitments (school/kindy)
Family unit	Values
	Family capacity (level of education, work)
	Parental well being
	Life balance/fitting therapy into life
	Needs of other family members (i.e. siblings)
Autism therapy experiences	Evaluating therapy (is child making progress?)

	Level of progress required
	Satisfaction with service
	Perception of therapist (initially)
	Relationship with therapist (ongoing)
	Impact on child (child enjoying therapy, child's preferences)
	Practicality (able to be maintained, easily implemented)

At this stage of data analysis, it was evident that a number of potential factors were influencing parental decision-making, however the relationships between these categories were not yet understood. Furthermore, though the concept of decision-making changing over time was evident in the stories of the participants, how this process aligned with the factors influencing decision-making was not entirely clear. Through the use of memo-writing, initial ideas relating to parental decision-making and the concepts of time and experience were recorded, which were then able to be explored with more focused coding. The following paragraph is an extract of an early memo relating to parents' experiences of diagnosis and feelings immediately post diagnosis, and reflects the initial emergence of the concept of decision-making shifting as parental perceptions change.

> *The expectations of what lies ahead often doesn't match reality. The thinking that "the worst is over" and "things can only get better" does not necessarily play out. Because at the start of this journey is something that is underestimated – hope. Hope is tightly bound to the 'early intervention' message that is so clearly communicated to parents.*

Having identified some frequently occurring codes and potential categories through the completion of initial line-by-line coding, focused coding was applied to the subsequent interview transcripts. To ensure that focused coding had been applied thoroughly to the data, the focused coding on three complete transcripts was reviewed

by one of the supervisors of this project, who agreed that that focused coding was an accurate representation of the data. A sample of an interview transcript with focused coding applied is shown in Table 5.

Table 5. Sample of interview transcript with corresponding focused codes.

Interview transcript (sample)	Focused coding
I think for Lachlan, that was the deciding factor in finishing. It was recognising that I wasn't actually doing him any good because I was going to burnout myself. So I needed to take a break for me, for his - for all of us, I needed to take a break. That was that one, finishing that.	Identifying own needs Prioritising family well-being
Finishing ABA for Hamish, it was just recognising that this just isn't working, and it wasn't doing any good. It was causing more stress. Because I think it was - in that regard, it was like well why isn't this working? It was then recognising that this just doesn't fit for Hamish. Being willing to make that stand as a parent, going this doesn't work. I know that you're a professional and I know that you know what you're talking about and I know that you've got many years of experience. But this is my son, and my gut tells me this isn't the way to go.	Evaluating therapy input Considering child's needs Parent as expert (standing up to professional)

Data that emerged from later interviews were used to refine the coding and provide a greater understanding of data provided in earlier interviews. Six primary categories (experience, motivation, information, understanding, needs, logistics) with clearly defined factors that influenced decision-making were established. The influence of personal and family values on decision-making was also identified. The use of memo-writing allowed ideas about the data to become more refined, and relationships between categories of data to become more clearly defined. For example, reflecting within the symbolic interactionism framework on how the confidence of one participant had changed over time led the researcher to review and refine the coding within earlier transcripts, looking specifically at the change in self-perception over time. The concept of the journey post-diagnosis became clear, and stages of decision-

making were proposed. The following extract is a more developed memo of the memo that was presented earlier, relating to parents' experiences with diagnosis and expectations post-diagnosis.

> *Receiving as ASD diagnosis is a life-changing event. Parents often know something is wrong but often don't believe it. Doesn't feel tragic at the time as a lot of hope is offered (early intervention). And while there is grief, there is relief and hope. A diagnosis brings answers and ends the searching. There are expectations of services, therapy and support – and without yet having experienced any of these things, the expectations are high. However, as parents take the first step beyond diagnosis, they find that their experiences of services do not often meet their expectations.*

This memo went on to form the basis for the first stage in the journey ("Diagnosis") and the first stage in the grounded theory. In order to understand the properties of the each category within the proposed theory, theoretical sampling was undertaken, where data collection continued to allow further information about the theoretical categories to be garnered. Within the context of this study, theoretical sampling was used to gain an understanding of how the specific factors influencing decision-making changed, at each stage of the journey, post-diagnosis. At this point, the influence of symbolic interactionism was evident, with consideration of how parents constructed meaning over time being central to the process. For example, within this study, 'experience' was established as a factor that influenced decision-making, and in turn, 'experience' contributed to how parents constructed meanings (e.g. whether they perceived themselves to be competent decision-makers). Theoretical saturation was achieved after interviewing 14 participants, whereby new data did not provide any further theoretical insights or information about the category properties (Charmaz,

2006). At this point, the factors influencing decision-making at each stage of the journey post-diagnosis could be clearly defined, within a model known as 'parent to expert'. The theoretical model was reviewed within the research team, who agreed that the model fit the data presented in the interview transcripts, and hence, data collection ceased. In order to increase the credibility of the study, a summary of the grounded theory was sent to the participants for review, to ensure that the theory reflected their experiences. One parent commented that the findings of the study would be very useful for the ASD community and asked to share the findings with her son's therapists. None of the participants requested changes to the theory, indicating that data analysis for the first research question was complete.

Thematic Analysis. Thematic analysis was undertaken to analyse the data related to research questions 2 to 5. A summary of the research questions analysed via thematic analysis is shown in Table 6.

Table 6. Research questions to be analysed via thematic analysis.

Question 2	What qualities do parents want in therapists working with children with ASD?
Question 3	What is the impact of the 'early intervention' message on parents of children with ASD?
Question 4	How do parents perceive supports available for decision-making?
Question 5	How can current practices be improved to support families during the decision-making process?

Thematic analysis is a method of data analysis in which coding is applied to data, and then examined for patterns and themes (Braun & Clarke, 2006). One of the central differences between grounded theory and thematic analysis is the role of theory. Given that the aim was not to produce a substantive theory explaining parents' perceptions of supports for decision-making and how current practices could be

improved, it was decided that thematic analysis was the most appropriate method of data analysis for research questions 4 & 5. Similarly, the aim in exploring the specific qualities that parents' want in therapists and the impact of the 'early intervention' message was to present parents' perspectives on these topics, not to produce a theoretical model.

As described by Braun & Clarke (2006), there are six phases involved with thematic analysis, as shown in Figure 3. Each step will be discussed with specific reference to the current study.
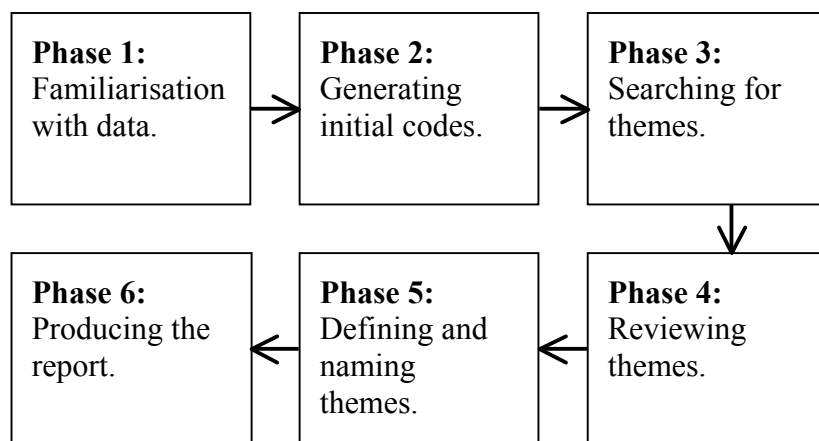
```
┌──────────────┐     ┌──────────────┐     ┌──────────────┐
│ Phase 1:     │     │ Phase 2:     │     │ Phase 3:     │
│ Familiarisation →   │ Generating   │  →  │ Searching for│
│ with data.   │     │ initial codes.│    │ themes.      │
└──────────────┘     └──────────────┘     └──────────────┘
                                                 │
                                                 ↓
┌──────────────┐     ┌──────────────┐     ┌──────────────┐
│ Phase 6:     │     │ Phase 5:     │     │ Phase 4:     │
│ Producing the│  ←  │ Defining and │  ←  │ Reviewing    │
│ report.      │     │ naming       │     │ themes.      │
│              │     │ themes.      │     │              │
└──────────────┘     └──────────────┘     └──────────────┘
```

Figure 3. The six phases in thematic analysis (Braun & Clarke, 2006).

The first phrase of data analysis involved becoming familiar with the data. Though the researcher had already spent a considerable amount of time working with the data to address research question 1, and therefore was very familiar with the data, it was important for the focus of data analysis to shift from parental decision-making to supports for decision-making. Therefore, the researcher re-read the transcripts, with a focus on data relating to supports for decision-making, and recorded initial thoughts and impressions. Following this, initial codes were applied to the data. The data relating to parents' perceptions of supports for decision-making was first coded

(sample shown in Table 7), and then coding was applied to data relating to how current practices could be improved.

Table 7. Sample of interview transcript with initial coding for thematic analysis.

Sample of interview transcript	Initial coding
You went and saw an autism advisor, and got given pieces of paper with these - this is what's available. There was no guidance, there was no offering of, 'this has been shown to have great', you know.	Receiving non-specific information Lacking guidance
I get that they can't be seen as directing you towards anything, but to go, 'this has got research. You can look here', that would've been incredibly helpful, I think.	Understanding professionals' perspective Wanting more detailed information

At this point, the coded data were reviewed by one of the research supervisors, who agreed that the coding has been applied accurately to the data. It was at the next phase of the analysis, once coding been applied to the data and the researcher commenced searching for themes, when it became clear that two overarching themes relating to research questions 4 and 5 could be constructed. It was evident from the coded data that a model could be developed, which could then be used as a framework within which to position both research questions. Thus, the initial focus on constructing themes from the coded data was to develop this model, which became known as the 'model of collaborative decision-making'. The two central themes within this model, 'the role of the professional' and 'the role of the parent', were reviewed and the core categories within each theme were described in further detail. Table 8 illustrates the process of developing codes into categories and themes.

Table 8. Thematic analysis process.

Quote	Code	Category	Theme
"Families having a lot of grief and upset, you could reassure them"	Grieving post-diagnosis	Support	Role of professional

A visual representation of the overarching model was developed, which was reviewed by the research team. The researcher then used the model to respond to research questions 4 and 5. The two themes remained consistent, as did the core categories, however the way these themes were represented in response to the research questions was different. This will be explained in further detail in Chapter 7.

Data analysis for research questions 2 and 3 also was completed using thematic analysis. The original articles in Appendices 6 and 7 provide specific detail how the codes and themes were developed for these research questions.

Rigor of Current Study

In order to judge the soundness and rigor of qualitative research, Guba and Lincoln (1989) established four criteria against which the research design and methods should be measured. The first criterion, credibility, refers to the degree to which the research is reflective of the participants' intended meanings and whether or not the research is considered to be credible by the participants. In order to increase the credibility of this study, data triangulation occurred, whereby data collected via interviewing, questionnaire and researcher field notes were all incorporated to allow conclusions about the data to be formed. Furthermore, participants were given the opportunity to review their verbatim interview transcript to ensure that it was an accurate reflection of the interview, and were asked to provide feedback relating to the research findings.

Additionally, terminology and phrases used by participants during interviews were incorporated into the names of categories and themes, to ensure that the data analysis reflected the participants' voices. Furthermore, a number of direct quotes from participants are provided within each of the categories within the results chapters, to support and provide transparency regarding the researchers' interpretation of the data. Given that the foundation of the methodology for this study is the assumption that knowledge is constructed through the interaction between the researcher and participants, it is also important to acknowledge the position of the researcher within this study. The researcher in this study is a practicing SLP, who believes that parental decision-making is influenced by a number of co-occurring factors and likely changes over time. Furthermore, the researcher believes that parents should be supported in their decision-making, especially in regard to accessing evidence-based intervention programs for their children with ASD.

The second criterion in determining the rigor of a study is transferability, which refers to degree to which the findings can be transferred into another context or setting. In order to allow the findings of this research to be transferred, a description of the context in which this research occurred, as well as the participants who were involved, have been included. Thus, other researchers should be able to make transfer judgments regarding the current study. Furthermore, the application of theory to explain the findings of the current study supports the transferability of the results.

The third criterion as described by Guba and Lincoln (1989) is dependability, which is related to the stability of the data over time. In order to demonstrate the shifts in the study over time, copies of both the original and final interview guide have been included to illustrate how data collection evolved with time. In addition, examples of memo-writing to illustrate how ideas and analysis evolved have been

included. Furthermore, decisions made by the research team (e.g. method of participant sampling) have been included and justified in this report.

The final criterion, confirmability, refers to the degree to which others can confirm the research findings. The confirmability within this study was established by having a research supervisor check the coding at multiple stages. Findings were also discussed with the supervisory team on a number of occasions, to ensure that the data were being analysed thoroughly. The nature of grounded theory analysis also lends itself to supporting the confirmability for the study, whereby data coding is checked and refined through the 'contrast comparison method'. Furthermore, examples of coding, as well as materials used in the study, have been included within this thesis so that readers can judge the confirmability of data analysis for themselves.

Summary

There were two stages to this study. Within the first stage, three participants generated questions to be included in a semi-structured interview guide. The second stage involved in-depth interviewing being conducted with 14 participants. The data were analysed using a constructivist grounded theory framework, which led to the construction of a theory relating to parental decision-making, and the journey of parents of children with ASD over time. Thematic analysis was undertaken on data relating to parents' perceptions of professional support for decision-making and how they believe that current practices could be improved, as well as to explore the qualities that parents want in therapists and the impact of the 'early intervention' message on parents of children with ASD. The results of data analysis for all of the research questions are presented in the following chapters.

CHAPTER 5: RESULTS

Introduction

Within this chapter, the results relating to the primary research question (Question 1) are presented. This research question relates to how parents of children with ASD make decisions regarding which intervention approaches to access, and encompasses both the factors influencing decision-making and changes in decision-making over time. In order to report this, a model is proposed in which decision-making is represented as a journey involving four distinct stages. The first stage, 'Diagnosis', acts as the antecedent for parents, and then decision-making is examined at each of the subsequent stages. The factors affecting decision-making are represented within six core categories, and though these factors remain consistent throughout the journey, how these factors influence decision-making changes as parents change over time. Thus, the factors influencing decision-making are presented within each stage of the journey following diagnosis.

Question 1: How do parents of children with an ASD make decisions regarding which intervention approaches to access?

The findings of this study revealed that the process of parental decision-making with regard to interventions evolves over time and with experience. Four distinct stages emerged in this journey, as represented below in Figure 4.
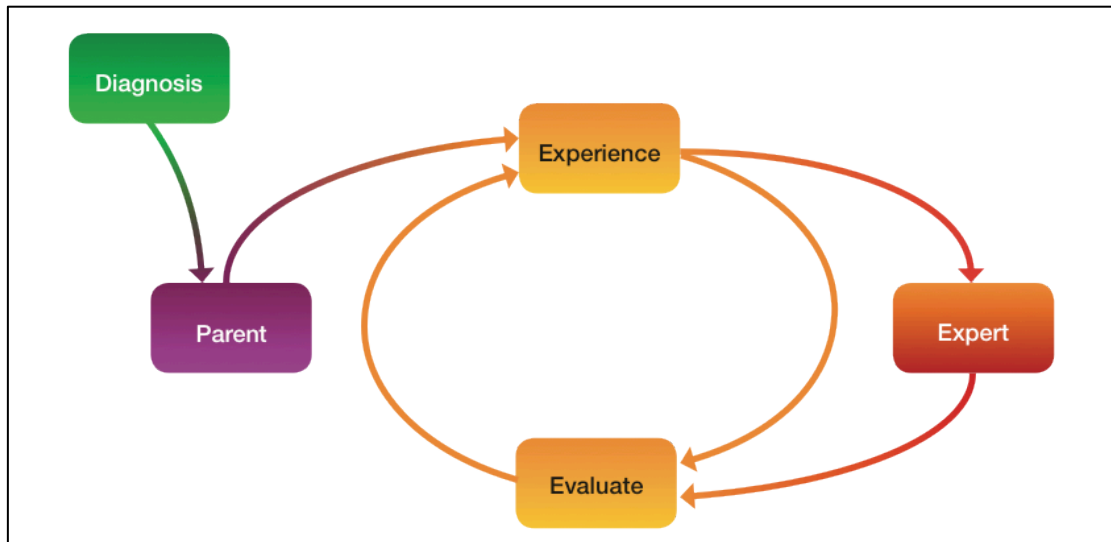
Figure 4. Visual representation of the journey from parent to expert.

With regard to the specific factors influencing decision-making, six categories of factors are proposed, as well as the overarching category of parental values, as represented in Figure 5. Under each of the six primary categories, the specific factors influencing decision-making are listed. This reflects the focused coding that was applied to the data during the constructivist grounded theory data analysis. 'Values' is represented within this figure as a stand-alone category, to represent the personal beliefs and values of each individual and family unit, which will invariably influence all the other categories. How these factors influence decision-making was found to vary according to the stage of parental-decision-making (Figure 4). Therefore, the findings for this research question will be presented by explaining each stage of parental decision-making, and how the specific factors influence decision-making at each stage.
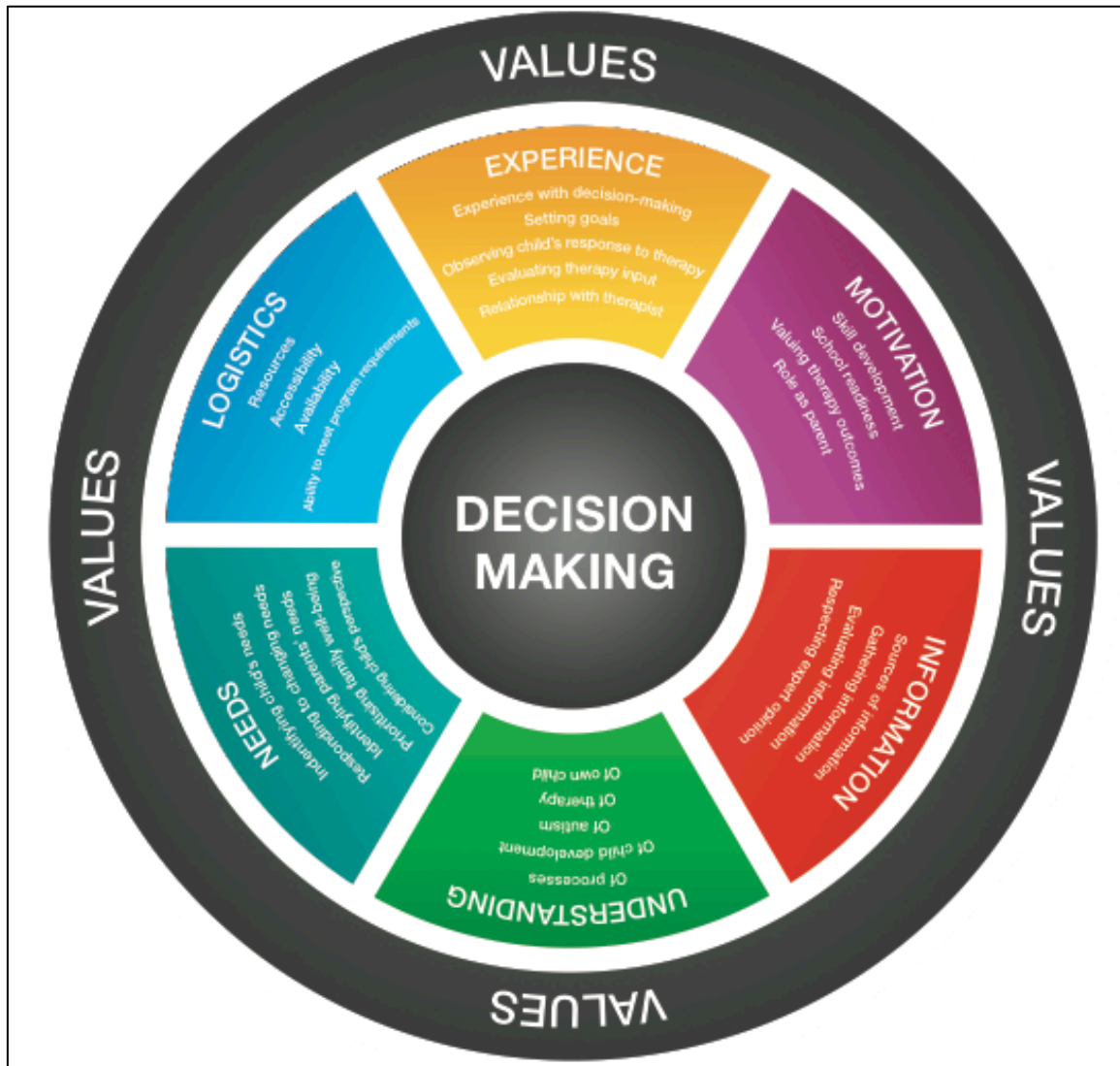
Figure 5. Factors influencing parental decision-making, arranged into categories.
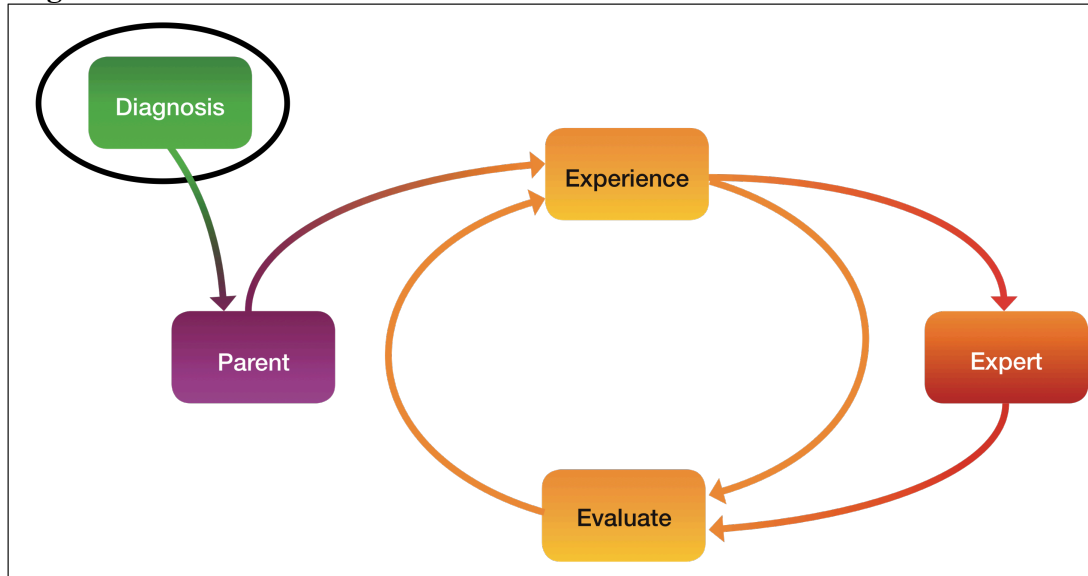
Stage 1. DIAGNOSIS: Grief and Relief

Figure 4. Visual representation of the journey from parent to expert ('Diagnosis' stage highlighted).

The diagnosis of child with ASD was a life-altering experience for the parents in this study. The process of receiving a diagnosis of ASD can best be summarised as a difficult and at times desperate search for answers. While there was grief associated with receiving a diagnosis of ASD, parents felt a strong sense of relief, and believed that services post-diagnosis would improve outcomes, thereby offering hope for the future. Obtaining an ASD diagnosis for a child is often a lengthy process, which can span across months or even years, beginning when parents identify developmental concerns and ending with a formal diagnosis. For the parents in this study, the task of accessing diagnostic services was in itself difficult, and represented the first step of having to navigate the 'autism industry'.

> Ellen: It was such a big job, because you've never thought of anything like that before, to actually navigate your way round, who do I go to for a diagnosis? No one can give you a clear answer, not even (the autism service). Who do I

go to, and what's the difference if I have a paediatrician's referral or I self-refer, or which paediatrician can I see, who's the best? Do I just want anyone quick so I get the Medicare item number so it's cheaper? Or do I want to pick someone who's an expert in autism?

Searching for an ASD diagnosis can be incredibly frustrating for families, who may have to consult with multiple health professionals before their concerns are acknowledged. This can be made all the more frustrating given that ASD diagnosticians are in effect the gatekeepers for ASD-specific services. Elka, whose son was diagnosed at the age of four, described the process of searching for an ASD diagnosis for her son.

Elka: Oh, hell, absolutely hell, I won't sugar coat it, there wasn't a day, I sat there just ready to bash my head against a wall, thinking does anybody know anything, like shouldn't you know this stuff, you know? And I thought I knew from the beginning, it's like I knew, I didn't want it to be the case but for me to just look on the internet and that's how I sort of looked it up … and in my head, I kind of knew, so you need someone to sort of tell-, you need a professional to say, 'This is what it is'.

Given the significant time span from when parents first identified developmental concerns to when a formal diagnosis is provided, it was often the case that parents had accepted the inevitability of ASD prior to the formal diagnosis.

Joanna: Although it was pretty disappointing, I knew that I had a child who was on the spectrum. It wasn't like, oh my God, it's a big surprise for us.

The formal diagnosis acted to confirm what in most instances the parents in this study already knew, and proved that their concerns were not unfounded. Michelle recounted how she felt when her son was diagnosed with ASD.

Michelle: Quite relieved, because it's like, we knew there was something wrong and nobody would believe us. So yeah, relief really, because (we) knew, it wasn't a shock to us.

Relief and grief were the two overarching and co-occurring emotions that the parents in this study experienced when their child received a formal ASD diagnosis. Parents faced initial feelings of grief when they realised that their child had ASD. Though in many cases the formal diagnosis acted to confirm parents' underlying suspicions, the parents in this study still felt an immediate, intense grief, and likened the experience to the serious illness or loss of a loved one.

Ellen: Although you keep telling yourself, look, the child isn't terminally ill - but I guess you feel almost the same as if you'd been told that they're really, really sick and they're going to get really, really sick, and you just want to be with them.

For some parents, grief was expressed by blaming themselves for their child's ASD, and also raised questions of causation.

Hannah: Oh, it was a bit scary at first, you know, you get upset, and you go through the usual emotions of, 'Did I do something wrong?', 'Did this happen because I was pregnant while he was so young again?', 'Was that an issue?'

Similarly, Alice was concerned that vaccinating her son as a child may have caused his autism.

Alice: It was really upsetting because I nearly didn't vaccinate him as a baby, because I was worried about autism. Never entered my mind for a minute that it could have been that. … The day she told me, I was really upset.

However on the whole, parents were unable to separate the strong feelings of grief from the overwhelming sense of relief that they experienced upon receiving a formal ASD diagnosis.

> Elka: And as I said as much as you didn't want to hear it, at the same time, it was awful, you felt like somebody had died, at the same time a big sense of relief came over me, at the same time.

This sense of relief felt by parents may seem counterintuitive, given that their child had been diagnosed with a lifelong disability. However for the parents in this study, a formal diagnosis represented the end of searching for answers, and more importantly, hope for the future. Parents equated receiving an autism diagnosis with being able to access ASD specific services. The notion that therapy input would improve the child's outcomes helped parents to cope with their child's diagnosis.

> Adriana: I think yeah, it um, you worry about the label that's going to come, um, but I think I, you go through a bit of a grieving process but I think at the end of the day I was almost relieved because that meant he was going to get some help.

Fiona recounted similar feelings when asked how she felt about her son's ASD diagnosis.

> Fiona: Relieved, because we'd - because by the time - because I think he's quite old to be - for us he was quite an old - an age to be diagnosed at. It was a relief because we thought now we can access services.

Upon closer examination, it became evident that hope was not just tied to being able to access services, but more specifically, the high expectations that parents had of therapy services. The journey to diagnosis had in most cases been tumultuous and navigated with little or no professional support. Parental perceptions of the services

available post-diagnosis were in stark contrast, with expectations of a high-level of support for decision-making and effective therapy that would produce meaningful outcomes. For Debra, perception of the services available post-diagnosis was a key factor in convincing her that a provisional diagnosis would place her in the best position to support her son.

> Debra: (We thought) it's probably better to get the diagnosis and then we'll get all the help and all the professionals will come and it'll be great and we'll get so much support, and people will tell us what we need to do and (the autism service) will help us and we'll be registered with them and get the right kind of services that we really needed, whereas if we went the other way with no diagnosis then we would kind of be floundering on our own what to do.

The parents in this study had an expectation that post-diagnosis, they would no longer have to search for information, and that experts in the field of ASD would help guide their decision-making.

> Fiona: I think we thought (they) would then link us in with all of the appropriate people. So they said here are our recommendations around what would be good for your son and your family, and we thought they would sort of do that.

The only parent who did not equate relief with receiving an ASD diagnosis was Nicola. Nicola already had two children diagnosed with ASD, and therefore had experienced the reality of life with a child with ASD.

> Nicola: I had a lot of people saying well you've been there before, so it shouldn't be so hard. But the fact that I'd been there before, actually I knew what perhaps I was getting into, which made it more difficult.

In retrospect, the parents in this study were able to reflect on their preconceptions regarding intervention services, and acknowledged the significant difference between their expectations and experience with services.

> Debra: Well I thought Henry would get fantastic support from (the autism service). I thought there would be an abundance of people, professionals contacting us and telling us this is - this is what you need and people said that he was, "He's so young and … you're lucky that you've got it so young and you can get fantastic early intervention". And so I guess I was just thinking well, 'We'll get the intervention and it's all going to be all right', and it just didn't happen.

For parents in this study, the journey to a diagnosis of ASD was often an arduous process. Equally though, there was a sense of optimism, whereby parents felt that the services available post-diagnosis would drastically improve the outcomes for their child and their family. In reality, the expectations that the parents in this study had did not necessarily match the services that were provided, which is significant given that this discrepancy shaped how parents felt about decision-making. This, as well as the factors influencing initial decision-making, will be explored in the following section.
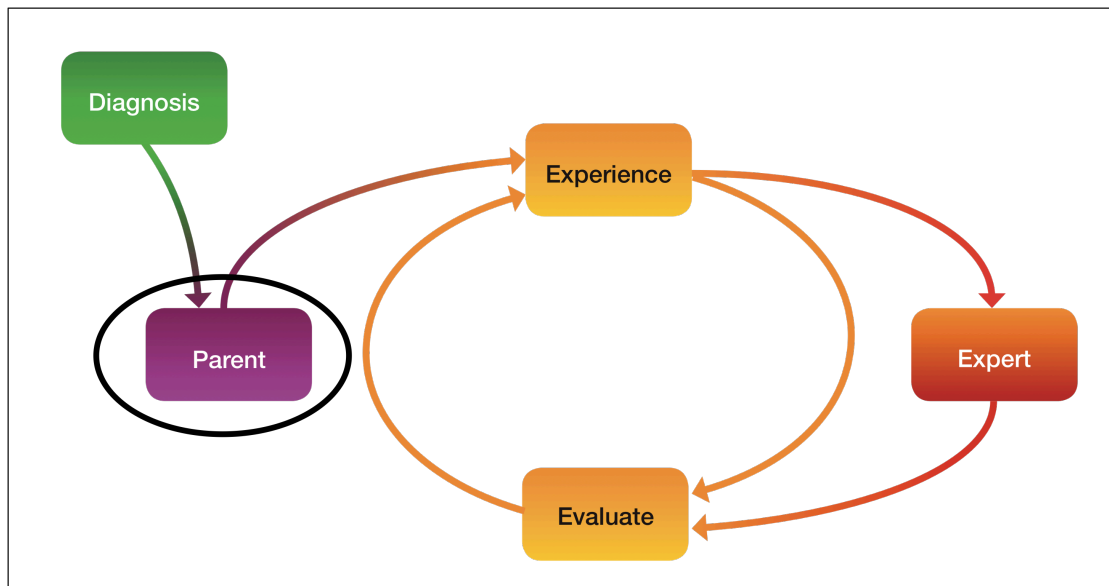
Stage 2. PARENT: Parent in a "Whole Other World"

Figure 4. Visual representation of the journey from parent to expert ('Parent' stage highlighted).

The first stage with regards to decision-making occurred immediately post-diagnosis, as described by the parents in this study, where they had to venture into unfamiliar and daunting territory. Elka summarized this sentiment when reflecting about decision-making in the initial period post-diagnosis.

> Elka: This is a whole nother [sic] world to me, it's a whole nother [sic] world, and you don't know it unless you're in it.

The overwhelming feeling expressed by the parents in this study regarding the period post-diagnosis was feeling unqualified to make decisions; of being 'just a parent', trying to make decisions that should be made by experts.

> Debra: She (the autism advisor) said to me, "Well, what do you think are Henry's priorities?" I'm like, 'Well, how am I supposed to answer that question? I'm not an expert in this field. I mean, he's two.'

The parents in this study were surprised and frustrated to find that the responsibility for decision-making post-diagnosis was placed solely onto them, which intensified the feeling of being unqualified to make decisions.

> Ellen: The person who is least able to make that decision is the parent who knows diddly-squat about - who knows very little about autism, and it's almost like the person who actually has to make the decision is the person with the least skill.

The parents in this study reported that immediately post-diagnosis, they felt significant pressure to make the right decisions with regard to interventions and feared running out of the time before the 'window of opportunity' for early intervention ran out.

> David: You're kind of very conscious at times … he's young, his mind's developing, you want to get it right, you don't want to start on the wrong track and then have to do something else. So that does put pressure on you and does put pressure on us, you know.

At the 'Parent' stage, decision-making is influenced by the six categories of factors (experience, motivation, information, understanding, needs, logistics), as represented in Figure 5. However, one of the defining elements of decision-making at this stage is that parents are often yet to have any direct experience with ASD-specific interventions or service providers. Therefore, the influence of 'Experience' on decision-making is limited, and the influence of other factors is more significant. The influence of each of these factors at the 'Parent' stage will be examined in more detail.

Experience. As described previously, immediately post-diagnosis the parents in this study had limited to no experience with autism interventions. Some families

had been accessing allied health services (e.g. speech-language pathology) prior to their child's diagnosis and this influenced their decision-making. Fiona's experience with speech-language pathology prior to her son's ASD diagnosis influenced her decision to access speech-language pathology services post-diagnosis.

> Fiona: Speech came from - we had a really positive experience with just the education department speechie that he saw through kindy. So she did an assessment and she was lovely. She was fantastic in working with the kindy around play that would promote his speech and all of that stuff. So we had a positive experience with a speech pathologist, so that - because we knew he had the language disorder it made sense for us to see a speechie.

The majority of families in this study though had not accessed any ASD-specific interventions. Consequently, they had limited experience upon which to draw when making decisions about which interventions to access. Though it is recognized that parents' previous experiences with decision-making will influence how they make future decisions, there are complexities associated with making decisions regarding interventions. To this end, although the parents in this study all had to make decisions, all of the participants in the current study reported feeling out of their comfort zone when it came to selecting autism interventions, which is exacerbated by the fact that there is significant debate amongst professionals about which intervention approaches are most effective, and there is not one intervention that is generally accepted as the gold standard, summarized by Sophie.

> Sophie: And what can you do with something like autism? Like, there are always going to be so many choices, because there are so many unknowns.

For the majority of families in this study therefore, making decisions about which interventions to implement was a new experience. There was however one family

who participated in this study who had previously made decisions regarding health in which there wasn't a clear-cut answer.

> Ellen: We're probably also quite influenced by - I've got a form of arthritis, I'm disabled off of work, and like, every man and his dog wants you to go and see their naturopath, oh if you'd only go and do this, do that, do this diet, I've read this article. You know, everybody thinks if you'd only do something different you could improve the situation … we learnt before we had Patrick that you could absolutely spend your life going around different people trying different things, listening to everybody, and making yourself pretty unhappy and poor in the process, so the way we've been with my health is really you pick your specialist and you stick with it. Unless there's some really good reason to change, you don't take a short-term view on these things.

The majority of families in this study however had not had to manage a chronic condition, which was to be expected, given that most parents were under 50 and therefore had not experienced significant health challenges. Therefore, it is reasonable to conclude that for the most part, parents of children with ASD have generally not encountered a scenario in which they have to make health decisions, and therefore have limited experience to draw on at this stage of the journey.

Motivation. At the 'Parent' stage, the participants in this study had very high expectations of intervention, and their motivation for participating in therapy was strongly influenced by their desire to minimise the impact of their child's disability, if not to cure their child's ASD. Deepak described his motivation for implementing interventions with his son.

> Deepak: Well, being close to a normal boy - that's the goal that I have to stick in my head … our goal is to make or close to as normal boy in every way [sic]. So that's the main thing.

As parents have often not had any direct experience with interventions at this stage, it is therefore difficult to gauge the impact that intervention will have on their child's behaviour. Sophie recalled that during the diagnostic process, it was reinforced to her and her husband that the outcome is difficult to predict before starting intervention, and consequently, they were motivated to engage in therapy to eliminate any features of ASD.

> Sophie: We thought we could make him normal. So that was probably the initial goal. Because you're thinking maybe if we do this and this - and I must say the girls who first flagged him as an autism person, they said something like that. Like you never know because you haven't actually done any therapies yet, you never know. Sometimes it can just be a severe language disorder or you know. So we did have some hopes like that. Like maybe he'll be normal.

Another related factor that motivated all the participants in this study who had children less than five years of age was the desire for them to attend mainstream schooling. The parents in this study expressed a strong preference for mainstream schooling, and held the belief that participating in intensive intervention programs would give their children the best change of attending mainstream schooling.

> Hannah: I would like him to be able to go to a mainstream school. That's what I would really like. I would like him to be able to socialize with the other kids.

For children who were already school-aged, parents expressed the preference for their children to be able to thrive in a mainstream school setting, and were motivated to participate in therapy programs to facilitate this.

> Fiona: I think our goals are for Ethan to be able to do as well as he can at school. So he's at a mainstream school, so our goal is for him to be able to go to school and feel okay about himself at school.

The parents of children who were attending mainstream schooling in this study were less motivated to make their children 'normal' and more focused on helping them to cope in different environments. However, this is potentially explained by the fact that these children had received a later diagnosis and their children presented with milder autism. Nonetheless, the motivation for all the participants at the 'Parent' stage was very much related to generally minimizing the impact of ASD on their child's daily functioning.

Information. With regards to information, the parents in this study reported that immediately post-diagnosis, they tended to rely on advice from experts. This reflected once again that parents were feeling unqualified to make decisions, and given that they had little to no experience, they were willing to accept the advice of professionals, as summarized by Elka.

> Elka: The decisions you make in the beginning are the ones that you sort of, I don't know, like, I think when somebody gets told that their child has any disability … you think, 'Okay well what do I do?' and you sort of don't know what to do, so I think you go with what someone else has recommended you to do, and then you do that…

Similarly, Adriana decided to pursue verbal behaviour therapy with her son, based on the recommendations she received from professionals at the point of diagnosis. This

also reflected on her construction of meaning with regard to herself as a parent in comparison to professionals as the experts.

> Adriana: I think I pretty much went with the recommendation of the diagnostic service, and what they were suggesting would be the most beneficial, because he was going to be re-assessed again in, I think 18 months, 2 years time, so yeah, I will just follow their ideas because I thought, 'Well, they're the experts and they're dealing with this all the time', so I was guided by that.

For some of the parents in this study, at this stage of the journey they were willing to follow the recommendations of professionals, even if they were unfamiliar with the intervention approach, because they trusted the information that was provided by professionals.

> Nicola: I think it was actually because I went through a psychologist to have them assessed, and she gave me the information about the early intervention program … So she gave us an application to apply for Lachlan and that was how I found out about that. So it was - and it wasn't even looking at as ABA, it was, 'This is a research project that we're doing. Did you want to be part of it?' We went, 'Well yeah, I'm happy to be part of anything.'

However, other participants at the 'Parent' stage felt the need to gather information and consider the different options before making a decision. With no experience and limited connections to other networks of information (e.g. parent support groups) at this stage though, parents were still relying on word-of-mouth or other factors (e.g. availability) to inform their final decision.

Ellen: So I did a bit of ringing round and everybody was agreed that SLP was the best, up in the hills, for preschool. So I got an appointment with the SLP, thankfully quite quickly.

Whether parents were more systematic in gathering information about the different intervention approaches or not seemed to be influenced by their personality and their approach to decision-making in general.

Sophie: So I spent like a year researching everything and online and reading and ringing everybody. I felt like I had to do it all myself. But yeah, that's just what I'm like anyway. So I just want to find out all about it and then work out a plan.

Understanding. Immediately post-diagnosis, parental understanding of ASD was still developing. Consequently, some of the parents in this study did not yet understand the potential impact of ASD on their child's daily functioning (e.g. sensory needs) and therefore were not aware of all of their child's potential therapy needs.

Hannah: I knew speech was definitely it. But OT and all the rest of it, I wasn't thinking about at that stage. It was just speech I was thinking about at that stage.

With regards to understanding of causation, few families in this study held strong views. There was though, one family unit with very clear beliefs regarding the cause of their child's ASD, which consequently influenced their decision-making post-diagnosis. Deepak described the need to implement biomedical interventions with his child, given his belief that the MMR vaccine caused his son's ASD.

Deepak: Well it seems that the MMR caused it…we believe that there is something wrong in his biology, in his physiology, which is one of the things,

perhaps his ability to detox, his ability to accept chemicals…it may influence

his brain development in some way … so if the biomedical is not fixed then

the ABA will affect less [sic].

While parents have not yet experienced interventions, the participants in this study held preconceptions about how interventions should be delivered in order to be effective. Debra reflected that in the early days post-diagnosis, her understanding was that the more therapy her son received, the better the outcomes.

Debra: I just remember just having this overwhelming kind of panic going on

that we need to do as many therapies and have as many therapists in our lives

as we can because this whole early intervention and window of opportunity

was always there … so we had like three speech therapists on the go and we

were doing OT and another kind of, chiropractic, sort of therapy as well and,

yeah I just felt like, the more we do, the better it will be.

Once again, with limited to no experience of autism service providers, some parents relied on preconceptions of service providers to inform their decision-making.

Elka: So you sort of looked at this list, and sort of thought, "Well, which one

do I go to?" and so I just sort of instinctively thought, "Autism - autism

service", and that's honestly why I went through them.

In summary, at the 'Parent' stage, parental understanding of a number of factors, including their child's ASD and the nature of ASD interventions and service providers, is significantly impacted upon by the fact that parents are yet to have any direct experience.

Needs. Parents' perceptions of their child's needs strongly influenced their decision-making at this stage of the journey. As previously described, parental understanding of ASD is still developing at this stage. Consequently, parents tended

to set broad goals for intervention, and attempted to match the intervention approach to the child's needs. Overwhelmingly, the goal that the participants in this study identified at the 'Parent' stage was the need for their children to start talking. This is logical given that social communication impairment is one of the central characteristics of ASD, and delayed communication development was often the initial cause of concern for parents in this study. Thus, at this stage, parents made the connection between communication impairment and the need for their children to access speech-language pathology. Elka described her decision to access speech-language pathology services for her son as a priority.

> Elka: First of all, would of, when I first started, obviously speech therapy was
>
> the first thing, like "I just want my child to talk", that's all I wanted, naturally.

Similarly, Nicola identified speech as the initial goal when trying to decide on interventions for her son.

> Nicola: My initial goal when I started with Lachlan was let's get him talking.
>
> That was my initial goal.

When asked about why communication was such an important goal, especially in the initial stage, participants expressed concerns about the impact that communication impairment would have on their children's ability to participate in daily activities and connect with other people.

> Hannah: He needs to be able to communicate with me, he needs to be able to
>
> communicate with everybody. He's never been in child care or anything like
>
> that because it concerns me that he can't talk. So I just think talking is really
>
> really important for him. And he needs to, to progress further. You know, he
>
> really does need to talk. So, that's why that's important.

The participants in this study felt so strongly about the importance of achieving outcomes for their children, that in the 'Parent' stage especially, the needs of the child with autism tended to be the priority. Debra spoke about prioritizing the needs of her son with ASD over the needs of the family.

> Debra: Some people did talk to us about family life and he's not the only one in your family, you need to consider other children, you need to consider the relationship with your partner and your - and I'd be like well, 'I don't care about any of that sort of stuff.' Amy (older sister) is fine, she doesn't have autism. We do the best that we can with her. We take her out and do little one-on-one things with her, she's okay and the relationship that I have with my husband is fine, but this is the most important thing to me.

In summary, parents at this stage tended to prioritize the needs of the child with ASD, and attempted to match these needs to specific therapy approaches.

Logistical Constraints. At all stages of the journey, the parents in this study had to filter their decision-making through the reality of logistics, for example, the cost and availability of services. This tended to be influenced by external factors (e.g. availability of funding) as well as factors related to the family (i.e. family income). Deepak described making the decision to start with diet rotation, because this was the least expensive option for intervention.

> Deepak: Yes, so the easiest way is from the diets. So we try to rotate the diets …. So because of that we choose to use the - a rotation diet - because it is cheaper rather than other interventions

As previously described, though there are many other factors that parents consider when making decisions, ultimately the final decision about which service provider to access services through initially was determined by logistics. In Adriana's case, for

example, the final decision in terms of a specific service provider was based on availability.

> Adriana: So my experience was basically the first one who rang back to say, "Look, I can fit you in", and it was within a week…and that's pretty much, we just went there because she could fit us in.

Similarly, though Hannah had an idea about which intervention approaches she wanted to access, she made the final decision about service providers based on accessibility.

> Hannah: She (the autism advisor) gave me a booklet and some written information, and that was it. She just said, 'Oh, these are the people that are registered, these are the therapists', so I just chose the ones that were closest to me.

Likewise, Fiona and her husband used factors related to logistics to filter their choice of service providers.

> Fiona: We were going on address, and would they visit us, and availability. Because sometimes there was a long waiting time, or - it was mainly waiting time and if they wouldn't visit us. Where if they wouldn't - if we couldn't see them at times that suited we would say no, we're going to try someone else. So that's what it came down to.

Overall, logistics relating to intervention programs often acted as the deciding factor with regard to selecting specific service providers. This was the case at all stages of the journey for the participants in this study. At the 'Parent' stage however, the parents in this study were in the unique and challenging situation of having to make decisions despite having little to no experience with autism interventions. This had implications on a number of other factors, including parents' willingness to follow

professional recommendations and parents' understanding of autism interventions, and ASD in general. In the subsequent stage of the journey, there was a significant change in decision-making, as the parents in this study started to gain experience and evaluate the services they were receiving. This will be explored in further detail in the following section.

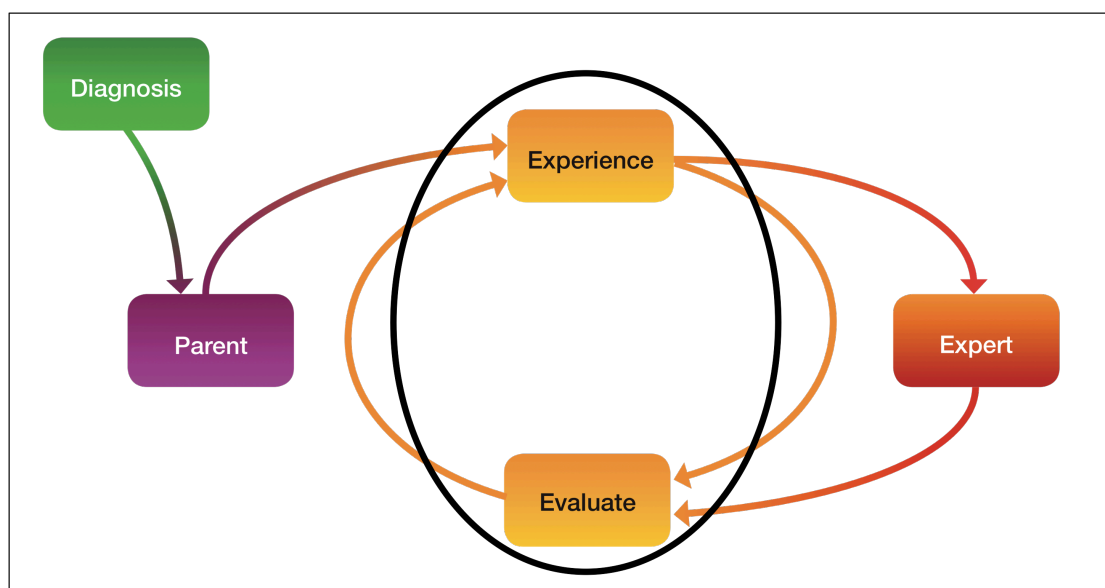**Stage 3. EXPERIENCE AND EVALUATE: A Process of Trial and Error**

Figure 4. Visual representation of the journey from parent to expert ('Experience and Evaluate' stage highlighted).

Having made decisions about which interventions to implement initially, the next stage of the journey for the parents in this study occurred when they were able to gain some experience with interventions. For the parents in this study, gaining experience with interventions influenced their ongoing decision-making. Parents started to change how they felt about decision-making, and started to see themselves as competent decision-makers. For Hannah, the process of gaining experience meant that she was more confident in the subsequent decisions she was making.

Hannah: Experience, just with anything in life, experience, once you've gone

through the process and you've got the experience, you get to understand.

The other element that emerged at this stage was evaluation. Once starting intervention programs, the parents in this study were constantly evaluating their child's progress and the value of therapy input. Ellen and her husband planned to continue monitoring their son's progress to ensure that the intervention they were implementing was still effective.

Ellen: So we can really see that it's working, we can really see that the

connections are coming at a very instinctive level … really, up until such point

as we think what we're doing isn't working, we'll just keep doing more of the

same.

For the parents in this study, decision-making was an ongoing process. Decisions were made and re-evaluated continuously. This once again is reflective of the construction of meaning through interaction, as outlined in the symbolic interactionism perspective. Deepak identified that he would judge whether an intervention had been effective, and if not, then decide to trial another intervention approach.

Deepak: I've found if there is no such big or significant change happen [sic]

with each of the interventions. So when we decide to choose one intervention

we have to put our feeling in two directions - working or not working. So if

not working then we have to think other intervention.

The cyclical nature of the 'Experience and Evaluate' stage is represented in Figure 4, which illustrates the constant process in which the parents in this study engaged, whereby experiences with interventions were evaluated, which then informed future experiences. The six factors, represented in Figure 5, still influence parental decision-

making at this stage. However, how these factors influenced the decision-making of the parents in this study changed, as parents gained experience with ASD interventions. Each of these factors will be explored in further detail.

Experience. As discussed, at this stage of the journey, parents begin to gain experience with autism interventions and consequently evaluate the interventions. On reflection, the parents in this study identified that this stage of the journey was very much a process of trial and error. Gaining experience with interventions and subsequently evaluating progress provided parents with information on which to base subsequent decisions. Alice reflected that the only way to determine whether an intervention would be effective for her child was to implement and subsequently evaluate it.

> Alice: I suppose, it's really just trial and error. Well, let's give it a go, because you read reviews, there are good and bad reviews on everything.

Overwhelming, the parents in this study identified that the primary means by which they evaluate interventions is how much progress their child was making. Parents identified that they were continuously monitoring their child's progress, and consequently re-evaluating the decisions that had been made.

> Elka: I always sort of like to focus on areas he's having trouble with at that particular stage, it might only be for 2 months or 6 months or 12 months, and then when that all seems that have a handle or that, start thinking, "Okay, that's going really well" and then we're going to drop off on that one for a while and we're gonna go take him to this one.

At this point in the journey, two approaches to decision-making clearly emerged; parents who were satisfied with the progress their child was making due to intervention, and parents who were not. For parents who were satisfied with the

progress their child was making from therapy, they felt relatively confident in the decisions they were making, and ongoing decision-making related primarily to implementing more of the same in terms of intervention.

> Ellen: I think because we've had so much success, we haven't had to stare it in the face of, 'Are we getting this wrong?'

These parents still engaged in the process of evaluating their children's progress, but this process only served to reinforce the decisions that they had made and encourage them to continue along the same path in terms of intervention.

> Adriana: We could see it was working, so I did at one stage start exploring something else and, I don't know, I just, I felt, 'No, we'll just stick with what was working', and we used all the money there.

When asked about how they specifically measured progress, the parents in this study often listed specific skill development or identified observable changes in behaviour. Joanna observed that her son was implementing the strategies that his speech-language pathologist was using.

> Joanna: I see that he's putting in (place) the things that she says to him to do. Even in the lesson, he uses the phrases that she suggests he might like to use, and that kind of thing.

Likewise, Alice and her husband observed improvements in their son's language and gross motor development.

> Alice: We're seeing changes, we were seeing things … there's been huge turnarounds with just the amount of expression he has now, his co-ordination is better…

Observing progress was generally encouraging for the parents in this study. However, for the parents whose children were not making what they perceived to be

adequate progress, decision-making was significantly different. When parents evaluated their child's progress and were not satisfied, they often made the decision to change service providers or intervention approaches. Debra finally made the decision to stop participating in an ABA therapy program because she did not feel that her son's development was progressing.

> Debra: We made the decision to stop I suppose because we felt like this really wasn't working. We weren't really getting anywhere with it.

Michelle expressed her frustration at having to try a number of different intervention approaches and service providers due to lack of progress.

> Michelle: I was seeing a psychologist and I was going every week and I just kept thinking, 'I don't want to come because it's not doing anything.' In the end I said, 'We're not getting anywhere, I won't come again.' Yeah, it's like, I'll try things, but nothing seems to work.

Fiona reflected that though she felt pressure to be implementing an intervention, it was difficult to decide on future intervention programs given that she was not observing progress from her son's current intervention.

> Fiona: We feel like we should even be doing more but it's hard to want to go ahead and launch into something else when you don't even know if what you're doing is achieving anything.

In summary, experience with intervention programs greatly influenced decision-making for the parents in this study. For parents who observed their child making progress, decision-making often related to maintaining intervention programs. Alternatively, for parents who did not believe their children were making sufficient progress, decision-making became increasingly difficult, as they had to grapple with stopping current interventions and choosing alternative approaches or service

providers. In both cases, parents were evaluating their experiences, and specifically their child's progress, to inform their decision-making.

Motivation. Attendance at mainstream schooling continued to be a significant motivating factor for parents at the 'Experience and Evaluate' stage. Debra decided to delay her son's school transition, in the hope that additional therapy input would enable him to attend mainstream schooling.

> Debra: We delayed his start to school because we sort of wanted to have six
>
> more months to try to get him to talk.

Adriana's decision-making was influenced by her need to complete intensive intervention prior to her son's school transition.

> Adriana: So in my mind, I wanted to do all the intervention I could before he
>
> started school, because I didn't want to be dragging him out of school all the
>
> time.

At this stage of the journey, parents also identified that the perception of the parenting role acted as a motivation for participating in interventions. This was particularly the case for parents whose children were not progressing as they would have liked from intervention. Debra recalled how she felt when she wasn't seeing the results she wanted from her son's intervention programs.

> Debra: Very stressed, very emotional, very like "We're failing him"…why is
>
> this not working, but just determined not to give up because we had to do
>
> something. I don't know, it's almost like you're trying to help yourself as well
>
> … you're at least doing something when you're trying.

Similarly, Michelle reflected that although she did not feel that intervention was helping her children to progress, she felt that stopping intervention would reflect badly on her as a parent.

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Michelle: I feel like if I don't do something I'm not trying to help them, I'm just not bothered about them. So I want to try everything to help them.

The motivation to continue therapy for families was also fundamentally linked to parents valuing the therapy outcomes. Even when parents in this study had not observed progress, they were still motivated to continue with therapy, because of the value they placed on the potential outcomes. Debra reflected on her decision to continue with ABA intervention with her son, even though they were not observing any significant progress.

Debra: I guess I was just motivated to continue because, because of what I read about the therapy and what people told me about the therapy and the results that I'd heard.

Information. During this stage, a number of the parents in this study started to make connections with other parents of children with ASD, and therefore were able to gain information regarding service providers and intervention approaches.

Sophie: I went to a support group for a while. Actually that was the best source of information - the only reason I went. Because I already had friends and family but everyone would say this is what I'm doing, this is what school my kids - you know and that was a huge source of information.

The parents in this study did specify however that there is a process of evaluating this information against their own knowledge and values, and considering within the context of their own situation before acting on suggestions from other parents.

Michelle: I had one the other day with some person who does something to their brains. … You take it and you're like, 'Not doing that.' But you get all different sorts of ideas coming from people, and I think you take what you want from it, don't you, you sort of know whether it's stupid or not.

For the parents who were feeling more confident in their decision-making based on their experience with interventions, they reported feeling better able to evaluate information, rather than follow professional recommendations. Elka reflected that she started to trust her instinct and make decisions more independently at this stage of the journey.

> Elka: I'm researching all this stuff and I can see this and that, so then you start making your own decisions based on that, instead of taking someone else's recommendations, so I think the first initial beginning steps you are gonna be guided through it … and then when you start talking to people, it opens up avenues and other doors and you make your own decisions from there, for what you think is best.

Alternatively, by participating in intervention programs and forming a relationship with therapists, some parents were willing take on recommendations from professionals that they trusted, that they had not been ready to consider previously. Hannah sought out occupational therapy for her son, based on the recommendation of her son's speech-language pathologist.

> Hannah: She said, told me, 'maybe you should look into doing OT now, in conjunction with it', and so it was on her advice that I went … That helped me, 'Right, okay, if the SLP said it, then it's got to be the right thing to do'.

Another interesting finding that emerged when looking at decision-making at the 'Experience and Evaluate' stage was the influence of empirical evidence. A number of the parents in this study considered clinical research, but this did not necessarily influence their decision-making. Nicola reflected that the heterogeneity of the ASD population meant that empirical evidence might not even be reflective of the experience for her children.

Nicola: I think research can show anything, depending on who has done the research … I think that research can only give the experience of those people that were involved in that research. It certainly doesn't give a picture for everybody.

For the parents in this study, the ultimate level of evidence was their perception of whether their child was making progress with the intervention, regardless of the level of empirical evidence available. Ellen reflected that although other intervention approaches may have more empirical evidence, she remained firm in her decision to implement the intervention that she had chosen.

Ellen: I know that if you want to prove something, you can prove whatever you want … and it's obvious that with Floortime® it's not set drills. So those things - you're not going to have the statistics and the proof. So to me, the fact that ABA supposedly had objective proof, it's just - so what? It is meaningless, it is really meaningless.

On the other hand, Debra was willing to consider some alternative therapies even though the empirical evidence was lacking, but equally did place limitations on what she was willing to try with her son because of the lack of evidence.

Debra: We sort of felt that the research is not really there yet, although we have dabbled a little bit with diet and fish oils and things like that. I'm not quite ready to start doing some strange - mixing different powders and things together.

Understanding. As time progressed post-diagnosis, the parents in this study reported feeling that they had a better understanding of ASD as a neuro-developmental disorder. With increased understanding, some of parents in this study started to accept the lifelong nature of ASD. Where parents were previously aiming for a cure,

parents then focused on achieving more functional goals. For Sophie, this influenced her decision-making, whereby she no longer felt the need to pursue intensive intervention as her expectations of intervention had changed.

> Sophie: You realise some of the things you were stressing about you didn't need to be stressing about anyway, because he is what he is. Like you're not going to make him normal … as soon as you accept it, you think, 'Oh well, I'll just celebrate the little things he does', and you know got a good speech therapist and you know you just let it go a bit. Because you can't, you can't keep killing yourself.

With an increased understanding of ASD, some of the parents in this study also developed their own opinions regarding the efficacy of the potential interventions available. Elka decided not to trial medication with her son, as she did not believe this would be effective.

> Elka: The medications that's used is like anti-psychotics and medication for ADD and stuff, so I'm not gonna do it, you know just purely for that fact that it's not for autism and their brain's completely different, functions differently, so I just don't believe that that will work.

The parents in this study reported that with experience, they started to gain a better understanding of their child's needs and learning style, which informed their subsequent decision-making. Elka felt that with time, she developed a better understanding of her son and his needs from intervention, and thus made decisions based on this.

> Elka: All the stuff you have to go through, so it changes as you realize, "Okay this is what my child's like, these are what his needs are", I'm getting to know him better and understand him better.

The parents in this study identified that having gained experience with interventions, their understanding of what intervention entailed had developed. After participating in intervention with her son, Sophie recognized the role of parent education in intervention, which as a consequence also meant that she didn't feel the need for such intensive therapy.

> Sophie: I remember at the very start with the private OT I said to her, 'Can I see you twice a week'? She was $100 but I was thinking I've got to do so many hours. But over time I realised that she's just showing me how I need to handle Andrew all the time at home and that's therapy in itself.

Furthermore, with experience, parents' developed a broader perspective on intervention, and how outcomes could be achieved. Debra started to consider playing and engaging with her son as therapy, which minimized the need to engage in intensive intervention with professionals.

> Debra: Our therapy is my husband and I like tickling him and singing to him and playing little games with him.

Needs. At the 'Experience and Evaluate' stage, the parents in this study began to change their focus for intervention. Parents began to target more functional goals, reflecting an increased understanding of ASD, and acceptance of the diagnosis. Elka reflected that once she developed more realistic expectations of intervention, she made the decision to pursue different intervention approaches.

> Elka: But as sort of time went on and I realized that, he wasn't necessarily going to just come out and talk and they'd be a chance … he wouldn't talk … I thought, "Is this what I should be focusing on now then? Maybe it should be other stuff that I should be focusing on?", so then we did move into OT and all of that sort of stuff, and just using his fine and gross motor skills.

Parents also began to think towards the future, beyond just schooling. Parents at this stage identified goals relating to independence and identified the importance of providing their children with strategies to cope in different environments, rather than attempting to eliminate the ASD. Michelle reflected that her later decision-making focused more on providing her son with strategies to enable him to have some independence when he is older.

> Michelle: Nothing's going to fix the autism but I need him to be able to live in harmony with other people, to be able to get on socially, to make some friends, because he doesn't have friends. I'm thinking towards the future more than now, because I just want him to get on in the world and be able to live independently, really … I always think, when I'm gone I want him to be okay, not me have to worry about him when I'm older or sick. So I'm trying to get in place now early on the things that he needs to live in the future.

Similarly, Joanna identified that her focus for intervention at this stage related to facilitating her son's participation in different environments, rather than trying to make him 'normal'.

> Joanna: I don't really care if he's not normal, but I don't want him to be upset that he's not normal … I'm hoping that he'll just be able to function, that he'll be able to have a job where he's not going to be bullied and he'll be able to go to high school.

However, in thinking towards the future, one family maintained the need to cure their child of ASD, for fear of the significant burden of disability.

> Deepak: We want to try everything and well because … we want to get rid of the autism; we want to escape from this autism. So any - perhaps issue that other parent have successfully done, we want to try it.

The experience of Deepak's family is closely tied to the influence of culture on decision-making. While the other families in this study were concerned about their children being able to function in society, within Deepak's family, the perception of disability as a burden was immense, and resulted in prioritizing intervention for the child above all else.

> Deepak: The burden having the disability is very, very high … so that's the difficult things of this disability … the impact for the social and future is very tremendous.

For the majority of the families in this study during the 'Experience and Evaluate' stage, there was an increasing recognition of the needs of the family, not just the needs of the child. With time, most of the parents in this study identified that prioritizing the needs of the family was actually in the child's best interest. Nicola decided to stop an intensive intervention program, recognizing that the negative impact it was having on her would in fact be detrimental to her son.

> Nicola: I think for Lachlan, that was the deciding factor in finishing. It was recognizing that I wasn't actually doing him any good because I was going to burnout myself. So I needed to take a break for me, for his - for all of us, I needed to take a break. That was that one, finishing that.

Similarly, Debra reflected that since deciding to stop intensive intervention, her family life had improved.

> Debra: Since we've stopped - I mean, he still has a little bit but somebody else does it, life's actually got a lot better … I just feel our family life is much better.

Also emerging during this stage was an increasing consideration of the child's perspective by the parents in this study. Parents reported that they considered the

child's perspective when making decisions regarding intervention. Hannah reflected that she learnt with time that her son enjoying intervention was critical to it being successful, and therefore she considered her son's perspective when making decisions.

> Hannah: I have to basically go with what Jacob wants to do, and not what I want him to do. And that was hard to learn, but I did. So yeah, I think he enjoys it, and I think it does help him, it helps. He loves to get out and do something different. I think if he didn't like it, it wouldn't work. I really don't think it would have.

Somewhat similarly, considering the impact that participating in intervention was having on her son influenced Michelle's decision to stop pursuing intensive intervention.

> Michelle: You're sort of wasting your life going through each one and wasting their time, they should be a child, you know, not having to go to therapists their whole life. Then they've lost their childhood. So yeah, I think I'll just keep him at home, let him play his Wii games, let him have fun. That's all he's got in his life

Considering their child's perspective is not always an easy task, given that children with ASD can have significant communication impairment. However, Elka reflected that the reality of raising a child with ASD meant that she became hyper-aware of her son's needs and preferences, even though he couldn't communicate verbally.

> Elka: So, when you're watching somebody constantly when they don't talk or communicate with you, you're having to look for the signs of things that they need or that are wrong, so that's how I've learnt, but I don't know if it's right or not, I don't know, I'll find out.

Logistical Constraints. As per the 'Parent' stage of the journey, the parents in this study reported that logistics still impacted on their decision-making. With experience however, there was an increased consideration about the ability of families to meet the intervention program's requirements. This was often linked to the needs of the family, and deciding to make the wellbeing of the family a priority.

> Nicola: I think once we reached that 20 weeks, I'd done my commitment to the program. … But also by about week 12, it was getting really hard to maintain. Now having three other kids, one of them was very young and so it was getting very, very difficult to actually maintain that time, because it's a huge amount of time per week.

For some families at this stage of the journey there was increased consideration of funding and cost. Sophie decided not to pursue intervention through one service provider because funding was no longer available.

> Sophie: As for all the other stuff, the money ran out … so I reckon that got us - we didn't pay any money privately to them. So that just kind of ran out.

The reality at the 'Experience and Evaluate' stage was that children had often started attending school, and in some cases parents' work commitments had increased. For Adriana's family, this was exacerbated by the fact they lived rurally, and therefore deciding to participate in an intervention required a significant commitment.

> Adriana: It's now time, work commitments, and just time … we've got to travel everywhere to see someone … so that comes into play with work and everything else, so yeah, it gets difficult I think, and that's why I think I had the mindset to do as much as I could before he started school.
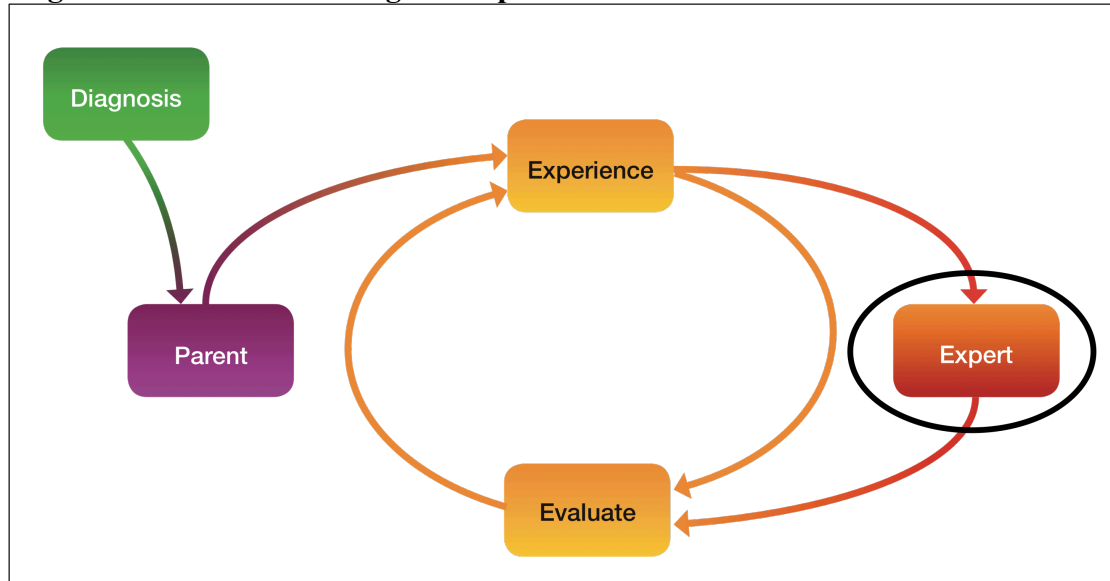
Stage 4. EXPERT: Becoming the Expert

Figure 4. Visual representation of the journey from parent to expert ('Expert' stage highlighted).

The final stage that emerged in this journey was the concept of the parent becoming the expert. The parents in this study identified that with time and experience, they trusted their own decision-making to the point that they felt that they understood the needs of their child better than any professional. With experience, Elka felt confident that she was able to identify her child's needs better than anyone else.

> Elka: So we're both understanding each other enough that's given me the confidence in our relationship that I can make the decisions for him, it's working, I think I know him better than anyone else, I think I know him better than any other therapist, and at the end of the day I think I know, I know what's best for him, over the top of everybody.

This is a vast change from the start of the journey, where parents felt as though they were unqualified to be making decisions, and that the decisions they were trying to make should be reserved for professionals. For the parents in this study who reached

this stage of the journey, they now perceived themselves as the experts. Debra reflected that she now felt that she understood her child's needs better than any therapist.

> Debra: I feel like I can pick now in therapists whether or not they know what they're talking about … a lot of therapists use very play based approaches and our last speech therapist we were paying a lot of money and Henry would go and it would be an hour of him playing with the same toy and obsessing over it for the whole session and I don't know, I just - I kind of feel like I know what works with Henry now and I know the best approaches to get results from him.

Though parents at this stage viewed themselves as the expert on their child, it was still difficult at times for parents to challenge allied health professionals. Nicola reflected that it took her some time before she was confident enough to challenge her son's therapists.

> Nicola: Being willing to make that stand as a parent, going this doesn't work. I know that you're a professional and I know that you know what you're talking about and I know that you've got many years of experience. But this is my son, and my gut tells me this isn't the way to go.

As represented in Figure 4, the change in self-perception by which parents viewed themselves as experts did not change the process by which parents continued to evaluate their experiences with interventions. Parents continued to observe their child's progress and used this to guide their decision-making. The other factors that influenced decision-making also did not appear to change. However, at the 'Expert' stage, the parents in this study started to construct and test their own theories based on their experiences. This progression was subtle, but reflected an overall development

in knowledge and confidence. The theories that parents developed applied not only to their own child, but to ASD in general.

> Debra: I feel like I understand about autism so much more than I did back then which I suppose is natural and obvious that that would happen, but you sort of feel so ignorant about how things work.

Parents at the expert stage developed theories on how children with ASD learn best and how they need to be taught. Elka shared her theory about teaching children with ASD to cope with change.

> Elka: These children to me in my eyes need to be pushed, it's, it's, I know not everybody likes to do it because they don't like being pushed, they're very stuck in their ways, they have routine, they like things being done a certain way, and Jackson does as well, and I like to throw things up a little bit, where routine does get thrown out the window a bit, and he doesn't really like it, but he's learnt to deal with it better every time we do it, so, sometimes it's like the saying 'you've got to be cruel to be kind' you know, and I think, so far I've learnt that with them.

Furthermore, parents' reflected on the position of children with ASD in society, and the assumptions underlying therapy programs. After years of experience with speech-language pathology, Nicola's perspective on communication, and the importance of verbal speech, changed.

> Nicola: All their Speech was focused on, was teaching them to talk. That, after a while, started to bother me. Because it was like well, why do they have to talk? Why is that so important? Society sees it as important. But why do we force these kids, who don't want to talk or can't talk or find talking difficult? Why are we forcing them to talk, when there's so many other options out

there? When they don't actually have to talk - they can communicate - which

is incredibly different to talking.

Some of the parents at this stage also developed strong opinions on early intervention,

based on their own experience. Debra reflected on her theory about the effectiveness

of early intervention.

Debra: So it does lead me to wonder whether these early interventions that

they all rave on about and that's why the Government has this FaHCSIA

funding because of the importance of early intervention, I wonder if it's

children that are milder on the spectrum and given the early intervention and

then they start working out, okay this is the way that life works and this is

what I need to do but kids like Henry that are, you know, non-verbal that have

a lot of the stimming sort of stuff and perhaps an intellectual disability….

At this stage in the journey, parents felt that they were in the position to share their

knowledge with other parents. Adriana reflected on becoming the expert in her

community when other families were about to embark on the same journey.

Adriana: I think I've, there's been others in the community now that have

come and I've been able to offer them suggestions in relation to the diagnostic

service, and I know one friend took her son there and got a diagnosis.

In summary, some of the parents in this study identified that with experience, their

self-perception developed to the point that they felt that they were the experts when it

came to their child. Parents at this stage of the journey had developed theories based

on their experience, and tested these theories based on their ongoing experience.

Parents at this stage however continued to evaluate their experience with intervention

programs. The shift in self-perception from parent to expert appeared to be linked to

how parents constructed meanings with regard to themselves, and their child with

ASD. For the parents in this study, the shift in self-perception appeared to take years, not months, which has implications for the level of support required by parents for an ongoing period post-diagnosis.

Summary

In this chapter, the results of the current study were presented. In examining how parents make decisions about which intervention approaches to access, a change in self-perception was identified following diagnosis, as parents transform from 'parent' to 'expert'. The factors influencing decision-making at each specific stage were discussed, as decision-making was found to change over time. For example, in the 'parent' stage, immediately post-diagnosis, parents prioritized the needs of their child above anything else, but with time and experience, parents started to recognize the importance of their own well being and the needs of the family, and this influenced their decision-making.

CHAPTER 6: RESULTS

Introduction

In this chapter, the results for research questions 2 and 3 are presented. These research questions, relating to what parents want from ASD therapists (Question 2), and the impact of the 'early intervention message' on parents of children with ASD (Question 3), build on the findings of Question 1. It was decided that these two specific topics warranted exploration in more detail given the strong influence on parental decision-making. Thematic analysis was undertaken on each data subset, and each set of results were written up for publication in peer-reviewed journals. At the time of thesis submission, both articles were under review. The complete articles are included as Appendices (see Appendix 6 and Appendix 7). However, the results sections from each of these articles have been included within this results chapter, given the pertinence of these results to the primary research question.

Question 2: What qualities do parents want in therapists working with children with ASD?

The findings related to this research question are presented within two central themes, *Partnership: I need you to give me more than blowing bubbles* and *Effective Therapy: Nobody wants to go to therapy and get nothing out of it*, which together summarize what parents of children with ASD want from therapists. Both themes are presented below, and the core categories within each theme are also examined. A visual representation of the results is provided in Figure 6.
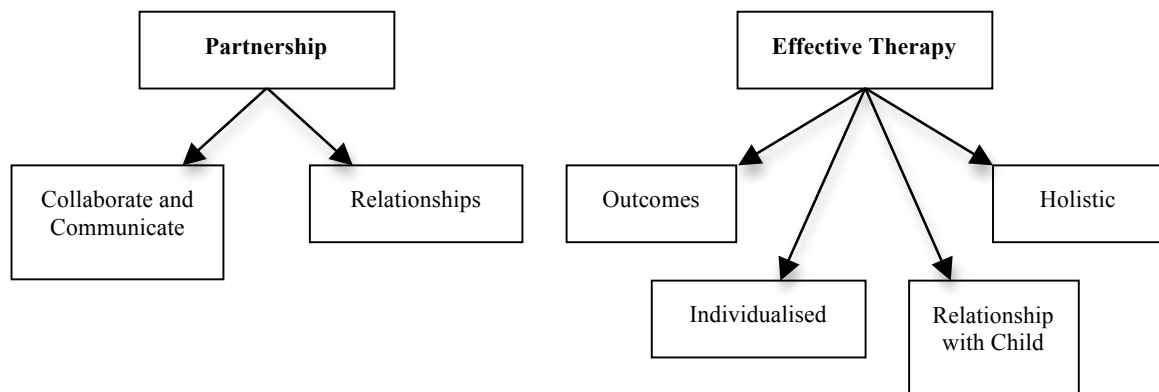
Figure 6. Model representing the themes and categories of the data

Theme #1 - Partnership: "I need you to give me more than blowing bubbles"

The first theme to emerge from the data was *Partnership*, in which participants described the need for therapists to provide more than just therapy in isolation. Rather, the participants in this study expressed the need for therapists to establish a relationship, and to work in collaboration with parents. Debra recounted her experience of working with therapists, and her desire for therapists to share information and work collaboratively with her.

> Debra: We've seen I don't know how many speech therapists, maybe about 12 and seriously if I have one more speech therapist that blows bubbles at Henry and taps her chest and says, 'More, you want more?', I'll just go, 'Okay, I need more!'. After four years I need you to give me more than blowing bubbles. And the same with OT. Put him on a trampoline, put him in a ball pit, put him in a hammock. Please tell me what you're doing, please tell me what the goals are, what are you working on? How is this helping? What do you see? Why is he doing that?

The belief that therapists need to provide more than just therapy emerged consistently from the data in this study, and the theme of *Partnership* evolved as a product of two core categories; '*Collaborate and Communicate*' and '*Relationships*'.

Collaborate and Communicate. The first core category, '*Collaborate and Communicate*', summarizes the need for therapists to work in collaboration with parents and communicate with parents throughout the therapeutic journey, in order to achieve the best outcomes for their children. The participants in this study spoke of their strong belief that therapy should be embarked upon as a joint enterprise, with therapists employing their knowledge and experience, and parents contributing their goals for therapy and knowledge of their child. Hannah recounted an interaction with her son's SLP in which therapy goals and processes were established collaboratively.

> Hannah: I did say to her, 'Look, I really want him to talk, it's really important for me that he starts talking, and starts communicating with me in that way', and so that's why, she then went on to suggest sign language, she went on to suggest flashcards, she went on to suggest that I take photos of everything ... it's great that she suggests these things, and using her experience and what she knows, she's the therapist, if she just lets me know what's next and what will get us to that goal, that's great.

A number of participants, including Alice, identified that it was important for therapists to be experienced, and in particular, to have experience working with children with ASD.

> Alice: I suppose, for me, you feel comfortable when they've had a lot of experience, when it seems like they really know their stuff.

However, though experience was considered important, several participants identified open and honest communication as being equally critical. Joanna spoke of the need for therapists to be honest about the scope of their knowledge.

> Joanna: I want someone who is honest, and that means honest if they're not sure. I actually want somebody to not pretend that they're an expert in a particular area if they're not an expert.

Joanna also identified the value of the information that parents are able to provide to assist with therapy planning and implementation, and expressed frustration that her input was often not considered.

> Joanna: I want someone to listen to me, because for six years, … we've been with him day and night, and we've got information that can help.

Other participants had encountered the other extreme, whereby therapists would seek information but would not reciprocate in providing information, as described by Fiona.

> Fiona: I want lots of information. I want lots of information about what they're doing, why they're doing it and how can I see that it's working? … If it's not working, it's not working. That's okay. But talk to me about well then, what does that mean? Should we keep seeing you? … I want an action plan … I want that, and it's really hard. I find that really hard. I find they want lots of information from you but they're loathe to give you information.

Therapists working collaboratively and communicating openly was firmly established as important by the participants in this study. Moreover, Nicola argued that a collaborative dynamic is not established spontaneously, and that it the responsibility of therapists to facilitate this collaboration.

Nicola: I think parents need to - it's important that they are encouraged to have a voice, and that therapists don't take it personally, 'I don't think this is working, or can we do it this way?' ... And therapists encouraging parents to actually do that. Which then empowers the parents to actually feel like they can actually do something with these kids, that they may feel like have no hope.

Relationships.   The second core category within the theme '*Partnership*' is the concept of '*Relationships*'. The participants in this study identified the importance of a relationship between parents and therapists being established, and a number of factors that they felt contributed to this. Fiona felt that therapists being willing to make a long-term commitment to working with her child was important in allowing the parent-therapist relationship to develop.

Fiona: I want someone who's going to take a long term view … I want to be able to envisage them working with my son for as long as they need to, to reach whatever goals they think they can reach with him … I want to feel like we've got a relationship with them.

One factor that emerged on a number of occasions as contributing to building relationships between therapists and parents was the concept of therapists going *above and beyond*. Ellen recounted the story of the support that a SLP provided to her and her husband after receiving their son's initial diagnosis of ASD.

Ellen: (The SLP) after that first meeting said, 'Look, what evening are you and your husband free? I'm always very concerned for parents that - at this stage they have no support and they don't really know what's happening next, I'll come round for an evening and I will just tell you everything I know and

you ask me questions.' So she was an absolute lifeline. … It meant we've got a very good relationship with (her).

Similarly, Hannah viewed the advice that her son's SLP had provided regarding an occasional care centre as going above and beyond her role as a SLP, but an act that had strengthened her relationship with the SLP.

> Hannah: I don't think she had to give me that much information, I really don't. I think really I mean her role is to just assist the speech therapy, but I think it was really handy of her and it was really good of her to give me that advice, because it then made me, really, I don't know, cement the relationship with her I guess in a way.

Another factor identified by participants as contributing to strengthening the relationships between parents and therapists was the concept of *shared values*. Participants reflected that they were better able to work with therapists when they shared like perspectives regarding child development and behaviour management approaches. Michelle recounted her experience of finding a psychologist who shared her philosophy about behaviour management for her sons with ASD.

> Michelle: She was more on my train of thought as in how to bring them up. Because there's me thinking, I don't know, should I take the stars off? This person said I shouldn't. I think you should. So at least she's telling me what I think anyway, she's just backing me up, which is a good thing for me to hear that I am doing the right thing.

In contrast, Fiona experienced a conflict of values when working with her son's psychologist, which impacted on her ability to establish a therapeutic relationship.

Fiona: I thought she was really inappropriate. I thought that the things that she was suggesting that we do around managing our son's behaviour, I would call abusive.

The participants also identified that emotional support offered by therapists was important, not only in terms of establishing and maintaining relationships with therapists, but for their own well-being, as described by Sophie.

Sophie: Just the fact they got a little personal sometimes as well, like I remember ringing one of the girls who diagnosed him the next day and she was really nice. She said you know, 'you're upset and maybe you could speak to a psychologist'. Like you know they didn't sort of hesitate to comfort you, and I thought that was a nice thing. Because it's not just about therapy for Andrew. You know, it's about us being mentally able to do it ourselves.

In summary, the participants in this study identified the importance of therapists working in collaboration with families and establishing a therapeutic relationship with parents, in order for the best outcomes for their children to be achieved.

Theme #2: "Effective Therapy: Nobody wants to go to therapy and get nothing out of it"

The second theme that emerged from the data within this study was the concept of *Effective Therapy*. The participants in this study reported that ultimately they want therapists who will deliver effective therapy, and identified factors that they felt needed to be present in order for this to happen. Elka summarized this sentiment, asserting that her measure of a therapist is based on the outcomes of therapy that they deliver.

Elka: What I'm paying for you to do is get the most out of this therapy session, and if you're going to get the most out of it, I don't really care how you are and how you're doing, keep doing it. That's definitely would be my thoughts, absolutely. Nobody wants to go to therapy and get nothing out of it, and think the lady's nice or you know, my kid likes them, you know he's not learning anything and he's not being pushed.

The theme *Effective Therapy* is composed of four core categories; *Outcomes, Holistic Approach, Individualized Therapy* and *Relationship with Child*. Each of these four categories is explored in more detail below.

Outcomes. The first core category, *Outcomes*, was central to the concept of *Effective Therapy*. The participants in this study felt strongly that the central role of a therapist was to provide therapy that produces positive outcomes. Debra stated that she was willing to persist with a therapist because the therapist was able to produce results for her child.

Debra: Now I've got an ABA/VB therapist working with him, getting him to say 'yes' and 'no' and 'I want' and things that we can use around the house and she is making amazing differences with Henry. She's a pain in the neck to deal with….but she's just the best therapist that we've ever had and she's getting the results.

Similarly, Elka felt that though parents may not initially connect with a therapist, if the therapist is able to prove him or herself by producing outcomes for their child, parents might change their opinion.

Elka: People can only see what sort of speech therapist they like or don't like, and I think it all comes down to whether it's working with your child, to

whether you like them or not, you know what I mean? So you might not like

them at first, but then you think, 'Hang on a second, this, wow, oh, I like it'.

The participants in this study reported that they wanted therapists to have high

expectations and to persist in achieving outcomes with their children, as described by

Adriana

Adriana: I suppose if they can pick up on the cues of the child, um, and not

you know just give up, because sometimes you know, these kids don't want a

bar of them, but if they can still keep trying a little bit, not just give up.

Holistic Approach.   Though the participants in this study considered producing

outcomes as an important measure of whether therapy was effective, there were

additional factors that participants perceived as important in contributing to effective

therapy. The first of these factors was a holistic approach to therapy. The parents

spoke of the need for therapists to consider the overall needs of their child. Fiona

recounted a story of when her son had a meltdown during an occupational therapy

group, and her disappointment that the therapist did not acknowledge her son's

behaviour, but rather focused only on his fine motor skills.

Fiona: How can you support him with his pencil grip if you're not addressing

the fact that his pencil grip is so weak that he becomes so distressed by it that

he's ruining the room? How can you ignore that and still keep talking about

his muscles in his fingers?…You're only looking at a tenth of the picture, to

me. You're not looking at that big picture.

Additionally, the participants in this study wanted therapists to consider their children

in a broader context than just therapy sessions. Joanna reported feeling frustrated

when a psychologist failed to acknowledge that her son's behaviour in a therapy

session might not be an accurate representation of the behaviour she was dealing with at home.

> Joanna: She was really nice, but then, when met with Nicholas, (she was) going, 'This is fine'. You're left going, but hang on a second, you're giving him one-on-one attention. Yeah, it's fine. If I could do that for my life and if he could have everybody in his life give him one-on-one attention doing exactly what he wants, I would be (fine) too.

Individualised Therapy. The participants in this study also perceived the need for therapy to be individualized in order for it to be effective. The participants, including Hannah, felt that it was important for therapists to understand the specific needs of their child, and to tailor their therapy approach to suit their child's needs.

> Hannah: That they understand my child, that's huge for me, that they understand Jacob. And they're willing to work with Jacob at the pace that he's at and the way that he is. That for me is really, really important. And not that Jacob's just another number, or just another client.

Likewise, Joanna asserted that she wanted therapists to provide therapy addressing her child's specific needs.

> Joanna: I want someone to actually address him, look at him and don't assume that he needs social skills training because he's on the spectrum… It just makes no sense to me, because people who are professionals surely need to know that one thing that you know about autism is that kids are all different. So, for me, I just want somebody to address his issues.

Relationship with Child. Finally, the participants in this study reported that it was important their child liked and had a relationship with their therapists, as described by Hannah.

Hannah: I'd like them to be able to have that sort of bond I suppose with them, that they're a therapist and client, but yeah, I just like to see that bond as well. That they are working, and it's working for Jacob.

In Sophie's experience, when her son didn't have a good relationship with his therapist, this made it difficult to continue with a therapy program.

Sophie: Sometimes Andrew just doesn't like someone. If their voice is too loud or - so that kind of slants how you feel about them. We did have one person…he didn't like and that was always a trial.

Overall, all the participants in this study maintained that achieving positive outcomes for their children was the most important quality that they wanted in therapists. However, the participants also recognized that there are qualities that facilitate these outcomes being achieved. The implications of these findings will be discussed within Chapter 8.

Question 3: What is the impact of the 'early intervention' message on parents of children with ASD?

The findings of this research question resulted in the construction of three central themes relating to the impact of the early intervention message on parents. The first theme, "Initial Perceptions of Early Intervention" details parental perceptions of early intervention following their child's ASD diagnosis. The second theme, "Consequences of the Early Intervention Message" relates to the pressure that parents feel with regard to early intervention, and how this can influence parental decision-making. The final theme, "Life After Early Intervention", explains how parental perceptions of early intervention change over time, as do their needs from service providers. Figure 7 provides a visual representation of the central themes.
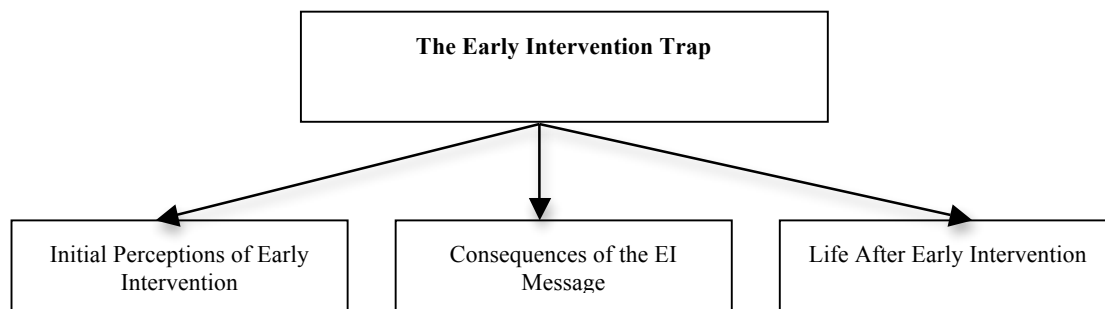
Figure 7. Visual representation of central themes

Theme #1: Initial Perceptions of Early Intervention: "Everyone was Just Saying It All the Time"

All the participants within this study reported that they were aware of the importance of early intervention, indicating that the early intervention message had well and truly been communicated to the participants in this research. Parents in this study reported that numerous medical and allied health professionals repeatedly had emphasized the importance of early intervention.

> Sophie: Everyone was just saying it all the time, every therapist, you know, 'Early intervention, early intervention.'

Moreover, the parents interviewed had developed an understanding of why early intervention is important, stating that early intervention can change the outcomes for children with ASD. Michelle, the mother of three children with ASD, reported that though there are differences in the abilities of her children, the impact of early intervention could not be underestimated.

> Michelle: I recognize they're all very different, but also that you can certainly make a big difference of early intervention and just having belief.

Nicola, who also had three children on the autism spectrum, reflected on her own perception that early intervention would be able to influence the future outcomes for

her children, and that wanting to know that her children would be okay in the future had been a motivating factor in implementing early intervention programs.

> Nicola: Yeah, especially at an early age. You think, 'I should get it all done now ready for the future.'

These parents' constructions of the importance of early intervention were somewhat influenced by their own perceptions of the cause and course of ASD. Several participants reported the importance of early intervention due to neural plasticity in the early years.

> Sophie: I think it's really important while their brain is forming.

Alternatively, Deepak held the strong belief that the MMR (measles/mumps/rubella) vaccination had caused his child's ASD. He believed that biomedical interventions would be able to cure his child but that early intervention would only be effective up until the age of seven.

> Deepak: The theory say [sic] that the curing period is up to seven years old.

While not every parent in this study believed that early intervention would be able to cure their child, the perception that ASD interventions needed to be implemented as early as possible was common amongst the participants in this research.

> Hannah: Because the younger they are that we start, the better it is. That's what they keep telling me. So it's great that we got in really, really early. And so you can't waste time, you've just gotta do it.

Many families in this study also reported that in order for early intervention to be effective, a high intensity therapy program was critical. In the case of one participant, information communicated through mainstream media about early intervention contributed to the development of this perspective.

Debra: Just I guess the idea in the media that the more therapy a child gets the better he will be, and the earlier you do it the better off, so I was motivated by doing as much as we could and as early as we could.

Though the parents in this study had developed an acute awareness of the importance of early intervention, at the same time, parents reported feeling the pressure of early intervention.

Joanna: One of the things that's really difficult…because there's the belief now that if you have early intervention, it can make such a huge difference… I'm constantly thinking, 'But they say that if you get it right, you can make such a huge difference to his life. What if I get it wrong?'

This gives rise to the second theme of this study; the consequences of the early intervention message.

Theme #2. Consequences of the EI Message: "The Window of Opportunity"

The promise of early intervention improving the outcomes for children with ASD certainly offered hope to families in this study, especially immediately post-diagnosis, as recounted by Debra.

Debra: People said, "He's so young"…I think he was about 20, 22 months when he was diagnosed. You know, "You're lucky that you've got it so young" and "You can get fantastic early intervention" and so I guess I was just thinking, "Well, we'll get the intervention and it's all going to be all right."

It is possible however that emphasizing the importance of early intervention for children with ASD inadvertently conveyed another message to parents that participated in this study; that the stakes are high, and the consequences of a wrong decision can be critical.

David: You're kind of very conscious at times … he's young, his mind's developing, you want to get it right, you don't want to start on the wrong track and then have to do something else. So that does put pressure on you and does put pressure on us, you know.

The pressure that the parents in this study reported to feel to make the right decision was immense, and though they appreciated the opportunity to access intervention services, some parents feared the consequences of making the wrong decision.

Russell: It can be very stressful. It's not like we're not grateful for all the services and the funding. It's fantastic that he's got access to help him with some of these things. But along with that comes a lot of baggage.

Though the parents in this study reported feeling significant pressure to make the right decisions with regard to selecting ASD interventions, they also did not want to be uninformed when it came to the importance of early intervention. Rather, the participants requested increased professional support when making such important decisions.

Joanna: I think that it's important that we know that. I'm not saying, don't tell parents that it's important, but to say how important it is, and then to be left with this.

Parents in this study reported that as a result of the pressure of early intervention, their decision-making was influenced. A sense of urgency overlaid parental decision-making regarding interventions for the families that participated in this study. Many of the parents in this study reported that they were unwilling to wait for services, given that they believed that intervention needed to be implemented as early as possible in order for it to be effective. To this end, some parents selected intervention programs based purely on availability.

Adriana: Well, you've given me this diagnosis, it's all about early intervention, and now you're telling me I'm going to have to wait 12 months? What's going on? That was a bit stressful. So my experience was basically the first one who rang back to say, "Look, I can fit you in", and it was within a week…and that's pretty much, we just went there because she could fit us in.

Debra reported that she felt she had no time to research the different intervention options, given the perceived need that intervention had to be implemented as soon as possible.

Debra: I think it would have been better if we'd just took two, three, four months to absorb the diagnosis and do all the research and try and be a bit calmer and a bit more strategic and systematic about the way that we approached things and kind of set out a bit of a plan. There was never a plan.

Other participants had similar experiences, where their decision-making regarding which interventions to access was influenced by the perceived need to have intensive therapy, as opposed to just accessing therapy to address their children's specific needs.

Sophie: You do think you've got to have all these appointments all week, you know, early intervention. So it is a bit of a trap like that.

Furthermore, the pressure these participants reported to make the most of the early intervention window of opportunity meant that they were unwilling to wait for outcomes from therapy programs. Many of the parents in this study reported that they preferred to frequently change therapists and intervention programs, rather than risk wasting time on therapy they perceived to be ineffective.

Nicola: We're going to spend six months, and if they haven't got it after six months, well maybe we'll change. Six months is an incredibly long time to spend on something that may not actually work.

Parents in this study reported that there could be another unintended consequence of the early intervention message if early intervention does not achieve the promised outcomes. As established, the parents that participated in this research strongly believed that early intervention could change the outcomes for their children and they felt pressure to make the right decisions in order to achieve these outcomes. Consequently, if children did not make the gains that parents were expecting, there was the potential for these parents to take the blame for a perceived lack of early intervention outcomes.

Debra: I still feel like we've failed Henry. I still feel like we didn't - we didn't do enough.

This sense of failure is perhaps another unintended consequence that could be occurring as a result of parents feeling the pressure of early intervention. It also gives rise to the final theme of this study; life after early intervention.

Theme #3. Life After Early Intervention: "What happens once the early intervention is finished?"

Although some parents in this study reported feelings of guilt when early intervention programs did not achieve the desired outcome, other parents reflected that with time and in retrospect, their perspective on early intervention had changed. With increasing acceptance of their child's ASD diagnosis, parents felt the pressure to undertake intensive early intervention reduce.

Sophie: After a while we could see that, when you finally accept it's a lifelong problem, I think that's when you calm down a bit.

Over time, some of the parents in this study developed more realistic expectations about the outcomes that could be achieved from early intervention.

Nicola: But early intervention really is designed to make these kids more normal. Is there a way of early intervention, of being able to be just as impacting, without the focus being making them more normal? Because the reality is they're on the autism spectrum. They're never going to be normal.

Although the parents in this study had well and truly been made aware of the importance of early intervention, they generally had no expectations of or hope for therapy beyond the early years. In some cases, parents were surprised to find that therapies implemented once their children were older were more effective than early intervention programs had been.

Debra: I feel like everybody talks about early intervention but I don't even know that the money we spent with therapies that we did in those early days helped Henry. I think it was almost too early. Now his speech is starting to develop, now the therapy is starting to have effects. ... It's like they have to get to a point where they are starting to get a little bit of language and they are starting to kind of work things out a little bit. So then you kind of can build on that.

The parents in this study recognized that the developmental age of the child had the ability to influence the effectiveness of therapy programs, and that the child's readiness and ability to participate in therapy developed with time.

Elka: Early intervention is great, but I believe that if that then was done between the ages of 5 to 8, you'd get so much more out of it then you would

of between the age of 4 to 7 … because I'm getting more from him now, then what I was then. He was prepared to listen, he was prepared to learn, he can sit down and look at you, he gives you complete eye contact now, he wasn't giving you anything back then.

This sentiment reflects the need to explore whether services should develop a broader primary focus than just early intervention. Though the parents that participated in this study came to discover that there was hope for life beyond early intervention, they felt that services did not reflect this. Parents reported that the networks of support that were available during the early intervention stage were not accessible once their children started school.

Sophie: I must say that's the thing that when Andrew went school, like I now feel completely alone. Like there's nobody you can talk to. … I kind of wish they would give a little bit more support for kids at school.

In prioritizing early intervention services, the belief that early intervention is the only hope for children with ASD, though misguided, could be inadvertently reinforced. The parents in this study believed that services needed to change to reflect that there is life and hope beyond early intervention, with one parent commenting

Debra: I would like more awareness about … what happens to the children after all the money has run out and once they get to school and once the early intervention is finished?

In summary, the participants in this study identified the importance of early intervention, however this did influence their decision-making with regard to which interventions to implement with their children with ASD. Parents felt pressure to make the right decision and requested increased supports beyond the early

intervention period. The implications of these findings will be discussed further within Chapter 8.

Summary

The findings related to Question 2 indicated that parents value the opportunity to work in collaboration with their child's therapists, but their priority is for therapists to produce positive outcomes for their child. This is in line with the results from Question 1, in which it was found that parents evaluate their child's progress in order to inform their decision-making. The findings of this study indicated that parental decision-making is also influenced by the 'early intervention message', as described in the results for Question 3. Parents acknowledged the importance of early intervention, and reflected on the pressure that this adds to decision-making. Once again, the impact of the early intervention message reflected the shift in the journey over time, as parents reflected that with time, they acknowledged that there is life beyond early intervention, and the need for increased awareness and services beyond the early years.

CHAPTER 7: RESULTS

Introduction

In discussing their experiences with support services, the participants in this study shared their perspectives regarding the ideal model of professional support[4] for decision-making. Thus, in order to present the results for Questions 4 and 5, themes relating to the ideal model professional support that parents' identified for decision-making will first be discussed. This framework will then be used to explain the results relating to parents' perceptions of current support for decision-making, and how parents believe services could be improved.

Parents' Perspectives on the Ideal Model Professional Support: A Model of Collaborative Decision-Making

The participants in this study described the complex nature of decision-making. It was often the case that parents in this study felt unqualified to be making decisions relating to ASD interventions, and yet simultaneously felt that they knew their child better than any professional. In discussing the process of making decisions for their child with ASD, married couple Ellen and David summarized the complexities of parents acting as decision-makers.

> Ellen: The people who are most stressed for time, most emotionally stressed, and have the least experience of dealing with autism are the ones making the decisions on what therapy to use, which is crazy.
>
> David: But they do know their kids the best.
>
> Ellen: But they know their kids the best.

[4] Within the context of this study, professional support refers to specific support for decision-making where it is the role of the professional to support the family and their decision-making (including but not limited to Autism advisors)

The tension between these two positions reflects the complexities of parental decision-making. Professional support for decision-making must utilize parents' existing skills and knowledge, while still providing adequate resources and support to ease the burden of decision-making. The participants asserted that both professionals and parents needed to contribute to decision-making in order for this to occur. Consequently, data analysis resulted in the construction of two themes relating to parents' perspectives on support for decision-making; the role of the professional and the role of the parent. Combined, these themes form a model of collaborative decision-making, which represents the ideal model of practice according to the participants in this study. Each of the themes will be discussed below, and the core categories within each theme will be addressed. Figure 8 provides a visual representation of the model of collaborative decision-making.
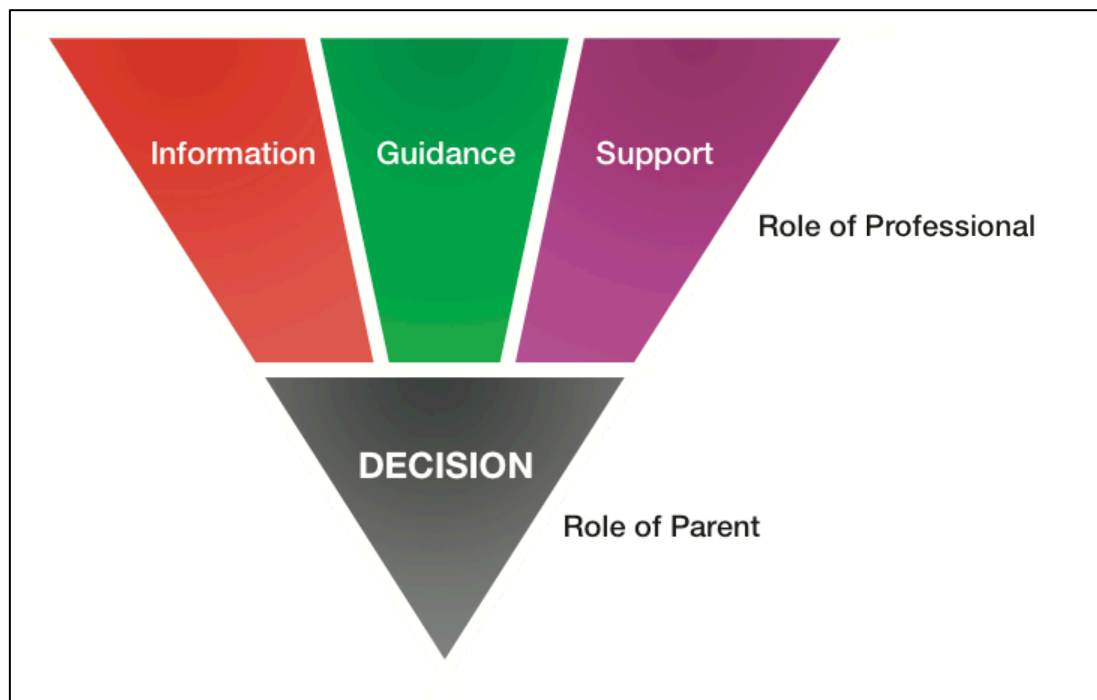

Figure 8. Collaborative model of decision-making.

Theme #1: Role of the Professional

The first theme related to collaborative decision-making was the role of the professional. The participants in this study detailed their expectations of professionals and the role of professionals in contributing to the collaborative decision-making process. Three categories emerged from the data with regards to the role of the professional: information, guidance and support. Each core category will be examined in further detail.

      Information. The first core category related to the provision of information by professionals to parents. The participants within this study suggested that professionals should provide introductory information about the range of interventions available for children with ASD. In the initial period post-diagnosis, the participants in this study were trying to gain an understanding of ASD, while still coming to terms with their child's ASD diagnosis. As such, parents in this study felt that professionals should provide information to allow parents to develop their understanding of ASD, which in turn would support them to make informed decisions.

      Sophie: It would be good if there was someone who could give a big overview or something.

The participants in this study also asserted that professionals should provide information directly to parents, rather than leaving parents to search for information themselves. Michelle, the mother of three children with ASD, reflected that the care needs of children with ASD were so significant that she did not have time to seek out information on her own.

      Michelle: That's what I need, somebody to tell me, not to say, you go away and find it yourself. I don't know, I'm struggling enough with looking after

him on the day-to-day basis. I don't know what I'm supposed to do with him.

Nicola, who also had three children on the autism spectrum, felt that the information provided by professionals should encompass both the types of interventions available and information relating to where and how these interventions could be accessed.

> Nicola: It would've been nice from the advisory role to be, you know, these are the therapies that are available locally. This is where you can find information on these therapies. These are the places that therapies are available. These are even reviews from other parents. This is the successes that other parents have had. These are alternative options. These are interstate options, if that's the way you choose to go. These are - this is the whole huge array of things that are available

Furthermore, the participants in this study requested that information provided should be relevant and specific to needs of their child. This is understandable, given that it has been established that for the participants in this study, their decision-making was strongly influenced by what they perceive the needs of their child to be. Fiona identified that she wanted professionals to support her to make links between the therapies available and the specific needs of her child.

> Fiona: I think it would be good if parents had someone to say okay, there's this thing called OT. Some people use it, some people don't. Here's what it is and here's what you might expect from an OT. Here's what an OT might think they can deliver for your child. Same with psychologists. To actually sit down and say okay, here are the recommendations that were made at the point of assessment, so let's talk through what they are.

As touched on by Fiona, the participants in this study felt that while the provision of

information was important, information alone was not enough. Participants identified the need for professionals to provide specific guidance with regards to decision-making, which gives rise to the second core category within the role of the professional.

Guidance. Within this study, the term guidance was used by the participants to refer to the provision of specific recommendations regarding ASD interventions and being given direction about which interventions to implement. A number of participants in this study asserted that professionals should provide specific guidance regarding which interventions would be appropriate in meeting the needs of their child.

> Joanna: But for me, the main thing is having somebody not give me information about what an OT does or what a speech path does, or a psych does, someone who says, I'm now looking at your child and I'm listening to what you're telling me about your child. This is where I think you should go.

Similarly, Nicola felt that the role of the professional should include providing guidance relating not only to intervention approaches that would meet the child's needs, but also service providers that could provide this intervention.

> Nicola: But okay, let's work out your child's profile. So let's do this. Let's work out the child's profile, work out what they need, and then you work out where you want to go to get that.

While the parents in this study understood that there are limitations in terms of the level of specific guidance that professionals are able to provide, they maintained it is essential for professionals to provide guidance for decision-making.

> Ellen: I just wish somebody, some professional, would say, in my opinion,

this would be a good thing for you to look at.

The parents in this study identified that guidance needs to extend beyond just choosing intervention approaches. Particularly in the time immediately post-diagnosis, participants identified the need for professionals to provide guidance more broadly about how decision-making should be approached.

> Debra: I just think more guidance in the early days about just breathe, just take a bit of time to just come to terms with this and what therapies are out there and let's have a bit more of a systematic approach to how we do it and more of a plan instead of being left up to the families to try and muddle their way through it.

Support. The final core category relating to the role of the professional as identified by participants in this study was support. Participants reported that especially in the initial stages, navigating the disability system and accessing services can be a daunting process. Consequently, participants identified the need for professionals to assist parents to navigate the system and minimise the time and effort required to access services. In Ellen's experience, the disability system was difficult to navigate, and consequently, she felt that the role of the professional should be to support parents through this process.

> Ellen: So putting someone in who could deal with all those issues - and what the family needs is their headspace freeing up to spend time with their child and pick the right therapy, not wading through, 'Well, I've got six different options for funding this', and 'Oh, I'm going to have to wait and get the info line to ring me back and wait until this workshop for behaviour'.

A number of other parents in this study also felt that professionals should provide clarity regarding the process of accessing funding and services post-diagnosis, so that

parents are not wasting time trying to understand processes and procedures, which are often not straightforward.

> Alice: Yeah, I think if there was a process, that there is a diagnosis, you can go see (the autism service) or here, or here, or here, or here and at least spell out the type of therapies that are available.

In addition to procedural support, the participants in this study also raised the need for professionals to provide emotional support to families following their child's ASD diagnosis. The parents in this study were able to reflect on the grief and loss they had experienced, particularly in the initial period post-diagnosis, and therefore saw the need for professionals to offer emotional support to families during this time.

> Ellen: Someone who could just listen to families, because you know, families having a lot of grief and upset, you could reassure them.

Furthermore, the parents in this study recognized that the role of the professional should encompass the provision of ongoing support, in order to assist families to accept and move forward following their child's ASD diagnosis. Nicola asserted that it is essential for professionals to provide emotional support for families and help them to come to terms with their child's ASD diagnosis.

> Nicola: But I think it's important if the autism advisor's role could also be included in that - of helping the parents come to terms with the diagnosis, because it's incredibly difficult to come to terms with that. Having to let go of your dreams that you had for your child, having to let go of them and perhaps just see things differently.

Thus, as identified by the participants in this study, it is critically important that parents are provided with emotional support post-diagnosis, in addition to being provided with information, guidance and support with processes.

Theme #2: Role of the Parent

The second theme that emerged from the data related to the role of the parent. While the participants in this study considered that professionals need to have a broadly ranging role in supporting decision-making, the role of the parent was considered to be much more specific. Within their ideal model of practice, the participants in this study proposed that the role of the parent should be to evaluate the information and guidance provided by professionals based on their own knowledge and experience, and then to make the final decision with regard to which intervention approach to access. At the heart of this model is the underlying principle that decision-making is collaborative, with professionals facilitating the decision-making for parents. Russell, the father of a child with ASD, felt that professionals should provide specific recommendations and guidance about intervention approaches, which would facilitate him and his wife to make the final decisions with regard to which interventions to actually implement.

> Russell: They can make recommendations that we can take or not take. I think that would have helped. But the decision would still be up to us, whether we think that's the right way to go.

Joanna, wife to Russell, expanded on this further, asserting that professionals can offer a level of expertise with regard to intervention services that should inform parental decision-making.

> Joanna: I would have liked somebody who was qualified or had more knowledge than I do about all of the different services and actually spent some time with Nicholas, and said, for him, this is what my view is. You make a decision.

A number of participants commented on the weight of responsibility in making

decisions regarding intervention approaches. Thus in proposing their ideal model of practice, the parents in this study argued the role of the parent should not be all-encompassing, and the responsibility for decision-making should not solely rest with parents. Debra, the mother of a school-aged child with ASD, reflected on the immense pressure she felt to make the right decisions with regards to interventions for her son.

> Debra: Having the responsibility is - I mean obviously he is my child and he is my responsibility, but you don't get another chance and the pressure of the window of opportunity and time slipping away, it's just awful to have that on your shoulders.

In spite of the significant demands associated with deciding which interventions to implement with their children though, the participants in this study did not want this decision-making role to be taken away. Rather, participants asserted that parental decision-making needed to be better supported through collaboration with professionals. Hannah, the mother of a son with ASD, maintained that she wanted to make the final decisions when it came to intervention programs for her child.

> Hannah: I think it's good that it's left up to us to do that. It just would have been nice if we had more guidance.

The parents in this study felt that although they do not have the same level of expertise that professionals are able to provide, they do have an intimate knowledge of their own children. With time, the parents in this study felt increasingly confident in trusting their own knowledge, however still maintained the need for professionals to offer information, guidance and support in decision-making. Elka, whose son was almost 5 years post-diagnosis, felt confident in being able to make decisions for her child, in consultation with professionals.

Elka: I think I know him better than anyone else, I think I know him better than any other therapist, and at the end of the day I think I know, I know what's best for him, over the top of everybody, but I would always take somebody's advice. Like it's not that I would reject it or whatever, sometimes I'll do it, and other times I won't. It just depends on the circumstances.

The need for parents and professionals to work collaboratively is at the centre of the ideal model of practice for decision-making as described by the participants in this study. However, parents' perceptions of the current supports available for decision-making are not necessarily in line with this model.

Question 4: How do parents perceive supports available for decision-making?

The participants in this study were able to identify the ideal model of practice with regards to decision-making. Within this model, professionals provided support in a number of domains, and facilitated parents in making the final decisions regarding which interventions to implement with their children. In reality, the participants in this study felt that on the whole, the supports available for decision-making did not meet their expectations. The participants in this study reported that rather than collaborative decision-making, they felt almost solely responsible for decision-making with limited professional support offered. Many of the parents in this study sympathized with the support professionals and understood the limitations of funding models. However, this did not reduce the frustration that some participants felt with regard to the professional support that was available. Debra summarized her perceptions of the current professional support available for decision-making.

Debra: So just basically a lack of support and guidance and advice throughout the whole process, not just in terms of the therapies that are available and the

therapies that you should try but also the administration and the paperwork and the funding, and all of that I think can definitely be improved so people are not running around all over the place and also trying to cope with their own emotional feelings.

Rather than a collaborative model of decision-making, data analysis relating to parents' perceptions of the supports available for decision-making resulted in the construction of a model entitled 'Parents as Sole Decision-Makers'. The core categories and themes were consistent across the two models, however how these were arranged was different. Figure 9 provides a visual representation of the model 'Parents as Sole Decision-Makers'.
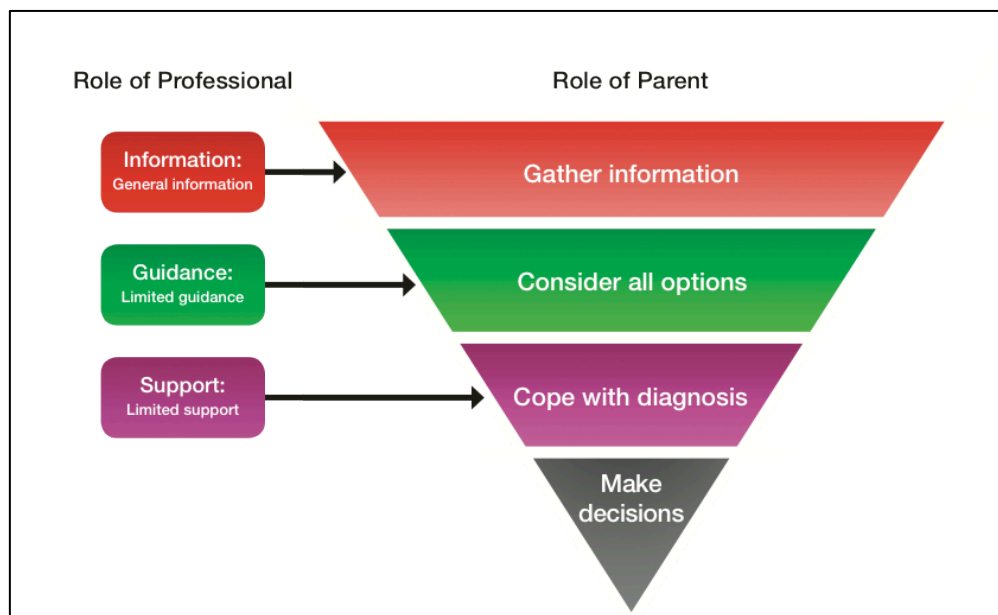

Figure 9. Model representing 'Parents as Sole Decision-Makers'.

As is evident, within this model, professionals provided a limited level of support, leaving the participants in this study to gather additional information, and make decisions with no guidance and limited support. Each of the core categories will be

examined in further detail below, and the influence of professional support on the role of the parent within each category will be discussed.

Information. The participants in this study had mixed perspectives about the information that was provided by support professionals post-diagnosis. The majority of participants were provided with general information about the scope of funding and the types of therapy available.

> Sophie: They were pretty good at explaining what we could get and what we could do.

However, parents identified that there were limitations in the information that was provided and the way in which it was communicated. For many of the participants in this study, they received information regarding the various interventions and service providers during a meeting with a support professional. For Adriana, who had traveled from a regional location to attend this meeting, the process was overwhelming, which therefore limited her ability to take on the information.

> Adriana: I remember the day, because I had my daughter who was just a baby screaming her head off, and I was just bombarded with all this information and I sort of couldn't get out of there quick enough.

During this meeting or soon after, the participants in this study reported that they were provided with a booklet, which listed the eligible services and therapists using the HCWA funding. Though this booklet was useful in providing general information about the services available, the participants in this study asserted that more specific information needed to be provided. As a result, parents were left to gather information about the types of therapies available, to determine whether the therapies would be beneficial for their children. For Ellen, there was a delay in receiving this

general information, and even after being provided with the booklet, found she had to do further research on her own about the types of therapies available.

> Ellen: I said, please can I have a list of what therapies are available in Adelaide? They go, oh no, we haven't got one, we're working on it. It's like, well, the first thing I need to know is, what actually is there on my doorstep? … Then subsequently I got that booklet and I go, well that's really what I'd asked for. But the booklet doesn't tell me what those therapies are…really it's just a shortcut to going through the phone book. I didn't really find it hugely helpful.

Similarly, Joanna reported the information provided in the booklet did not necessarily provide an accurate representation of the service that would be received, resulting in parents having to undertake further research regarding the service providers and their level of experience.

> Joanna: Like we were saying to the autism advisor, 'How do I know that the people that we're going to be dealing with are experienced and qualified?' It's like, 'They can't be in the book unless they are'. But those people that are in the book, they then hire other people, and so you're dealing with people who I don't know what type of experience they have or anything, so you're trying to find out.

A number of the parents in this study felt that meeting with a support professional, and the provision of written information, represented the point at which the responsibility for decision-making was handed over to the parents, rather than feeling that decision-making would be pursued collaboratively. Fiona shared that following her meeting with the support professional, she had a realization that the responsibility for contacting service providers and gathering further information was now hers.

Fiona: Then when they came to talk to us and went through their spiel about what they do, we got the okay, now it's actually our job to do that.

Likewise, when asked how she felt about the support provided following her son's diagnosis, Debra reported that the process of being provided with information did not ease her anxiety, and left her feeling solely responsible for navigating the disability system and deciding which services to access for her son.

Debra: Very confused and overwhelmed and kind of a bit like, 'Well, here's your diagnosis, now go on your way and best of luck to you'. So no real support as to what to do next…and then I remember (an ASD service) contacting me and calling us in there and we went in and had a meeting with them and it was just awful. I didn't find them helpful at all. It was, 'Here's a bunch of reading material and basically go and work out what you need to do'.

For most of the participants in this study, the information that was provided during the initial meeting was inadequate to inform their decision-making. Furthermore, some participants felt that they were abandoned and left to navigate the processes without any guidance, which gives rise to the second core category.

Guidance. Overwhelmingly, the participants in this study reported that there was a lack of guidance from professional support services when it came to decision-making, and this was their biggest concern with the current support services. Particularly in the initial stages post-diagnosis, parents were not feeling confident in their own decision-making, given that they generally had limited to no experience with the disability system. This led Adriana to question the decisions she was making.

Adriana: I do remember thinking, you know, "Am I doing the right thing?" You've got this list of providers but how do I know what's right? You just, really, there was no real guidance, which was frustrating.

For the participants in this study, the lack of guidance at the time of decision-making impacted on the level of confidence they had in their decision-making. When the parents in this study made decisions without any guidance, their confidence in the process was undermined, especially when they were already feeling unqualified to make these decisions. Though Fiona understood why support professionals couldn't offer specific guidance to parents, she felt uncomfortable with having to pick therapists with no prior knowledge about the services.

Fiona: They didn't point us to anywhere in particular, which we were sort of - we understood that they couldn't, but we were sort of wanting that. It just felt overwhelming to have to basically pick a name out of a book, because that's all you've got. It's a name, it means nothing to you more than that … you're just picking a name out of a hat and going.

Similarly, while Nicola understood the position of the support professional with regards to the level of guidance they were able to provide, she maintained that the level of guidance provided for decision-making was inadequate.

Nicola: You went and saw an autism advisor, and got given pieces of paper with these - this is what's available. There was no guidance, there was no offering of, 'this has been shown to have great', you know. I get that they can't be seen as directing you towards anything, but to go, 'this has got research. You can look here', that would've been incredibly helpful, I think.

The participants in this study reported that they went into support services expecting a level of guidance, and were disappointed when this did not occur. This mismatch

between the ideal model of practice and the reality of the support available left some of the participants in this study feeling abandoned, trying to work out how to proceed. Alice reported she felt the expectation that she needed to be the expert and determine what her child's needs were.

> Alice: I just thought there would be some kind of process that we go see someone and they'd say, 'Here are the services, this is what they do, this may suit him', and it really wasn't that. So, we were all left hanging to be the specialist to figure out what he needed … it's been 12 months on and we're fumbling our way through, working out what works.

Support. The participants in this study identified that the level of emotional and procedural support available to parents was limited, which in turn impacted upon the parents' ability to cope post-diagnosis, let alone gather and evaluate information to make informed decisions regarding which interventions to implement with their children. Debra commented on the limited support that she experienced following her son's ASD diagnosis.

> Debra: There's not really a lot of support for the parents out there that - and I don't mean in terms of what therapies we should do and how we should choose and things like that. I mean just the support for, 'How are you feeling?'

The perceived lack of support had implications on decision-making for the participants in this study. One of the assumptions underlying parents as the sole decision-makers was that they would use their knowledge of their child and the information they have been provided with to make an objective decision about which interventions were appropriate. However, as Debra explains, without support particularly in the challenging period post-diagnosis, it became difficult to make objective decisions.

> Debra: You can't think clearly when you're just tired and you're upset all the time.

Similarly, the lack of support places the burden of responsibility for decision-making solely on parents, which can in turn produce feelings of stress and guilt.

> Joanna: You need support and it's a big responsibility to have all these burdens that we were talking about before, and guilt and all the rest of it, without [having] somebody you can sit down and have a conversation with…

The participants in this study also felt that the support provided in order to navigate the disability system could be improved. On the whole, the parents found the system difficult to understand, which was exacerbated by not being provided with clear guidelines about how to access funding and services. Alice reported that trying to clarify the processes in order to access funding was not straightforward.

> Alice: So, sometimes you've been to the doctor, only to find out you could have had a mental healthcare plan that could have helped you support that. I needed to know that weeks ago. So things are just very back to front.

Likewise, Debra felt that she had expended a significant amount of time and energy trying to understand and navigate the funding channels, which could have been avoided had adequate supports been provided from professional support services.

> Debra: If somebody had sat down with us and kind of explained all of that, I felt like I was backwards and forwards to the GP and backwards and forwards to Medicare and backwards and forwards to the pediatrician. To work out how all that worked was an absolute nightmare and the paperwork was a nightmare.

Question 5: How can current practices be improved to support families during the decision-making process?

In terms of changes to current practices, the overwhelming need reported by the parents in this study was for decisions to be made collaboratively between parents and support professionals, as represented in Figure 8 (see page 152). The parents in this study made two primary recommendations with regard to how this model could be practically implemented, namely the allocation of a case manger to each family and simplifying the processes associated with accessing services. Each of these recommendations will be discussed within the context of the model of collaborative decision-making and the role of the professional, with specific reference to the three core categories (support, guidance and information).

The first recommendation that the parents in this study identified was the need for a case manager to be allocated to each family. A number of parents felt that the establishment of a case management role would facilitate collaborative decision-making, and improve the outcomes for families of children with ASD. Debra articulated the need for a case manager from immediately post-diagnosis.

> Debra: I feel very strongly that from the point of diagnosis you almost need a
> caseworker with you.

Similarly, Fiona asserted the need for a case manager to be providing support for decision-making, rather than leaving parents to navigate the disability system.

> Fiona: I think it's crazy that families who are already dealing with much more
> than lots of other families then have to become - it's a case manager role. I
> think it's a case manager role. A case manager should be - or could be
> providing this service. Not mums and dads.

The parents in this study argued that a case manager would be able to provide parents with the guidance, support and information required to enable collaborative decision-making to occur. Ellen envisioned that the case manager would provide support in all these areas.

Ellen: When people got a diagnosis, if that person went for, say, two mornings a week into that family for six weeks or a month and helped that family with everything from the emotional adjustment to what are your immediate problems and I can get you these leaflets and these booklets and a real shortcut to accessing information say on meltdowns or transitions or whatever who could say to that family, okay, so those are your thoughts, I think these are the areas you haven't considered. You don't have to consider them but I'm just highlighting some gaps in maybe what you're looking at.

Similarly, Joanna and Russell articulated that a case manager would be able to provide information and guidance, to assist parents with decision-making.

Russell: It's like you need a consultant to help you wade through all of the…

Joanna: That's what I would have liked. I would have liked somebody who was qualified or had more knowledge than I do about all of the different services and actually spent some time with Nicholas, and said, for him, this is what my view is. You make a decision.

Nicola felt that the role of current support professionals could be extended to become more of a case management role. By doing this, she suggested that the case manager could include the provision of emotional support to families.

Nicola: I think it's important if the autism advisor's role could also be included in that - of helping the parents come to terms with the diagnosis, because it's incredibly difficult to come to terms with that. Having to let go of what your

dreams that you had for your child, having to let go of them and perhaps just see things differently.

The other recommendation that the parents in this study made was to simplify and streamline the processes relating to accessing funding and services. Though not directly related to support for decision-making, the parents in this study argued that by streamlining processes and making systems more accessible, it would reduce the need for support and allow parents to focus on decision-making.

Ellen: People need the funding to be made very simple and the process to be made very simple so that they can concentrate on choosing therapies.

Fiona argued that if the same service provider could provider both diagnosis and multi-disciplinary intervention, it would reduce the need for parents to search for alternative providers and consequently would ease the burden of decision-making.

Fiona: If the service provision could all happen there, or through them. Because they've met us, they've made the assessment, they've met our son, they've made recommendations. So it would have - it would make sense to me that they then actually are the point at which you are linked in with someone.

Similarly, Sophie argued that centralizing systems would reduce the amount of searching the parents had to do to gather information.

Sophie: I always wish there was a central place we could ring.

Further to this, Debra suggested that clarifying the processes would enable parents to better navigate the disability system and reduce some of the stress associated with decision-making.

Debra: Maybe a flow chart of what you should do first. You know probably the most important thing is the diagnosis … and then the next box is okay, let's

get this paperwork done, so let's get the carer's allowance, you need to go and see this person, blah, blah, blah and you need to get your FaHCSIA stuff sorted out and then the next box is okay, now you need to consider your therapies, what's available and how they're going to work, how it's going to fit with your family.

In summary, the parents in this study identified that the implementation of a collaborative model of decision-making through the introduction of case managers and simplifying processes, would act to support parents in making decisions and potentially improve the outcomes for children with ASD and their families.

Summary

In this chapter, parents' perspectives on the supports for decision-making were explored. A model of collaborative decision-making was presented, which parents identified as their ideal model of professional support for decision-making. Within this model, the role of the professional involved the provision of information, guidance and support, while the role of the parent involved using their knowledge of the child to make the final decision about which interventions to access. This model is in stark contrast to parents' perceptions of the current supports for decision-making, which was represented as a model in which parents were the sole decision-makers. The participants in this study identified two main strategies to support the implementation of a collaborative model of decision-making, namely; the allocation of a case manager to each family, and the simplification of the processes associated with accessing services and support for children with ASD.

DISCUSSION

Introduction

In this chapter, the key findings of the study are discussed within the context of the existing literature and in relation to established theoretical frameworks. By nature of the qualitative methodology employed within this study, some of the findings that emerged from this study had not been anticipated. Consequently, another review of the literature was undertaken following data analysis, in order to explore the theoretical implications of the key findings.

Within this chapter, the progression of parents as decision-makers will be considered, by comparing the decision-making of parents of children with ASD to an existing model examining the progression of parental decision-making for children with chronic illness (Dixon, 1996). The concept of transformation will then be explored, to explain the shift in self-perception from 'parent' to 'expert' as reported within the current study. The theoretical framework of 'fateful moments', as proposed by Giddens (1991), and an existing model of parental transformation (Scorgie, Wilgosh & Sobsey, 2004) will be applied to explain the findings of this study. A specific theoretical model of parental decision-making will be proposed, which will subsequently be used to explain the support needs of parents at different stages of their transformative journey. The findings of this study relating to factors influencing parental decision-making will also be explored within the context of the previous literature, and directions for future research will be discussed. In addition, the implications of the findings of this study for support professionals, therapists, health communication and policy development will be explored. Finally, the limitations of the current study and directions for future research will be discussed.

Stages of Decision-Making

Within the system as it currently stands, there are challenges that parents face when having to adopt the role of sole decision-makers with regard to intervention approaches for their children with ASD. One of the key findings of the current study related to how the approach and attitude of parents towards decision-making changed over time. This finding has not been widely examined within the disability literature. However, the progression of parental decision-making over time has been studied within the context of parents making decisions for their children with a chronic illness. Dixon (1996) conducted a review of studies examining the processes by which parents of children with a chronic illness manage relationships with health care professionals over time, as parents became more experienced in managing their child's illness. One of the themes that emerged from this review related to decision-making. Dixon (1996) reported that decision-making between parents and professionals shifted over time as parents' knowledge and experience increased, and proposed the following model reflecting the change in decision-making over time:
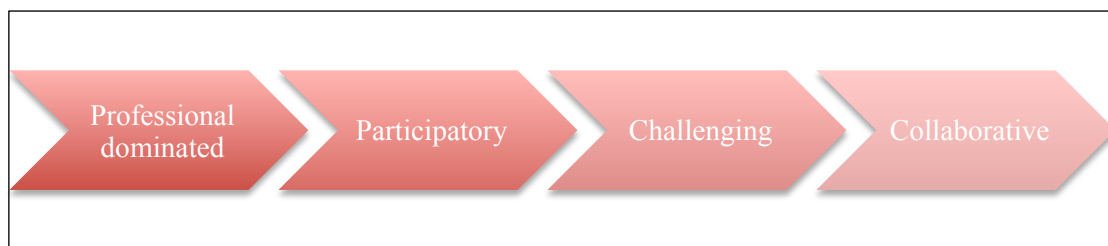
Figure 10. Model representing the four stages of parental decision-making with regard to their children with chronic illness (Dixon, 1996).

As illustrated in this model, Dixon (1996) proposes four stages of parental decision-making. The first stage, professional dominated decision-making, occurs whereby parents of children with a newly diagnosed chronic illness are only starting to develop their knowledge and skills, and therefore place a high level of trust in, and defer

decision-making to, professionals. The next stage is described as participatory decision-making, in which parents become increasingly involved in decision-making because of their expanded knowledge and expertise. Within this stage, parents still tend to accept options recommended by professionals, but are more aware of the importance of their input in decision-making. The third stage is referred to as challenging decision-making, in which parental expertise increases to the point that parents will question decisions that do not fit with their holistic view of their child however they may struggle with being able to express this to professionals. The final stage involves collaboration in decision-making, where parents and professionals make decisions in collaboration, and parents will challenge professionals if they feel decisions are not in the best interest of their child. In order for collaborative decision-making to occur, parents need to perceive themselves as having the authority to challenge professionals. As represented within this model (Dixon, 1996), parents of children with a chronic illness initially take a relatively passive role in decision-making, and then with time and experience, become more actively involved in decision-making, until they are considered to be making decisions collaboratively with professionals.

Though the context is different, this model can be applied to parents of children with ASD, and provides a basis for explaining the challenges that these parents face when making decisions about which intervention approaches to access. Within the context of this study, parents of children with ASD were required to make decisions regarding interventions immediately post-diagnosis, with limited or no professional support. At this stage of the journey, similar to parents of children with chronic illness, parents of children with ASD are still coming to terms with their child's diagnosis and only just starting to develop their knowledge and skills.

However, unlike parents of children with chronic illness who often defer to professionals to make decisions at this stage, parents of children with ASD are required to make decisions and to act as the expert. It is this conflict between the stage of decision-making, and the position that parents are forced to adopt as sole decision-makers, which contributed to the significant stress and angst reported by parents post-diagnosis. The difficulties that the participants expressed regarding decision-making, particularly in the period immediately post-diagnosis, are also reflective of the parents' perception at this time that they are unqualified to be making decisions. This perception changed over time as parents journeyed from 'parent' to expert', which was critical in understanding how their parental decision-making evolved over time.

Transformation: From 'Parent' to 'Expert'

One of the central findings of this study related to the change of self-perception as the parents shifted from 'parent' to 'expert'. This change in self-perception was aligned with decision-making regarding intervention approaches, because with time, parents were able to use acquired knowledge and experience to inform their decision-making. The journey from 'parent' to 'expert' reflects a broader transformation, the antecedent of which is the diagnosis of a child with a lifelong disability. The concept of transformation of parents of children with a disability has been previously reported in the literature. In their study examining interactions between education professionals and parents of children with profound and multiple disabilities, De Geeter, Poppes & Vlaskamp (2002) acknowledge that the information and experience gained by parents transforms them into experts regarding their own children. Similarly, Lutz, Patterson and Klein (2012) examined the experiences of raising a child with ASD from the

perspective of mothers. The findings of this study were represented as a journey towards adaptation, and described mothers of children with ASD taking on multiple roles, including advocate, in order to meet the needs of their child. Similarly, the findings of Shaked (2005) indicated that with time, parents of children with ASD start to advocate for the rights of their children within the community. DePape and Lindsay (2015) conducted a review of the literature exploring parents' experiences of caring for a child with ASD. Thirty-one qualitative articles were included in the review, and from this, six themes were generated relating to raising a child with ASD. One of these themes, entitled 'Parental Empowerment', referred to the transformation of parents as a result of their experiences. The review referred to specific findings of other studies, including Woodgate, Ateah & Secco (2008), who reported that as parents of children with ASD became empowered, they started to challenge information provided by others if they did not believe it was in the best interests of their child. DePape and Lindsay (2015) reflected that becoming empowered allowed parents to challenge the traditional medical model style of interaction, in which professionals are considered to the experts and possessors of knowledge.

An explanation of this transformation can be garnered by applying the theoretical model of 'fateful moments', proposed by sociologist Anthony Giddens (1991). Giddens (1991) described fateful moments as moments in which individuals are required to make decisions that are likely to have significant consequences for their future, often as the result of an unexpected event. In the case of parents of children with ASD, the fateful moment relates to the diagnosis of their child with ASD. After this point, parents are faced with decisions about how to proceed in relation to which intervention approaches to access. As reported by the participants in the current study, parents of children with ASD feel the pressure to make the right

decision about which interventions to implement and are concerned about the consequences of making the wrong decision. Thus, there are fateful consequences associated with decision-making. Giddens (1991) proposes that when faced with a fateful decision, individuals are likely to call on an expert to address the fateful moment, though the expert may not necessarily be able to provide definitive advice on how to proceed. It may also be the case that an encounter with an expert has led to the fateful moment. Again, these concepts described by Giddens (1991) can be applied to the experiences of parents of children with ASD, whereby experts in the form of medical or allied health professionals provide the diagnosis of ASD (thus leading to the fateful moment). It is also the case that parents of children with ASD desire professional support with decision-making, in particular at the 'parent' stage of the journey, however the constraints of the current system as described by the participants in this study mean that parents are left solely responsible for making decisions for their children. With time and experience however, parents of children with ASD undergo a transformation and change in self-perception. Parents develop into experts, as a result of being faced with a fateful moment. Giddens (1991) explains that when faced with a fateful moment, individuals are often moved to devote time and energy to achieve mastery of the circumstances that they have been forced to confront. Within this framework therefore, the transformation of parents to 'expert' is considered to occur as a result of a conscious decision by parents to master the situation that they find themselves in. That is, parents of children with ASD dedicate time and resources into becoming experts with regard to their own child. This was observed specifically in the participants in the current study, whereby parents engaged in their own research, formed connections with other parents and underwent a process of evaluating their experiences in order to develop their

knowledge and expertise. Thus, the theoretical concept of the 'fateful moment' explains the transformation of parents of children with ASD over time.

Another model developed to represent the transformation processes that parents of children with disabilities may undergo is the 'Parent Transformation Process Model' (Scorgie, Wilgosh & Sobsey, 2004). The model represents three transformational processes that occur following the diagnosis of a disability. Within the Parent Transformation Process Model, it is acknowledged that the diagnosis of a child with a disability is a life-altering experience for parents, which has the potential to challenge their beliefs and trigger a transformative process, though this is not explicitly represented within this model. This is an important concept however, and is comparable to Gidden's 'fateful moments' theory. The aim of the Parent Transformation Process Model is to represent the critical elements that facilitate the transformation and lead to the construction of a new self-identity (Scorgie, Wilgosh & Sobsey, 2004). Though these critical elements are represented separately, there is an acknowledgement that all of these elements interact, and will influence each other. The first of these critical elements relates to a transformation of self-identity or "image-making". As a result of the diagnosis, parents of children with a disability have to construct new images of their children, themselves and their lives. This may be informed by their previous experiences with disability, the information that is provided at the time of diagnosis and their expectations for the future. The second of the critical elements pertains to 'meaning-making', that is, the parents' interpretation of what has happened, why it has happened and how this impacts of the parents' belief system. For example, with the diagnosis of a disability, there may come the realization that the child may not meet parental and societal expectations, and therefore the parent may reconsider and reconstruct their definition of a meaningful

life. The final critical element relates to 'choice-making', that is, questions about how parents will manage their lives, and the life of their child with a disability. This is influenced in part by external factors, for example, the options that are available to each family. The Parent Transformation Process Model can be applied specifically to parental decision-making regarding the management of childhood disability. However, in order to more closely reflect the transformation from 'parent' to 'expert' and the progression of decision-making over time, the 'fateful moments' theoretical framework (Giddens, 1991) and the stages of decision-making (Dixon, 1996) can be applied to produce a theoretical model explaining the transformation of parents as decision-makers.

Theoretical Model: Transformation of Parental Decision-Making

A theoretical model of parental decision-making is proposed that incorporates elements of the existing theoretical models relating to transformation (Giddens, 1991; Scorgie, Wilgosh & Sobsey, 2004) and the practical model relating to the progression of decision-making (Dixon, 1996). The resulting theoretical model is represented below in Figure 11.
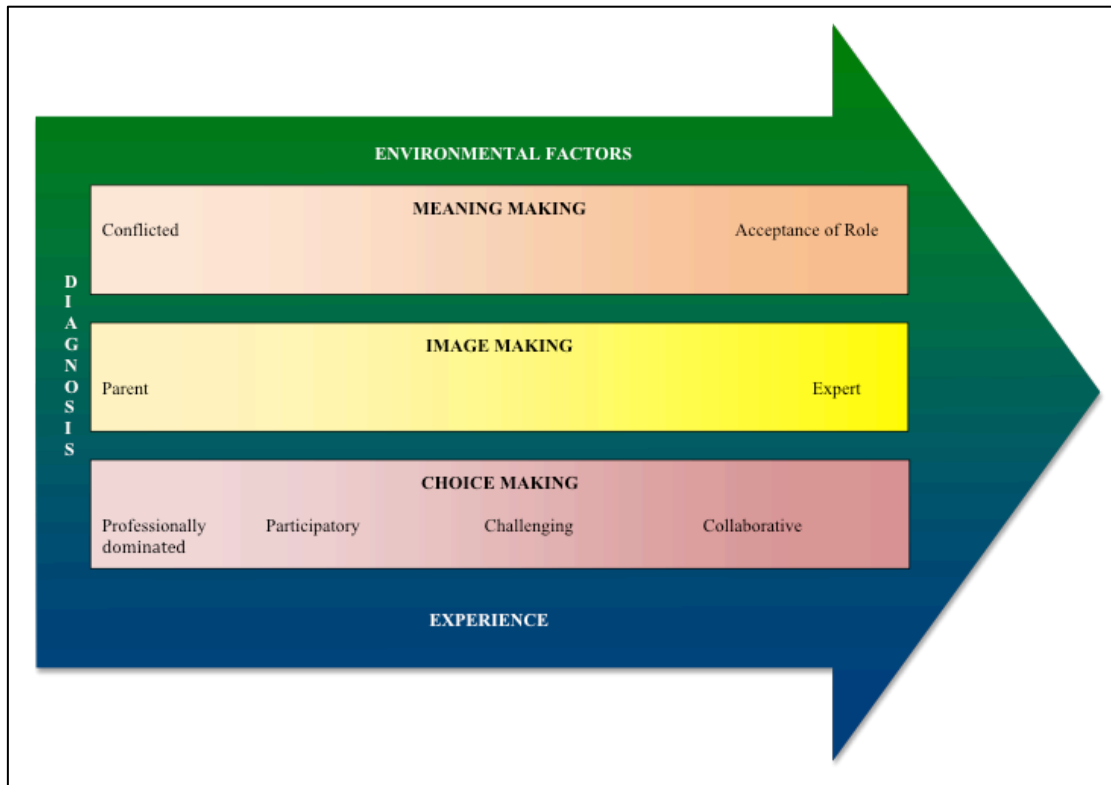
Figure 11. Transformation of parental decision-making.

Within this model, the 'fateful moment' of 'diagnosis' has been represented as the antecedent to transformation. The model has been arranged to represent the concept of time, which though discussed within the Parent Transformation Process Model (Scorgie, Wilgosh & Sobsey, 2004), is not clearly represented. The three critical questions as identified within the Parent Transformation Process Model (Scorgie, Wilgosh & Sobsey, 2004) are represented, but more specific subheadings are included to represent the process of decision-making. With regards to 'image making', the key concept of the transformation from 'parent' to 'expert' is represented, as a change in self-perception. The critical question of 'choice making' draws on the work of Dixon (1996) in representing the transformation in choice making over time. Finally, the critical question of 'meaning making' is applied specifically to parental decision-making, with labels applied to represent the progression of parents feeling conflicted

about their role as decision-makers, to accepting the role. Other elements included within the theoretical model include the concept of 'experience', given that this is critical to facilitating the progression from 'parent' to 'expert', as well as environmental factors. In summary, the 'Transformation of Parental Decision-Making' model applies specific knowledge relating to parental decision-making to theoretical models of transformation (Dixon, 1996; Giddens, 1991; Scorgie, Wilgosh & Sobsey, 2004), in order to provide an insight into the journey of parents as decision-makers for their child with a disability.

The practical utility of such a model lies in supporting the understanding of medical and allied health professionals in working with families of children with a disability. It is clear that the support needs of parents will change, as parents gain experience and transform over time. The implications of this model will be discussed in relation to parental perspectives of support for decision-making.

Factors Influencing Decision-Making

With regard to the specific factors influencing decision-making, the findings of the current study will be compared the findings of previous studies under each of the categories proposed within this study. Some of the factors identified within the current study have been more widely considered within the existing literature than other factors. The implications of this for future research will also be discussed.

Factors relating to 'Understanding' have been covered relatively well by the existing literature. Parental perceptions of ASD (Al Anbar, et al., 2010) and perceptions of cause (Dardennes et al., 2011; Shyu, Tsai & Tsai, 2010) were identified as factors within the current study, and were represented as parental understanding of ASD. Another factor relating to 'Understanding' identified within

the current study was parental understanding of therapy, which had been raised within the study by Valentine (2010). One of the findings that emerged from the current study that has not been examined in depth within the previous literature is how parental understanding of ASD changes over time. Within the current study, parents' perceptions of ASD changed over time (i.e. from expecting that a child would be cured to accepting that ASD is a lifelong disability), and consequently, their decision-making was influenced. It would be beneficial for future research regarding parental understanding of ASD to consider a longitudinal examination of changes to understanding over time.

With regard to 'Information', the findings of the current study supported the findings of previous work by Green (2007) and Miller et al. (2012), with regard to the sources of information that informed decision-making (e.g. information from other parents, allied health professionals). What emerged from the current study however, as described by participants, was the process of evaluating information, and considering whether the information provided matched the needs of the child and the needs of the family. In some cases, the information that was provided did not correspond with the parents' values, or resources available to the family, and therefore the information was not acted upon. Thus, the findings of the current study indicate that though parents seek out multiple sources of information, and this information has the potential to influence decision-making, parents of children with ASD may engage in a process of evaluating information, rather than accepting the information provided as accurate or useful. This process of evaluation would be a worthwhile area for further research to explore, in order to provide professionals with an insight into how to best present information to families of children with ASD.

The results of the current study highlighted the strong influence of 'Experience' on parental decision-making. This supports the findings of previous studies (Bowker, D'Angelo, Hicks & Wells, 2010; Goin-Kochel, Mackintosh & Myers, 2009; Shyu, Tsai & Tsai, 2010), which highlighted the influence of parents' experiences with ASD interventions on their decision-making. The findings of the current study emphasized just how influential past experiences are on parental decision-making, and in particular revealed a process by which parents are continuously monitoring their child's progress and evaluating their decision-making. An interesting avenue for future research would be to explore parental perceptions of progress against formal measures of progress to determine whether parental perceptions of progress accurately reflect changes in their child. This would be worth exploring, given the tendency of parents to implement interventions both with and without the backing of empirical evidence (Green et al., 2006; Carlon, Stephenson & Carter, 2014).

The category of 'Needs' has also been raised within previous studies (Hebert, 2014; Pituch et al., 2011), though these studies have tended to focus on the needs of the child influencing decision-making. While this is certainly the case, the findings of the current study indicate that parents' respond to the child's changing needs over time. Parents within the current study also recognized that they considered their child's perspective when making decisions, a factor that has also been previously reported in within the literature (Carlon, Carter & Stephenson, 2013; Shyu, Tsai & Tsai, 2010). One factor related to 'Needs' that was identified within the current study that has only been raised briefly within the literature (Carlon, Carter & Stephenson, 2014) is the impact of intervention on the family. The findings of the current study indicated that with time, parents started to acknowledge their own wellbeing and the

needs of the family in addition to the needs of the child with ASD. This appears to reflect an increased acceptance of the lifelong nature of the ASD, as well as recognition that the well being of the family is central to the wellbeing of the child with ASD, but further research is required to explore these concepts further.

Factors relating to 'Logistical Constraints' have been identified within previous studies, for example accessibility and affordability (Hebert, 2014; Shyu, Tsai & Tsai, 2010). The influence of logistical constrains on decision-making will vary according to the influence of factors external to the child and family, such as the funding and service delivery models. Thus, it is important that future studies continue to explore funding and service delivery models that best support parents to access effective interventions for their children with ASD.

Finally, the findings of the current study indicated that factors related to 'Motivation' influence parental decision-making. Hebert (2014) and Carlon, Carter and Stephenson (2014) had previously reported that parents' 'need to do something' influences their decision-making. One factor that was identified within the current study that has previously been unexplored is parents' motivation for their children to attend mainstream schooling. For the participants in the current study, it was their strong preference that their children attend mainstream schooling, and they made decisions regarding interventions based on trying to prepare their child for school. It would be beneficial for future research to explore the perceptions of parents of children with ASD about schooling placements.

In conclusion, a number of factors were identified as influencing parental decision-making, which were grouped into six overarching categories. Many of these factors had been previously identified in other studies, however the influence of some factors that had previously not been considered was identified within the current

study. Furthermore, the findings of the current study indicate that how certain factors influence decision-making will evolve with time and as parents gain experience.

Implications for Support Professionals

The findings of this study indicated that parents perceive the ideal model for professional support as one in which collaborative decision-making occurs (Figure 8). This is in stark contrast to how parents perceive the current supports available for decision-making, which was represented as a model in which parents are the sole decision-makers.
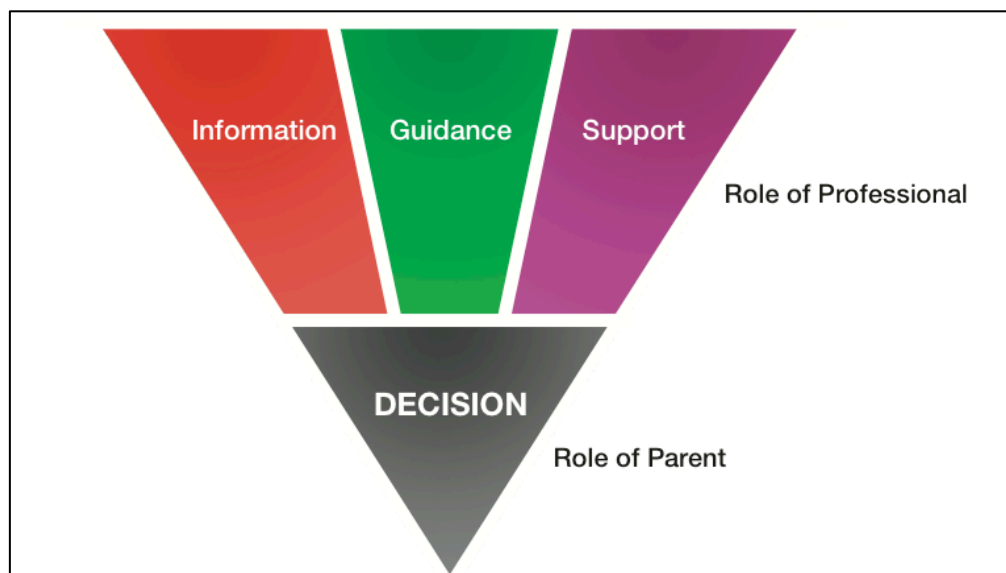
Figure 8. Model of collaborative decision-making.

Within the 'Transformation of Parental Decision-Making' model, it is evident that parents' perceptions of themselves as able decision-makers progress over time, and thus it stands to reason that their needs from support professionals will also change. At the 'Parent' stage of decision-making, all three elements of collaborative decision-making (information, guidance and support) are critically important. Parents at this stage of the journey often do not have access to support networks (i.e. other parents of

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children with a disability) and have not built relationships with trusted professionals. Consequently, it is essential that the role of the support professional at this stage includes the provision of specific information regarding intervention approaches.

One issue that is often raised in relation to use of interventions is that parents of children with ASD commonly choose to implement interventions both with and without empirical evidence (Green et al., 2006; Carter et al., 2011). The findings of this and other studies indicate that parents often do not consider empirical evidence when they are deciding which interventions to implement (Miller at al., 2012). Thus, the role of support professionals in providing information could include a process of supporting parents to consider empirical evidence.

This gives way to the second element of collaborative decision-making; guidance. In the initial 'parent' stage, parents report the need for guidance in decision-making. One of the challenges for support professionals is to achieve the balance between remaining impartial and offering guidance to assist parents with decision-making. Thus, although professionals may not be able to endorse one particular intervention approach, discussions regarding empirical evidence for intervention approaches could be used to guide parental decision-making. Furthermore, at the 'parent' stage, parents are still trying to understand their child's ASD, and therefore, what the child's therapy needs are. Thus, professionals could offer support by way of supporting families to identify their child's intervention needs. Tools such as the Family Goal Setting Tool: ASD Version (Jones, 2013) could be implemented to facilitate this process.

Supporting parents with decision-making at this stage of the process also extends to providing emotional and procedural support. At this stage of the journey, parents are still coming to terms with their child's diagnosis, as well as trying to

navigate the disability system. In addition, parents are often feeling conflicted about their new role as decision-maker and grappling with their own future and the future of their child. Given that the process of transformation hinges upon how individuals respond to the 'fateful moment', the role of the support professional at this stage is potentially very important in facilitating parents to transition from parent to decision-maker. Further research however is needed to test this hypothesis.

Over time, there is a shift in parental decision-making, as represented in 'Transformation of Parental Decision-Making' model, as 'parents' become 'experts'. There is however still the need for professional support at this stage. De Geeter, Poppes & Vlaskamp (2002) considered the role of parents of children with profound and multiple disabilities as experts within the Netherlands disability system. This system has some similar features to the current disability funding models being implemented in South Australia, whereby parents are given control over their child's disability services. Funding can be allocated directly to service providers selected by the family, or the family can self-manage a sum of money to fund services. De Geeter, Poppes & Vlaskamp (2002) reflect that this system places additional demands on parents, whereby they must be aware of all the options available for their child and make decisions regarding which services will be meet their child's needs, and though parents may be the 'expert' when it comes to their own child, this does not necessarily mean that they have access to all the information to support their decision-making. Furthermore, though parents may have developed other networks for sourcing information at the 'expert' stage, ASD is one of the few disabilities where new interventions are frequently being developed and marketed to parents (Schreck & Miller, 2010), often without empirical backing. Thus, it is important for support professionals to provide some information, even when parents are at the 'expert'

stage, in order to continue to support parents to understand their choices and to make informed decisions.

The need for support professionals to provide guidance at the 'expert' stage however is reduced. By this stage of the journey, parents have accepted their role as decision-maker and perceive that they are in a better position than any other expert to be making decisions regarding interventions for their child. By this stage, parents have gained experience with interventions and developed a better understanding of their child's needs, and therefore are not as reliant on professionals to provide guidance with regard to intervention choices. From a broader perspective, there are other areas in which guidance may be beneficial for parents even at the expert stage (e.g. deciding on school placement), however further research is required to explore the role of support professionals in providing guidance at this level.

Finally, with regard to the provision of support, the third component of the model of collaborative decision-making, parents may still require some support at the 'expert' stage. This can be explained by considering the 'constant sorrow' model of grief, first proposed by Olshansky (1962). Olshansky (1962) proposes that grief may re-emerge throughout the parent's lifespan as the child fails to meet developmental milestones and the impact of the child's disability is realized. Thus, even for parents who are 'experts', there may be the need for ongoing emotional support, and in particular during stages of transition (e.g. child transitioning to school). This was raised by some of the participants in the current study, when discussing life after early intervention. It was the experience of some parents that the support networks that they had forged while participating in early intervention programs had dispersed once their children started school. Therefore, though the need for emotional support is not

as pressing for 'experts' as compared to parents immediately post-diagnosis, the need remains for some level of ongoing support to be provided.

In summary, the 'Transformation of Parental Decision-Making' model can be used to understand the needs of parents from support professionals. Immediately post-diagnosis, parents require information, guidance and support. As parents transform into 'experts' over time, though their needs from support professionals are reduced, there is still the need for the ongoing provision of information and emotional support.

Implications for Therapists

There are three key implications for therapists that will be discussed in relation to the findings of this study. The first relates to working directly with families to implement intervention for children with ASD, the second relates to therapists providing support for decision-making, and the third relates to the role of therapists within health promotion. Each of these implications will be discussed in further detail.

Working with Families.[5] From the specific subset of data examining the qualities that parents want in therapists, two central themes emerged: the concept that parents and therapists need to work in 'Partnership' to achieve therapy outcomes, and the factors that parents believe should be present in order for 'Effective Therapy' to be implemented. One of the important findings that emerged from this study was the value that the participants placed on therapists achieving positive outcomes for their children, above all other factors. In previous studies (Bachner et al., 2006; Carroll, 2010), parental satisfaction has been reported to be higher where therapists work in collaboration with parents. While it is certainly the case that the participants in this

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[5] This section is adapted from the original article (Appendix 6).

study want to work in collaboration with therapists, it is also the case that they placed more value on whether the therapist was able to produce positive outcomes for their child. Moreover, the participants in this study were willing to sacrifice other factors, for example, having a therapeutic relationship with the therapist, if they perceived that their child was making progress. A similar finding was reported by Auert, Trembath, Arciuli and Thomas (2012), who examined parents' experiences of accessing evidence-based SLP services for their children with ASD. Although some of the participants in the study expected therapists to implement evidence-based practice, other participants did not believe this was critical, as long as their child made progress in therapy (Auert et al., 2012). Thus, parents consider the ability of therapists to produce positive outcomes for their children with ASD to be very important.

This is not to say that the need for therapists to work in partnership with parents should be disregarded, because in actual fact, the participants in the current study considered a situation in which they were working in partnership with therapists and effective therapy was delivered to be ideal scenario. However the participants in this study maintained that partnership alone is not enough. This finding is not unexpected, given that the aim of intervention for a child with ASD is to develop a specific skill or behaviour. Therefore, the challenge for therapists from a clinical perspective is being able to work in partnership with parents, while also achieving the positive outcomes that are valued so highly by parents. Not only has this been identified by the participants in this study as the way in which they want to work with therapists, but the literature also cites family-centered practice, in which collaboration occurs regarding service planning, delivery and evaluation, as best practice when working with families of children with disabilities (Carpenter & Russell, 2005; Hanna & Rodger, 2002). The experiences of the participants in the current study and

previous studies (Auert et al., 2012) however indicate that despite having been established as best practice, not all families feel that they are working in collaboration with their child's therapists. The reasons for this may be wide and varied (e.g., expectations of family, therapists' level of experience), and further research into the barriers that prevent therapists from working in collaboration with parents of children with ASD would be beneficial. Regardless of the cause, the findings of this study would indicate that further support of trainee therapists, including SLPs, with regard to the implementation of family-centered practice would be beneficial. It is potentially the case that though therapists acknowledge the importance of collaboration with parents (Watts Pappas, McLeod, McAllister & McKinnon, 2008), specific practices implemented by therapists may not consistently embody this approach. Offering trainee therapists increased opportunities to practice implementing family-centered practices, and specifically how to work in collaboration and communicate with parents of children with ASD, may facilitate therapists to transfer the principle of family-centeredness from theory to practice.

Another strategy to support the implementation of family-centered practice is for therapists to routinely use goal setting and specific outcome measures in collaboration with parents during initial intervention planning. Measurement tools such as Goal Attainment Scaling (Kiresuk, Smith & Cardillo, 1994) offer therapists a means by which to measure progress due to intervention (Schlosser, 2004). Furthermore, measurement tools can serve as an initial point of discussion in which parents identify their goals for intervention, and therapists explain the steps in achieving these goals. Alternatively, formal and informal measures specific to each discipline can be implemented to measure outcomes from therapy programs (e.g. progress record of an ABA program). Incorporating outcome measurement tools as

part of standard practice within intervention planning fosters collaboration, with therapists and parents working together towards a specific positive outcome for the child.

Participants in this study also identified the need for therapists to communicate honestly and openly, and to share the reasoning behind their clinical decision-making. The participants felt it was important that they understood the necessary steps to achieve therapy goals, and how therapy activities were targeting specific goals. This finding once again supported the results of the study by Auert et al. (2012), in which participants had identified open communication as an important skill for therapists to possess. Interestingly though, the participants in the current study wanted therapists to be open and honest in particular when therapy wasn't achieving the desired outcomes. This is perhaps a more difficult conversation for therapists to have with parents, but is something that the participants in this study valued equally as much as communicating about therapy when positive outcomes were being achieved. Thus, it is important for therapists to be able to engage in reflective practice, and to be able to give parents open and honest feedback about all aspects of a child's progress and participation in a therapy program.

Supporting Decision-Making. The findings of this study indicated that immediately post-diagnosis, parents would often accept the recommendations of professionals with regard to intervention programs. Miller et al. (2012) previously reported that professionals might not consistently be recommending evidence-based interventions to families. Given the willingness of parents to accept recommendations from professionals, especially initially, it is the responsibility of therapists to understand evidence-based practice and keep up to date with the most recent evidence relating to the efficacy of intervention programs. Though therapists

often have a number competing demands for their time, it is important that keeping abreast of empirical evidence is prioritized, given the weight that parents place on recommendations from therapists during decision-making. Furthermore, it is important for therapists to have discussions with parents about evidence-based practice, as highlighted by Auert et al (2012). Therapists are in the unique position of being able to objectively evaluate intervention programs and offer support and advice to families as a trusted advisor. It is important also that therapists share information with families about how to evaluate interventions and the importance of ensuring that the interventions they are implementing are effective in producing outcomes for their children with ASD.

In supporting parental decision-making, it is important for therapists to understand the parents' perceptions with regard to their child's ASD, and specifically beliefs related to causation. The findings of this and previous studies (Dardennes et al., 2011) have indicated that parents' perceptions of causation will influence their decision-making. Case in point, one participant in the current study chose to implement predominately biomedical interventions, based on the belief that his son's ASD had been caused by the MMR vaccination. While it is important for therapists to respect the individual and cultural beliefs of the families they are working with, it is also important to ensure that children with ASD are protected and not exposed to potentially harmful interventions. Consequently, therapists need to make parents aware of the risks of certain intervention approaches and support them to objectively evaluate the outcomes of these programs.

Furthermore, it is important that therapists support parental decision-making in the initial 'Parent' stage post-diagnosis, given that parents may prioritize certain needs and overlook others when selecting intervention approaches. Several

participants in this study identified that immediately post-diagnosis, accessing speech pathology intervention to address their child's communication impairment was their main concern. However, at this stage, many parents did not understand and identify the need for occupational therapy input, for example. It is the responsibility of therapists therefore, to assist parents to develop a more rounded and holistic perspective of their child's development. This is particularly important within the current context of the NDIS, which has adopted a person-centered approach to service planning and delivery. One potential challenge in adopting this approach is that parents may not completely understand their child's needs immediately post-diagnosis, and yet they are required to advocate for and make decisions regarding therapy services. The findings of this study are able to provide some potential insights into parental decision--making and supports within the context of the NDIS, however Further research is needed to explore the role of therapists in supporting parents within this context.

Finally, in supporting decision-making, it is important that therapists acknowledge and understand the previous experiences of parents with regard to interventions programs. Parents of children with ASD who are at the 'Expert' stage may be less likely to accept recommendations from professionals, and may challenge information provided by professionals. This does not mean that therapists should not make recommendations or engage in discussions with parents; rather, it highlights the importance of therapists understanding the parents' perspectives and making individualized recommendations, specific to the child and family's needs. Families at the 'Parent' stage, though less likely to challenge information provided by professionals, may also have specific expectations about intervention programs, and the outcomes that will be produced. In order to support parental decision-making,

therapists should assist parents to understand the purpose of specific therapy input (e.g. providing parents with strategies to support the implementation of therapy at home) and to set goals to measure the progress of therapy input.

In summary, the findings of this study highlight the importance of therapists in supporting parental decision-making. Though within some service delivery models there may be a specific professional role (e.g. Autism advisor) established to support parental decision-making, parents are still likely to seek decision-making support from therapists.

Health Promotion. While the primary role of therapists when working with families of children with ASD is to provide intervention and assessment specific to their discipline, the findings of this study highlight the potential role of therapists in supporting health promotion efforts for this population of children and families. This is particularly pertinent given the recent changes to the NDIS funding model for disability services. The concept of therapists being involved in health promotion activities is not new. With the focus on primary health care increasing at an organizational and political level, there has been a call for therapists to focus on primary prevention and specifically for therapists to promote health equity (Holmberg & Ringsberg, 2014; Law, Reilly & Snow, 2013).

Within the field of health promotion, three core activities have been identified; advocacy, enabling and mediating (Saan & Wise, 2011). Each of these activities will be discussed in relation to the role of therapists in supporting health promotion within the context of self-managed disability funding for this population. Enabling refers to achieving equity in health, regardless of factors such as cultural background and socio-economic status. For parents of children with ASD, the deciding factor with regard to which intervention approaches to implement was often logistical (e.g.

availability and accessibility of services and funding). Within the current NDIS funding model, parents are required to advocate for funding for their child with ASD. Therefore, there is the potential for parents from lower educational backgrounds or with poor literacy skills, for example, to receive less funding for their child based on their ability to advocate for funding. It is critical therefore for therapists, particularly at the point of diagnosis, to support parents in requesting funding for intervention, in order to enable all children with ASD to access intervention services, regardless of their background.

The second health promotion activity, advocacy, refers to work at a policy level to create conditions that are favorable for health (Kokeny, 2011). When considering parental decision-making, it is evident that decision-making is generally influenced by the policies that are implemented at a particular point in time. For example, the HWCA funding allowed parents to select from a range of approved interventions, based on the level of empirical evidence supporting each approach (Roberts & Prior, 2006). Therefore, in order to ensure that parents have access to effective, evidence-based interventions, it is important that therapists continue to evaluate intervention approaches and lobby policy-makers to ensure that policies regarding disability services reflect the current evidence for best practice. This is particularly important with regard to intensity of intervention programs for children with ASD, where historically in spite of evidence regarding the required intensity of intervention, the funding available does not match this intensity.

The final health promotion activity involves mediation between different agencies to achieve health outcomes (Saan & Wise, 2011). Within the context of this population of children and families, the role of therapists in mediating involves participating and advocating for a coordinated approach to health for parents of

children with ASD. For example, it has been recognized that parents of children with ASD have higher levels of parenting stress than parents of children with other disabilities (Hayes & Watson, 2013). Thus, in order to achieve optimal outcomes for children with ASD and their families, it is important for therapists to employ practices that reduce parenting stress, including the provision of parent training (Keen, Couzens, Muspratt & Rodger, 2010). However, in order to best support parents of children with ASD, therapists need to collaborate with other disciplines and agencies to promote and maintain the health and well-being of these parents. This may include, for example, parents having access to professional support for decision-making (e.g. a case manager), funding being allocated within NDIS plans for counseling support for parents, and the continued provision of a Government allowance (e.g. carer's payment) for parents caring for a child with a disability. If therapists are able to participate and support a coordinated approach to health for parents of children with ASD, it is possible that the outcomes of children with ASD will also improve (Tonge et al., 2006).

Implications for Health Communication[6]

The participants in this study revealed an acute awareness of the importance of early intervention, which placed pressure on parental decision-making. Though not intended, this was the inadvertent outcome of the early intervention message for the parents in this study. A similar phenomenon was observed in the study of infant mental health promotion (Lawless, Coveney & MacDougall, 2014), where participants were acutely aware of the importance of infant mental health promotion, referencing the 'window of opportunity' and critical period of brain development in

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[6] This section is adapted from the original article (Appendix 7)

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the early years, and the role of parents in achieving these outcomes. However, similar to the current study, there was a reported misinterpretation of the health promotion message, with parents being viewed as risks to their children's development. One of the sociological critiques of health promotion is that there is a risk of 'victim-blaming', in which health promotion efforts inadvertently blame individuals for their poor health, rather than looking more broadly at the structural conditions that have contributed (Green, 2008). Within the context of the current study, it is possible that with health promotion efforts focused on the early intervention message, which seemingly shifts the responsibility for intervention outcomes onto parents, broader issues relating to funding, support and access to early intervention services may not have received sufficient attention. Rossi, Newschaffer and Yudull (2012) also raised concerns about communicating risk information to parents of children with ASD, given the potential for inadvertent harm to be caused to the recipients of this information, and advised caution in how this information was communicated. The results of the current study also indicate that further exploration regarding how information about early intervention is communicated to parents of children with ASD is required, given that there is the potential for this information to negatively impact on parents.

Implications for Policy Development

One of the broader implications that arose from this study relates to the role of parents in developing policies relating to health and disability. At the time of the current study, the HCWA initiative allowed parents to control an allocation for funding for early intervention services. Since this time, the HCWA funding has been phrased out within South Australia, as the NDIS is being introduced. The NDIS has progressed

the role of parents in managing their child's disability even further, requiring parents to first advocate for funding for their child with a disability, and then subsequently decide on how to allocate the funding and which intervention approaches and service providers to access. The rationale behind these initiatives was that individuals with a disability, and their parents or caregivers, should be given every opportunity to make their own decisions and exercise choice and control over their own lives (Department of Social Services, 2015; National Disability Insurance Agency, n.d.). However, the findings of this study indicate that particularly immediately post-diagnosis, parents do not feel comfortable adopting the role of sole-decision makers, and instead propose a model in which collaborative decision-making occurs. Thus, it is important for policy makers to work collaboratively with parents of children with ASD, in order to ensure that the policies and funding models introduced meet the needs of the community.

The involvement of parents of children with ASD in the creation of policy can be considered within the theoretical framework of community participation. Within this framework, 'participation' refers the involvement of citizens in making decisions that affect their lives (Hart, 1992). Arnstein (1969) proposed a theoretical model describing community participation, entitled 'A Ladder of Citizen Participation'. Arnstein's framework represents different levels or 'rungs' of citizen participation, spanning from non-participation to degrees of citizen power (Arnstein, 1969). According to Arnstein's (1969) framework, in order for true participation to be achieved, the involvement of members of the community in policy development needs to move beyond consultation to the point where parents of children with ASD are actively involved in decision-making related to policies. This will help to ensure that the policies that are implemented best support children with ASD and their families.

Quality and Limitations of Current Study

A number of measures were implemented to ensure the quality of the current study. Data triangulation occurred, with data collection occurring through semi-structured interviewing, the use of a demographic questionnaire and researcher journaling. The participants were given the opportunity to review the interview transcripts and were sent a summary of the results, to ensure that the findings constructed were an accurate representation of their experiences. Furthermore, quotes and phrases used by the participants have been used in reporting the findings of this study, to ensure that the findings reflect the voice of the participants. The quality of this study was also maintained by nature of the methods used, including constant comparison and the use of memos to construct the categories, themes and theory related to this study.

As a qualitative methodology was implemented, the degree to which the findings of this study can be generalized to the broader population is limited. This is especially the case given that convenience sampling was implemented within this study, meaning that there is a potential that the participants who opted into this study had particularly strong opinions about the topic under investigation. Furthermore, the participants' perspectives were based on experiences with one particular funding model, and service provision and supports can vary significantly across the county and internationally. Additionally, all of the parents interviewed had male children with autism, factors that may influence parents' experiences. However, the application of theory, namely Giddens' (1991) theoretical model of 'fateful moments' supports the generalization of the study, and led to the development of a model (transformation of parental decision-making) which can be tested within other populations of parents and across service delivery and funding models.

Future Research

It would be beneficial for future research to further explore how parental decision-making transforms over time within different contexts, including different geographic regions, service delivery models and for parents of children with a range of diagnoses. Specifically, it would be beneficial for future studies to consider a longitudinal research design, in order to provide further insight into the transformation of decision-making by following parents as they access interventions and make decisions over time.

As discussed earlier, further research is required regarding the influence of specific factors that have been under-examined within the existing literature (e.g. motivation for mainstream schooling) on parental decision-making. In particular, further research on the impact of the 'early intervention' message on parental decision-making, and more broadly on parents of children with disabilities is warranted.

This study only considered the perspectives of parents relating to the qualities that they want in therapists. It would be useful therefore for further research to not only explore the perspectives of therapists, but also to observe parent-therapy interactions, to determine if the perceptions of parents and therapists are reflected in their interactions. The results of the current study also indicated that there might be some potential barriers to therapists working in collaboration with parents. It would be beneficial to explore this further, and more importantly, to consider potential strategies to overcome barriers and support parent-therapist collaboration.

Finally, it would be useful for future research to compare the various strategies for supporting parental decision-making. This study focused on parents' perceptions on professional support for decision-making, as this was the strategy of support for

decision-making that was being implemented at the time of data collection. Parents identified the need for a collaborative model of support for decision-making, however other strategies to support decision-making, for example parent education programs, may be more effective. Thus, it would be worthwhile comparing and evaluating different strategies for supporting parental decision-making.

Summary

In this chapter, the findings of the current study were discussed in relation to the existing literature and theoretical frameworks. Giddens' (1991) theoretical framework of 'fateful moments' was used to explain the transformation from 'parent' to 'expert' and a model of 'transformation of parental decision-making' was proposed. The implications of the findings of this study for therapists, support professionals, health communication and policy development were discussed. Finally, the limitations of the current study and directions for future research were outlined.

CONCLUSION

Introduction

In this chapter, a recap of the aims of this thesis and research methods is presented. The findings from each of the research questions are summarized, as are the clinical implications from these findings. Finally, a concluding statement commenting on the outcomes of this study and future directions within this field of research is presented.

Summary of Thesis Aims and Objectives

Parents of children with ASD are required to choose which from a myriad of intervention approaches to implement with their child. Overall, there is limited understanding of parental decision-making with regard to intervention approaches for children with ASD, and specifically with regard to how decision-making changes over time. This study aimed to explore how parents make decisions regarding which intervention approaches to access, including the factors influencing decision-making. Furthermore, this study aimed to examine parents' perceptions of the current supports available for decision-making and how current practices can be improved to support parental decision-making.

A constructivist grounded theory methodology was implemented to explore parental decision-making and the supports available for decision-making. Data collection was undertaken in two stages; the first stage involved the construction of an interview guide and the second stage involved in-depth interviewing being undertaken with 14 parents of children with ASD. Data collection and analysis occurred concurrently, with analysis of the initial interview transcripts guiding the direction of subsequent data collection and analysis. Constant comparative methods and the use

of memos allowed a substantive grounded theory related to parental decision-making to be constructed. Thematic analysis was undertaken on the data relating to supports for decision-making, and this led to a model being constructed representing parents' perspectives of the ideal supports for decision-making. The research findings are summarised by research question below.

1) How Parents Make Decisions about Intervention Approaches

The findings of this study indicated that parental decision-making changes over time, as parents transform from 'parent' to 'expert'. Six categories of factors were identified as influencing parental decision-making: experience, understanding, needs, information, motivation and logistical constraints. How these factors influence decision-making changes with time. Immediately post-diagnosis, parents felt unqualified to be making decisions and often had few experiences upon which to base their decisions. With time, as parents gained experience with interventions, they started to evaluate interventions, based on their perception of their child's progress. At this point, parents started to perceive themselves as 'expert' when it came to their own child, with parents describing increased confidence in their decision-making.

The theoretical framework proposed by Giddens (1991) of 'fateful moments' was applied to explain to the process of transformation from 'parent' to 'expert'. Using this framework, a model explaining the transformation of parental decision-making over time was constructed. The findings of this research also had implications for future research regarding parental decision-making, with some factors that had not been identified in previous research being identified in this study.

2) The Qualities That Parents Want in Therapists

Parents' experiences with intervention programs were found to strongly influence their decision-making. Therapists were central in shaping parents' experiences with interventions, and therefore the qualities that parents want in therapists working with children with ASD were explored in further depth. The findings related to this research question indicated that parents want to work in partnership with therapists, and more importantly, want therapists to deliver effective therapy that produces positive outcomes for their children with ASD. Parents identified that they wanted to work in collaboration with their child's therapists, though this was not always the experience of the parents in this study. Thus, though family-centered practice, in which parents and therapists work in collaboration to plan and implement intervention has long been established as best practice for children with disabilities (Hanna & Rodger, 2002), there is still a disconnect between theory and practice as reported by some parents. There are a number of implications from this finding, including for trainee therapists to be offered increased opportunities to practice collaborating with parents and having open discussions with parents about therapy goals and outcomes.

3) The Impact of The 'Early Intervention' Message

The findings of this study indicated that parents' understanding of therapy, and specifically their understanding of the importance of early intervention, influenced their decision-making with regard to intervention approaches. This topic was explored more broadly, and the impact of the 'early intervention' message of parents of children with ASD was considered. The results relating to this research question indicated that the parents in this study were acutely aware of the importance of early intervention. This influenced parental decision-making, where parents were not

willing to wait for intervention services, out of fear of missing the "window of opportunity" of early intervention. This placed a great deal of pressure on parents' decision-making, with parents also fearing the consequences of making the wrong decision with regard to intervention. Parents also reflected on life beyond early intervention, and were surprised to find that intervention during this time was still effective in producing outcomes, however services did not necessarily prioritize intervention beyond the early years. Though the purpose of educating parents about the importance of early intervention was not to place pressure on parental decision-making, this was one of the inadvertent consequences of this health promotion effort for these parents. This phenomenon has been previously reported (Lawless et al., 2014), and the findings from the current study highlight the need for careful consideration of health communication to this population of parents.

4) Current Supports for Decision-Making

The findings of this study indicated that with regard to supports for decision-making, there were two overarching themes: the 'role of the parent' and 'the role of the professional'. In relation to the current supports available for decision-making, parents perceived the responsibility for decision-making as lying primarily with them, with only general information and limited guidance and support being provided by professionals. Parents did not perceive the current supports available for decision-making as adequate to meet their needs, especially immediately post-diagnosis. As parents moved from 'parent' to 'expert', their support needs reduced, however it is still important for parents to receive ongoing support, especially when considering impact of the chronic sorrow model of grieving (Olshansky, 1962).

5) How Supports for Decision-Making Can Be Improved

Parents' perspectives on the ideal supports for decision-making were represented as a model of collaborative decision-making. Within this model, the role of the professional was more broad-ranging, and included the provision of information specific to the child, offering guidance to parents about which intervention approaches to implement and offering support both to navigate the disability system and to cope with their child's ASD diagnosis. The role of the parent within this model was to use their knowledge of their own child to make the final decisions about which interventions to implement. Parents identified two primary strategies for implementing a collaborative model of decision-making, namely the introduction of a case manager for each child with an ASD diagnosis, and simplifying the processes related to accessing funding and interventions for children with ASD.

Concluding Statement

The findings of this study provided a greater understanding of parental decision-making, and the supports required by parents of children with ASD. It would be beneficial for future research to explore parental decision-making across a broader range of contexts, including different service delivery models and parents of children with different diagnoses, to test the theoretical model of parental decision-making proposed in this study. Furthermore, some specific factors influencing decision-making identified within this study (i.e. motivation for mainstream schooling) have not been as widely examined by the existing literature, and would benefit from further consideration within future research.

It is hoped that the findings of this research will lead to increased consideration of the supports available for parents of children with ASD, and an

increased understanding of parental decision-making by professionals working with children with ASD. Furthermore, it is hoped that the pressure and stress of decision-making can be reduced by increasing the professional support and considering how health messages are communicated to this population of parents. Ultimately, in order for positive outcomes to be achieved for children with ASD and their families, effective, evidence-based interventions need to be provided by responsive therapists, who work in collaboration with parents. By providing an insight into parental decision-making and the supports required by parents, it is hoped that in some small way, this study will contribute to families of children with ASD being able to access effective intervention programs, and consequently, the best possible outcomes being achieved for children with ASD and their families.

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<div align="center">**APPENDICES**</div>

Appendix 1: Participant Information Sheets

Appendix 2: Original Interview Guide

Appendix 3: Final Interview Guide

Appendix 4: Demographic Questionnaires

Appendix 5: Summary of Data (For Member Checking)

Appendix 6: Original Article ("Me More Than Blowing Bubbles": What Parents Want From Therapists Working With Children With ASD)

Appendix 7: Original Article (The Impact of the 'Early Intervention' Message on Parents of Children with ASD)

APPENDIX 1: Participant Information Sheets

Participant Information Sheet: Stage 1

Dept. of Speech Pathology and Audiology

Flinders University, Adelaide
GPO Box 2100
Adelaide SA 5001

Tel: 08 8201 5942
Fax: 08 8201 5935
http://www.flinders.edu.au/speechpath/

CRICOS Provider No. 00114A

XXth XXXXXX, 2011

Dear Parent or Guardian,

My name is Amelia Edwards, and I am speech pathologist and PhD candidate at Flinders University. I am currently undertaking a research project entitled 'How Parents of Children with Autism Spectrum Disorders (ASD) Make Decisions about Which Interventions to Access'. The supervisors of this project are Paul McCormack (Department of Speech Pathology and Audiology, Flinders University), Colin MacDougall (Department of Public Health, Flinders University) and Chris Brebner (Department of Speech Pathology and Audiology, Flinders University).

You are invited to participate in this research project but you do not have to be involved, whether you wish to or not is entirely up to you. You were chosen as a potential participant for this project as you have previously, or are currently, receiving services from XXXX (FMC or private practice).   Whether you take part or not, the services you receive from XXXX (FMC or private practice) will not be affected in any way.

The aims of this project are to:

- Find out how parents of children with ASD make decisions about which interventions/services to access.

- To see if practices can be improved to support parents better during the decision-making process.

It is expected that this project will be completed by February, 2014.

This research project will be undertaken in three stages. In the first stage, participants will be asked to generate some questions to be asked of parents during the second stage of the project, which will involve interviewing parents about their experiences. The final stage will aim to improve current practices based on the experiences and recommendations of parents.

You are invited to participate in the first stage of this project. This would involve meeting with myself at a location of your choosing (e.g. your home, an office at Flinders University or another mutually agreed location) for no longer than an hour. You will be asked what questions you think should be asked of parents to learn about their experiences in making decisions about interventions for their child with ASD. The purpose of this stage is to ensure that the questions asked in the second stage of the project will generate insightful information. The meeting would be audio recorded, and then transcribed by the researcher. A summary of the transcript would be sent for you to approve following the meeting. Any personal information in the audio recording or transcript will remain confidential and no information which could lead to your identification will be released, except as required by law.

By participating in this research, you will be contributing to the information base we have about how parents of children with ASD make decisions about which interventions to access. This information will then be used to generate a 'plan of action' to improve current practices, so that parents can be better supported during the decision-making process in the future. If participation in this project causes distress, you will be provided with list of services from which support can be accessed.

The results of this study may be published in scientific journals at a later date. It is possible that the results may not be published for scientific or other reasons. If you wish to know the outcomes of the study, you are welcome to provide a contact email or postal address to the researcher, by which a summary of the project results will be sent at its completion.

Your participation in this study is entirely voluntary and you have the right to withdraw from the study at any time without giving a reason. If you decide not to participate in this study, or if you withdraw from the study, you may do so freely, without affecting the standard care or services you or your child will receive. You will not receive any payment for participation in this study apart from compensation for reasonable travel costs for visits made during the study.

If you are interested in participating or have any questions, please contact myself (principle researcher) by email (amelia.edwards@flinders.edu.au) or phone on 0407 896 227, or Paul McCormack (Principal Supervisor, Lecturer in Speech Pathology, Flinders University) at the address given above, by telephone on 8204 5595, or by email (paul.mccormack@flinders.edu.au).

Kind regards,

Amelia Edwards

Speech Pathologist, PhD Candidate

Flinders University

This study has been reviewed by the Southern Adelaide Clinical Human Research Ethics Committee. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer on 8204 6453 or email research.ethics@health.sa.gov.au

Participant Information Sheet: Stage 2

Dept. of Speech Pathology and Audiology

Flinders University, Adelaide
GPO Box 2100
Adelaide SA 5001

Tel: 08 8201 5942
Fax: 08 8201 5935
http://www.flinders.edu.au/speechpath/

CRICOS Provider No. 00114A

Title: How Parents of Children with Autism Make Decisions About Which Intervention Approaches to Access

Researchers: Amelia Edwards (PhD Student, Flinders University)

Dr Chris Brebner (Department of Speech Pathology and Audiology, Flinders University)

Associate Professor Paul McCormack (Department of Speech Pathology and Audiology,

Flinders University),

Associate Professor Colin MacDougall (Department of Public Health, Flinders University)

We are inviting you to participate in this research project but whether you wish to or not is entirely your decision. Whether you take part or not, your relationship with (organisation name) will not be affected in any way.

The aims of this project are to:

- Find out how parents of children with autism make decisions about which interventions/services to access.

- To see if practices can be improved to support parents better during the decision-making process.

It is expected that this project will be completed by February, 2015.

You are invited to participate in the second stage of this project. This would involve meeting with me at a location of your choosing for a maximum of 2 hours. During this time, I would

interview you to find out about your experience making decisions regarding intervention/services for your child. It is expected that the interview itself will take 60-90 minutes. You will also be asked to complete a questionnaire. The interview would be audio recorded, and then transcribed by the researcher or a professional transcription company (Pacific Transcription). A summary of the transcript would be sent for you to approve following the meeting. You will also be left with a 'log book' in which you can record any other thoughts that you would like to be included in the research after the interview has taken place. Any personal information in the transcript, questionnaire and log book will remain confidential and no information which could lead to your identification will be released, except as required by law.

By participating in this research, you will be contributing to the information base we have about how parents of children with autism make decisions about which interventions to access. This information will then be used to generate a 'plan of action' to improve current practices, so that parents can be better supported during the decision-making process in the future. You will be provided with list of services from which support can be accessed, in case participation in the research project causes distress.

The results of this study may be published in scientific journals at a later date. It is possible that the results may not be published for scientific or other reasons. If you wish to know the outcomes of the study, you are welcome to provide a contact email or postal address to the researcher, by which a summary of the project results will be sent at its completion.

Your participation in this study is entirely voluntary and you have the right to withdraw from the study at any time without giving a reason. If you decide not to participate in this study, or if you withdraw from the study, you may do so freely, without affecting the standard care or services you or your child will receive. You will receive an honorarium of $50 for participating in this study, which will be posted to you with the transcript of the interview. You will have two weeks to review the transcript. Up until this point, you can choose to withdraw the data. After these two weeks, if you approve the final transcript, the data will not be able to be withdrawn from the study.

If you suffer injury as a result of participation in this research, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

If you are interested in participating or if you have any questions, please contact myself (principle researcher) by email (amelia.edwards@flinders.edu.au) or phone on 8204 5960, or Chris Brebner (Co-Principal Supervisor, Lecturer in Speech Pathology, Flinders University) at the following address (c/o Department of Speech Pathology and Audiology, Flinders University, GPO Box 2100, SA, 5001), by telephone on 8204 5940, or by email (chris.brebner@flinders.edu.au).

Kind regards,

Amelia Edwards

Speech Pathologist, PhD Candidate

Flinders University

This study has been reviewed by the Southern Adelaide Clinical Human Research Ethics Committee. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer on 8204 6453 or email research.ethics@health.sa.gov.au

Key Theme Questions	Probe Questions (if needed)
Opening Questions Tell me about the process of getting your child diagnosed with ASD. How did you feel about the diagnosis?	Did you try any interventions before your child was diagnosed? Was it a shock? How did you cope? What did you know about autism before your child was diagnosed?
Experience with Interventions Tell me about your experiences with Autism interventions. What do you want from an intervention? Tell me about deciding to stop an intervention approach.	How do you know if an intervention is working? What are your goals from intervention? What makes you keep going with an intervention? Do you feel pressure to see results? How long will you try something before deciding to stop? Why did you decide this?
Deciding on Interventions	

Tell me about the interventions you are doing with your child at the moment.	
Tell me about the process of deciding on which interventions to implement with your child.	Why did you decide on this intervention approach? Who makes the decisions in your family? What all the things you have to think about when deciding to try an intervention? What helped you make these decisions?
Tell me about where you get information about interventions.	What makes you trust the information you're getting?
Feelings About Decision-Making How does it feel to choose interventions for your child? Tell me about if you have changed because of making these decisions. How confident do you feel in the decisions you are making?	Is it easier to make these decisions with more experience? How has your confidence changed over time? Do you feel like you know what you're doing?
Support from Professionals	

Tell me about the support that professionals have you when you were making decisions about interventions.	Can you tell me a story about support you received that was helpful/unhelpful? What makes you trust a professional? What makes a therapist good to work with?
Tell me about anything else that you think should be done to help parents to make decisions.	Why would this be helpful?
<u>Closing Question</u> Is there anything else that we haven't mentioned that you would like to talk about?	
<u>Feedback about interview (lamination)</u> What did you think of the questions? Was the order okay? Was there anything else that should have been asked?	

APPENDIX 3: Final Interview Guide

Key Theme Questions	Probe Questions
<u>Opening Questions</u> Tell me about the process of getting your child diagnosed with ASD. How did you feel about the diagnosis? What did you expect was going to happen after you got the diagnosis?	Did you try any interventions before your child was diagnosed? What did you know about autism before your child was diagnosed? What actually happened?
<u>Experience with Interventions</u> Tell me about your experiences with Autism interventions. What do you want from an intervention? Tell me about deciding to stop an intervention approach.	How do you know if an intervention is working? How much change is required? What are your goals from intervention? Why were they important? What are your long term goals? What are your aims for school? What makes you keep going with an intervention? Do you feel pressure to see results? (from early intervention?) Why did you decide this? How long will you try something before deciding to stop? How do you feel if something doesn't work?

Does your child like the interventions they are doing? Tell me about one they like/don't like. Does cost come into decision-making? Do you feel like you have to do a certain amount of therapy?	How long will you do something they don't like? Would you change what you were doing if cost wasn't as issue?
Deciding on Interventions Tell me about the interventions you are doing with your child at the moment. Tell me about the process of deciding on which interventions to implement with your child. What did/do you know about early intervention? Tell me about where you get information about interventions. Tell me about school/your plans for school.	Do you feel the need to "try lots of things"? Why did you decide on this intervention approach? Who makes the decisions in your family? What all the things you have to think about when deciding to try an intervention? What helped you make these decisions? Do you think research? Do you get information from TV? What makes you trust the information you're getting? Does this change what you want out of interventions? If yes, how?
Feelings About Decision-Making	

How does it feel to choose interventions for your child? Is it stressful? Do you feel like you have to justify your decisions to other people? Do you ever doubt your decisions? Tell me about if you have changed because of making these decisions. How confident do you feel in the decisions you are making? Do you have experience making decisions re therapy?	How does making decisions make you feel about yourself as a parent? What makes you doubt them? Is it easier to make these decisions with more experience? How has your confidence changed over time? Do you feel like you know what you're doing?
Support from Professionals Tell me about the support that professionals have you when you were making decisions about interventions. Tell me about anything else that you think should be done to help parents to make decisions.	Can you tell me a story about support you received that was helpful/unhelpful? What makes you trust a professional? What makes a therapist good to work with? What do you want from a therapist? Is it important for therapists to consider the 'bigger picture'? (i.e. holistic perspective of child) Why would this be helpful?
Closing Question Is there anything else that we haven't mentioned that you would like to talk about?	

<u>Feedback about interview (lamination)</u> What did you think of the questions? Was the order okay? Was there anything else that should have been asked?	

Black = original questions

Red = questions added before first interview

Blue = questions added before interview 2

Green = questions added for interviews 3 & 4

Purple = questions added before interview 5

Orange = questions added before interview 6

Pink = questions added before interview 7

Yellow = questions added before interview 8

Dark blue = questions added before interview 9

Demographic Questionnaire: Stage 1

Data collected from this questionnaire will be stored in a de-identified form. Please
note that you are not obligated to answer all of the questions if you do not wish to.

<u>Information About Parent Completing Questionnaire</u>

Parent's Age:

_____

Relationship to child (e.g. mother, father):

_____

Highest level of completed education (e.g. secondary education, undergraduate

degree, masters, etc.):

_____

Accessed (FMC/CEDAS) services for (e.g. assessment, intervention):

_____

Currently accessing services from:

_____

_____

_____

<u>Information About Child with ASD</u>

Child's Age (year; months):

_____

Child's Gender:

_____

Age of child when diagnosed:

_____

Child's Diagnosis (e.g. Autism, Aspergers):

_____

<u>Any Other Comments or Information You Wish to Provide?</u>

_____

_____

_____

_____

_____

Demographic Questionnaire: Stage 2

The purpose of this questionnaire is to gather some basic information about you and your family, and to find out about the things that you have used, or are currently using, to help your child. There are three sections to be completed.

1) Information about Parents/Guardians

Age of Parents/Guardians: Father's age (in years; months) _____

                                       Mother's age (in years; months) _____

Highest level of completed education: *(please circle)*

Father: Year 9   Year 10   Year 11   Year 12

                   TAFE Course   Trade qualification   University certificate

                   University diploma   University degree

                   University post graduate diploma   University research degree

Mother: Year 9   Year 10   Year 11   Year 12

                   TAFE Course   Trade qualification   University certificate

                   University diploma   University degree

                   University post graduate diploma   University research degree

Annual family income: *(please circle)*

                   $0 – $9,999 $10,000 – $24,999 $25,000 – $34,999

                   $35,000 - $49,999 $50,000 – $74,999 $75,000 - $99,999

                   More than $100,000

<u>2) Information about Child</u>

Date of birth: _____

Child's gender: *(please circle)*   Male   Female

Child's diagnosis: _____

CARS score (If known): _____

Age of child when diagnosis was confirmed *(in years and months):*
_____

Age and gender of siblings *(in years; months):*
_____
_____
_____

_____

Any other information?:
_____
_____
_____
_____
_____
_____
_____
_____

3) The purpose of this section is to find out about all the things that you have used, or are currently using, to help your child.

List any interventions /approaches that you have used or are currently using to help your child.	When did you start using this approach? (date in years; months)	When did you finish using this approach? (date in years; months). Write 'present' if you are still using the approach.	**Effectiveness** How effective was this approach in helping your child. *(please circle)*	**Affordability** How affordable was this approach for your family. *(please circle)*	**Feasibility** How feasible was this approach for your family. *(please circle)*
			1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown
			1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown
			1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown
			1 Not at all 2 Somewhat 3 Very	1 Not at all 2 Somewhat 3 Very	1 Not at all 2 Somewhat 3 Very

|			☐ Tick if unknown	☐ Tick if unknown	☐ Tick if unknown
			1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown
			1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown	1 Not at all 2 Somewhat 3 Very ☐ Tick if unknown

Thank you for your time.

PhD Research Project: Summary of Results
Amelia Edwards, PhD Candidate, Flinders University
Email: amelia.edwards@flinders.edu.au

<u>Parental Decision-Making Over Time</u>
Four stages related to decision-making were constructed from the data (represented in the figure below). A brief summary of each of these stages is provided.
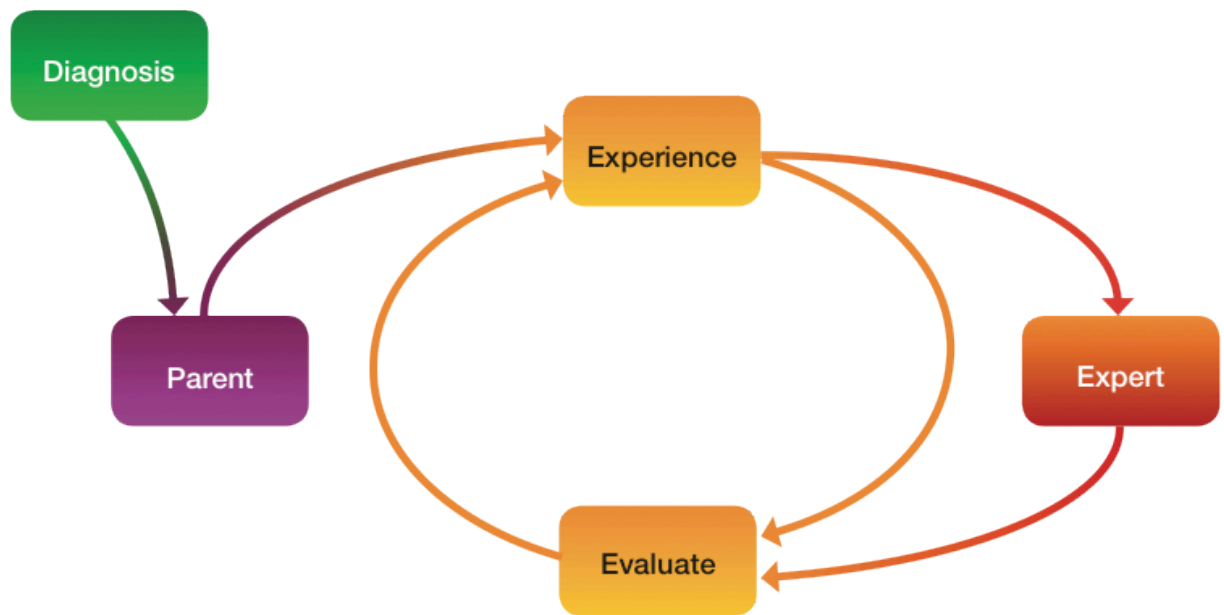
Diagnosis
o Life-changing event
o For many families, diagnosis is met with relief; often ends months of searching for answers
o For many families, while there is a grieving process, there is also hope, as presented with the diagnosis is the idea of early intervention
o Parents have high expectations of intervention and support services

Parent
o Parents often feel unqualified to make such big decisions
o Parents feel the pressure of making the right decision and getting results before the window of early intervention closes.
o Parents may rely on perceptions of services providers as they have no direct experience and are not yet connected with other parents of children with ASD.
o Parents match the needs of their child to a service provider – often it is related to the behaviour that caused concern, leading to diagnosis.
o Parents are unfamiliar with the range of services available and how these services can assist their child, and therefore certain services (e.g. occupational therapy) may be overlooked initially.
o Parents have high expectations of therapy and set broad goals

- Parents have preconceptions about what therapy should look like, e.g. 'more is better'.
- Parents may have very clear beliefs about the cause of their child's ASD, and therefore this will dictate decision-making from the early stages.
- Initially the needs of the family may not be a priority. Families will make great sacrifices in the name of early intervention.
- Parents have to filter their expectations of services through logistics, for example, cost and availability. Often the choice of therapist comes down to factors such as where they are located and who is available.

Experience and Evaluate
- Parents gain experience with therapy and evaluate based on the progress that their child is making
- Learning through trial and error
- Parents feel the pressure of time and worry that they are not getting results fast enough (before the window closes)
- Parents develop a broader understanding of their child's needs (e.g. sensory needs – OT input)
- Parents start to account change/progress to therapy, and make the decision to continue or to stop
- Parents have an increased trust in their own instincts
- Begin to develop support networks and gain information from these sources which information decision-making
- Parents also have developed relationships with therapists and decisions may be informed by information provided by trusted therapists
- Have an increased ability to evaluate information based on their own experiences
- May start to consider broader needs of the family

Expert
- Parents become experts through experiencing ASD interventions and evaluating their experiences.
- Experts construct and test their own theories.
- This is broader than just theories relating to their own child; parents develop theories about ASD, management, early intervention, parenting the child with ASD.
- Parents at this stage feel able to judge therapists and therapy programs
- Have expectations of services and are able to set clear, functional goals
- Share advice/knowledge with others
- Seek advice but evaluate against own situation
- Continue to evaluate decisions made and refine theories

Factors Influencing Decision-Making

A number of factors were found to influence parental decision-making (see figure below), and these factors changed over time. A brief summary of each of these categories is provided below.

1) Experience: this may include experience with decision-making, and experience with ASD interventions

2) Motivation: factors that influence decision-making may include valuing the therapy outcomes, wanting to prepare the child for school and wanting to fulfill role as a parent.

3) Information: information may be gathered from a number of sources, and parents often evaluate information gathered and judge against own knowledge/values.

4) Understanding: this refers to how parents' construct their own understandings of a number of phenomena. For example, what parents believe to be the cause of their child's ASD may influence their choice of intervention, or how parents believe children best learn may influence the therapy approach that is selected.

5) Needs: this may include the perceived needs of the child, and the needs of the family.

6) Logistics: for example, availability of interventions and the ability to meet the requirements of the program.
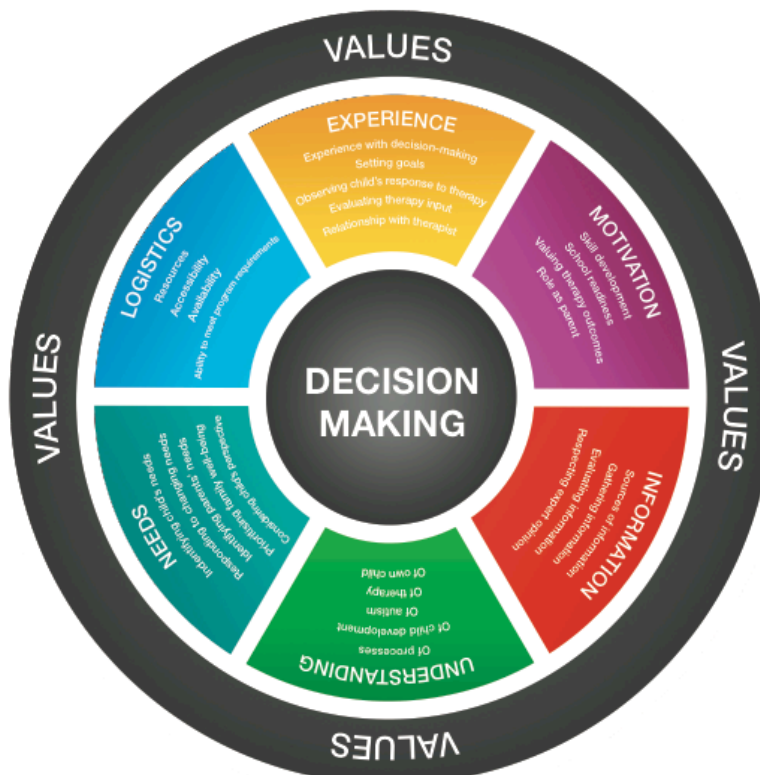
<u>Support for Decision-Making</u>

Current Supports for Decision-Making
At the time of data collection, parents described a model in which they were required to act as the sole decision-makers. Professionals (autism advisors) provided general information, and limited information and support.
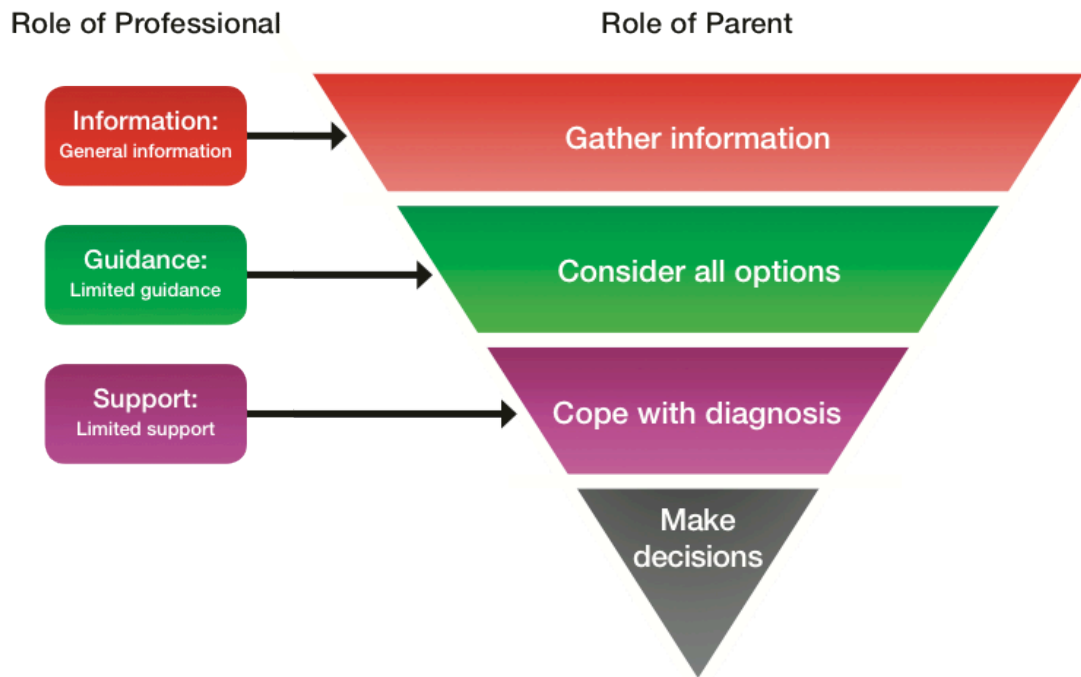
Changes to Current Practice
Parents described a model of collaborative decision-making as the ideal model of practice. Within this model, the role of the professional is to provide the parent with information, guidance and support. The role of the parent is to make the final decision about which interventions to access.
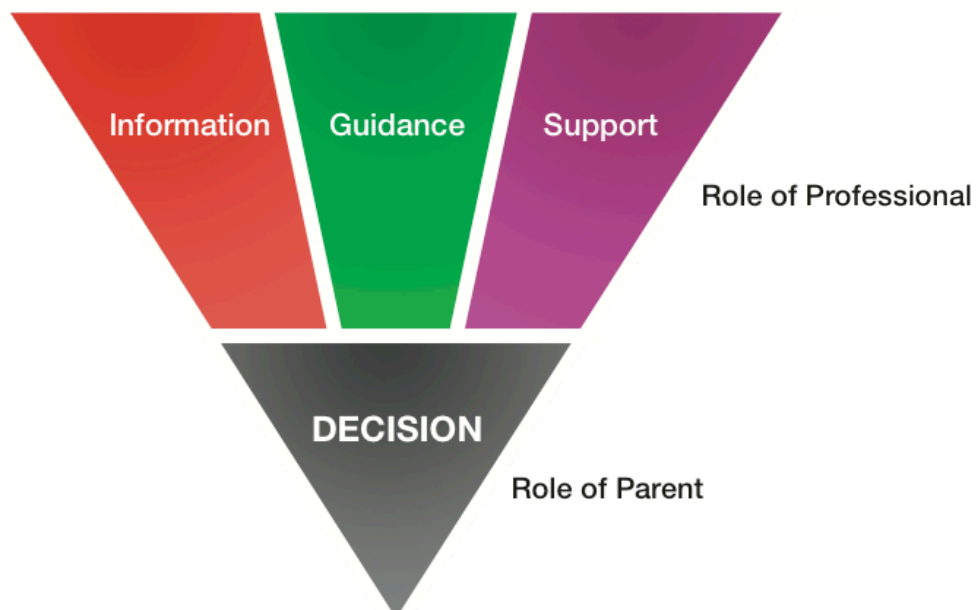
```
┌──────────────────┐                          ┌──────────────────┐
│   Partnership    │                          │ Effective Therapy│
└──────────────────┘                          └──────────────────┘
```
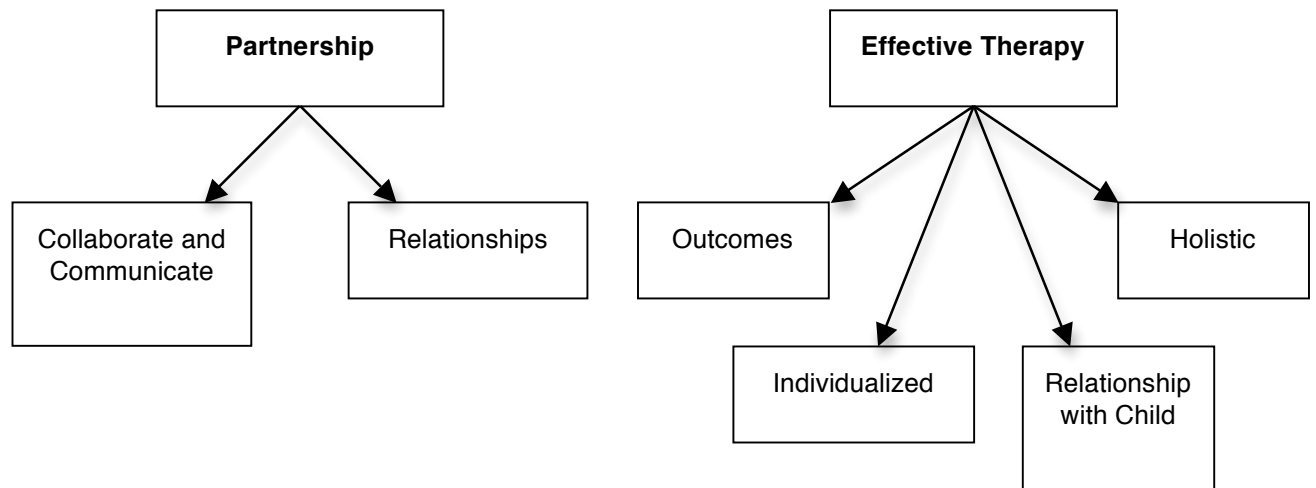
Collaborate and Communicate	Relationships		Outcomes	Holistic

Individualized	Relationship with Child

Parents want to work in **Partnership** with therapists, by:

- **Communicating and Collaborating:** This occurs when therapists seek and provide information to parents, and take on board the knowledge that parents have about their own child. Parents want therapists to communicate openly and honestly, and want therapists to provide feedback about therapy outcomes.
- Establishing a **Relationship**: This often occurs when parents and therapists share the same values. When therapists offer emotional support and go 'above and beyond', it helps to strengthen their relationship with parents.

Most importantly, parents want therapists to deliver **Effective Therapy,** by:
- Delivering therapy that produces positive **outcomes** for the child
- Delivering therapy that is **individualized** for the child.
- Building a **relationship with the child**
- Delivering therapy that is **holistic** and considers the broader needs of the child and family.

"More Than Blowing Bubbles": What Parents Want From Therapists Working With Children With Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neuro-developmental disorder for which there is no known cure. However, participating in intervention programs has been shown to improve the outcomes for children with ASD and their families (Eldevik et al., 2009). The evidence suggests that families of children with ASD often implement multiple intervention approaches concurrently in the hope of improving outcomes for their children. Speech-language pathology (SLP) is the most frequently implemented intervention for children with ASD, followed by 'generic early intervention' and occupational therapy (Carter et al., 2011). The nature of these interventions, particularly in the early years, dictates that therapists will need to work together with families in some capacity.

It is generally accepted that in order for the best outcomes for children with ASD to be achieved, therapists should implement a family-centered model of practice, where parents and therapists collaborate to plan, deliver and evaluate intervention (Hanna & Rodger, 2002). In order for positive outcomes for children with disabilities to be achieved, parents and therapists must work in partnership (Carpenter and Russell, 2005). Parents of children with profound and multiple disabilities are considered to be experts when it comes to their own children, however parents being able to act as the expert and contribute their knowledge and experience is determined whether or not professionals facilitate this (De Geeter, Poppes & Vlaskamp, 2002). Thus, professionals must actively facilitate the collaboration with parents of children

with disabilities. Furthermore, parental perceptions of professionals can influence parents' experiences with specific interventions, with one study reporting that parents often perceive the therapist as more important than the therapy itself (Hinojosa, 1990). Thus, it is reasonable to conclude that therapists have the potential to influence the outcomes of intervention programs, based not only on the specific therapy that is provided but also on the relationship that is established with parents. Though the importance of therapists working in collaboration with parents of children with ASD has been established (Hanna & Rodger, 2002), parental perspectives on the qualities they seek in therapists have been not been widely examined.

What Parents Want From Therapists

Within this research, a therapist working with children with ASD was defined as an allied health professional delivering intervention to a child with ASD, including SLPs, occupational therapists, psychologists and applied behaviour analysis (ABA) therapists. Overall, there is limited evidence examining the qualities that parents seek in therapists working with children with ASD. However, intervention approaches involving parent training have been reported to be effective in improving outcomes for children with ASD (McConachie & Diggle, 2007; Siller, Hutman & Sigman, 2013). Furthermore, parents perceive parent training to be an effective approach to intervention (Hume, Bellini & Pratt, 2005), and report an increased understanding of ASD (Cutress & Muncer, 2014) and reduced parenting stress (Keen, Couzens, Muspratt & Rodger, 2010) as a result of completing parent-training intervention programs. Thus, the involvement of parents in intervention for children with ASD is important not only to achieve intervention outcomes, but also in terms of supporting parents.

A broader search of the literature relating to parent interactions with allied health professionals was undertaken to identify specific qualities that are considered important to parents when working with therapists. It has been reported that parents' perceptions of caring from and collaboration with therapists were the only significant predictors of satisfaction within a rehabilitation service (Bachner, Carmel, Lubetzky, Heiman & Galil, 2006) and parental satisfaction in support services for children with learning disabilities is lower when parents feel that their expertise regarding their child own child is overlooked (Robert, Leblanc & Boyer, 2014). These findings reinforce the importance of therapists and professionals working in collaboration. Furthermore, in addition to working in collaboration, it has been identified that parents of children with ASD want therapists to communicate openly and share information (Auert, Trembath, Arciuli & Thomas, 2012). The findings of this study, investigating parents' experiences of accessing evidence-based SLP services for their children with ASD, also indicated that while some parents expected that EBP would be implemented, other parents expressed that as long as their child was making progress, it was not critical that EBP was being implemented. The link between parental satisfaction and therapy outcomes has previously been established, with parents of children with an intellectual disability reporting that they were satisfied with SLP services if they perceived that the therapy was 'fixing the problem' and the child was making progress (Carroll, 2010). Thus, a review of the literature suggests that while parents value working in collaboration with parents, satisfaction may also be linked to the child's progress in therapy.

Current Study

The aim of this paper is to explore the qualities that parents want in therapists working with children with ASD. It is important to consider parental perspectives

given that previous research indicates that parents and therapists may not necessarily have the same perceptions (Marshall, Goldbart & Phillips, 2007), and therefore therapists' perceptions of how they should work with parents may not necessarily line up with what parents want. Furthermore, having established the potential for the partnership between parents and therapists to influence on therapy outcomes and parental satisfaction, it is important to ensure that therapists have an insight into parents' perspectives, in order to inform and support their practice.

The data presented in this paper was part of a larger study exploring how parents of children with ASD make decisions about which intervention approaches to access. A constructivist grounded theory (CGT) methodology was deemed to be an appropriate methodology to explore this topic. Constructivist grounded theory is a qualitative research methodology, which provides a framework of processes and principles to facilitate an understanding common social life patterns (Charmaz, 2006). As opposed to earlier approaches to grounded theory, within a constructivist approach, theory is viewed as being constructed through interactions between the participants, the researcher and the phenomenon of study. In order for this to occur, an iterative research process is implemented, in which initial data collection and analysis shapes subsequent data collection and analysis (Charmaz, 2006) and therefore the researcher is open to the ideas and experiences of the participants relating to the phenomenon under investigation. Semi-structured interviewing is frequently used as a method of data collection within constructivist grounded theory, where the researcher uses an interview guide to ensure that the same basic lines of questioning are pursued with each participant while also providing flexibility with regards to the wording of questions and the ability to follow up topics raised by participants (Patton, 2002). Within constructivist grounded theory studies, there is an argument for increased

involvement of participants in construction of the interview guide, given the need for questions to fit the experiences of the participants (Charmaz, 2006).

Method

The data presented within this paper emerged from a larger constructivist grounded theory study examining how parents of children with ASD make decisions about which intervention approaches to access. This research, which received ethical approval from the Southern Adelaide Clinical Human Research Ethics Committee, was conducted in two stages. The first stage involved the construction of the interview guide. The second stage was a larger CGT matrix study, with semi-structured interviewing the primary source of data collection, in addition to a demographic questionnaire and researcher journaling. Figure 1 provides an overview of how the subset of data presented within this paper fits within the larger constructivist grounded theory study.
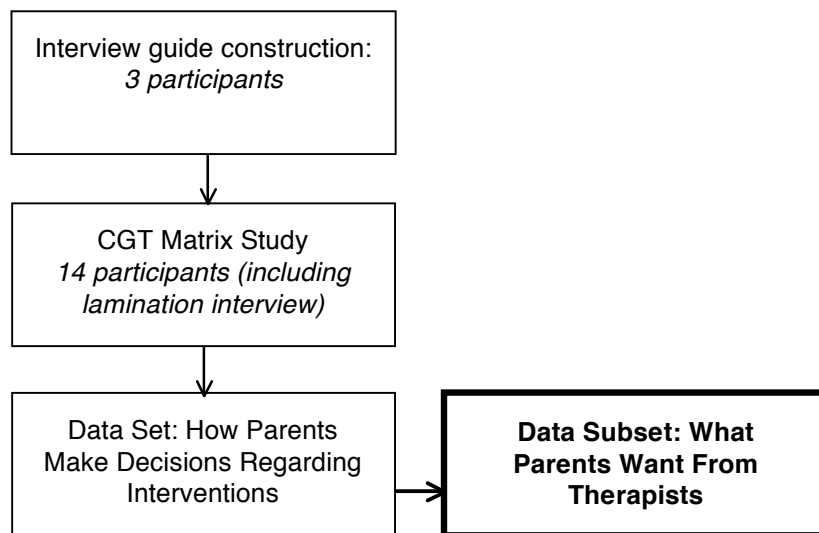

Figure 1. Research process.

The initial interview audio recordings within the larger CGT study were transcribed verbatim into Microsoft Word and de-identified, with pseudonyms allocated to

participants and family members. Names of organisations and professionals were substituted for broader terms (e.g. the acronym SLP replaced names of SLPs). Line-by-line coding was then applied to the initial interview transcripts. One of the categories that emerged from the early interviews in the CGT study was the influence of experience on parental decision-making, and specifically, how interactions with therapists can shape parents' experiences. Thus, the decision was made by the research team to pursue this topic in subsequent interviews. The aim therefore in exploring this topic was not to present a substantive theory, but rather to explore parents' perspectives on working with therapists. Consequently, thematic analysis was undertaken on this subset of data, whereby the coded data relating to the qualities parents seek in therapists was examined for patterns and themes (Braun & Clarke, 2006).

Participants

Participants for both the interview guide construction and the CGT matrix stages of the study were recruited from public and private agencies serving children with ASD in South Australia. This ensured that a range of experiences was encapsulated within the data. The eligibility criterion for the study was parents who had a child diagnosed with autism in the last five years, given that intervention methods have changed over time. At the time of data collection, the DSM-V (American Psychiatric Association, 2013) diagnostic criteria had not been released, and therefore autism existed as a sub-diagnosis of ASD. Convenience sampling was implemented in this study, whereby the participants who met the eligibility criteria were selected based on their availability. Thus, the participant sample was not balanced for gender, age or any other demographic attributes. Three female participants were recruited into the first stage of the study. Fourteen participants (11 women and three men) from 12 family units were

interviewed as part of the second stage of the study. All 17 participants had male children with autism, with ages varying from two to 11;3. The findings relating to the qualities that parents seek in therapists were consistent across the span of ages of the participants' children. Refer to table 1 and table 2 for summaries of key participant demographic information. The questionnaire used to collect the demographic information within the CGT matrix study has been included as an Appendix.

Table 1. Key participant demographic information for Stage 1 participants.

Participants	Highest level of completed education (mother)	Child's gender	Child's age at diagnosis	CARS[a] score at diagnosis
Jane	University degree	Male	2;3	43
Marjorie	Secondary school	Male	4;0	N/A
Rachael	University degree	Male	5;2	30.5

Table 2. Key participant demographic information for Stage 2 participants.

Participants	Highest level of completed education (father)	Highest level of completed education (mother)	Child's gender	Child's age at diagnosis	CARS[a] score at diagnosis
Elka	Trade qualification	Trade qualification	Male	3;6	46
Adriana	Trade qualification	Diploma	Male	2;10	39
Michelle	Trade qualification	Diploma	Male	8;10	39.5
Ellen & David	University research degree	University degree	Male	1;8	34.5
Nicola	Trade qualification	Diploma	Male	N/A	N/A
Debra	University degree	University degree	Male	1;8	32
Hannah	University post graduate	University post graduate	Male	1;10	33

	diploma	diploma			
Fiona	Diploma	University degree	Male	4;6	N/A
Deepak	Research higher degree	University degree	Male	5;3	45.5
Sophie	Trade qualification	Secondary school	Male	3;0	31.5
Alice	Diploma	Diploma	Male	8;5	N/A
Joanna & Russell	Trade qualification	University degree	Male	3;6	N/A

[a] Childhood Autism Rating Scale (Schopler, Reichler, DeVellis & Daly, 1980)

Interview Guide Construction

The first researcher met individually with three parents of children with ASD (who were not involved in the subsequent semi-structured interviews) to assist with the development of an interview guide. Participants were asked to generate questions that they felt would allow them to share their experiences with decision-making. The questions were compiled and grouped into broad categories (e.g. journey to diagnosis, deciding on interventions, experience with interventions). The interview guide was reviewed within the research team and no amendments were made. Topics covered within the semi-structured interview included: getting a diagnosis, selecting intervention approaches, support available for decision-making and changes in decision-making over time. A copy of the original interview guide is included as an Appendix.

Data Sources

Semi-Structured Interviews. The first researcher met with participants at a location of their choosing; most chose to meet at their home, but a few participants selected at Flinders University or a local café. On average, interviews ran for 60 minutes, though interviews where two parents were involved naturally ran longer. The first semi-structured interview was conducted as a lamination interview, whereby the

participant was asked for feedback regarding the interview guide and structure of the interview. The participant provided feedback that the interview guide was appropriate and did not suggest any changes. Line-by-line coding was applied to the initial interview transcripts within the larger CGT study. As codes began to emerge from the data, the interview guide was updated to further investigate and confirm initial findings. Case in point, the initial codes regarding the role of therapists in shaping experiences and informing decision-making prompted the researchers to investigate the qualities parents seek in therapists more in depth. Data collection continued until 14 participants had been interviewed, at which point data saturation had been achieved as no new insights or information was raised. A sample size of 14 is considered to be an adequate number of participants to achieve data saturation within qualitative research (Francis et al., 2010).

Questionnaire. At the conclusion of the semi-structured interview, participants were asked to complete a questionnaire to collect demographic information, as well as information regarding the interventions implemented with their child. Within the questionnaire, parents were asked to provide a timeframe for each intervention and to rate each intervention in terms of effectiveness, affordability and feasibility on three-point Likert scales. The development of this questionnaire is detailed further in the larger CGT study (authors, manuscripts in preparation). A copy of the questionnaire is available as an Appendix.

Researcher Journaling. Following each interview, the first researcher recorded field notes and relevant observations to add depth to during data analysis. The first researcher reflected on several elements of the interview, including the language used by participants to describe their experiences and the non-verbal communication of the participants during the interview.

Analysis

Once the 14 interviews has been undertaken, thematic analysis of the subset of data relating to the qualities that parents' seek in therapists was undertaken. Coding had already been undertaken on the data in relation to the larger CGT study, however initial coding was re-applied to this subset of data, with a focus on the qualities that parents want in therapists. The second author then reviewed the initial coding, and agreed that the coding had accurately captured the meaning of the data. The initial coding was refined, and categories of data and potential themes began to emerge. A mind map was generated to represent the potential categories and themes of data. In discussion with the second author, refinements to the mind map, and subsequently to the data analysis, were made. Key phrases and terminology used by participants were used to label themes and categories, and categories and themes were finalized. The participants were sent a summary of the findings (central themes and core categories) in order to ensure that the findings accurately represented the participants' perspectives. None of the participants requested any changes and consequently data analysis was deemed to be complete. Refer to table 3 for a representation of the process of thematic analysis.

Table 3: An example of data coding and refinement of themes.

Quote from participant	"I expect you to give me written feedback about what's going on."
Initial Code	Sharing Information
Category	Collaborate and Communicate
Theme	Partnership: I need you to give me more than blowing bubbles

Credibility and Trustworthiness

Guba and Lincoln (1994) assert that credibility and trustworthiness are two important factors to consider when designing and implementing qualitative research. In order to increase the credibility of this study, data triangulation occurred, whereby data collected via interviewing, questionnaire and researcher journaling were all incorporated to allow conclusions about the data to be formed. Additionally, participants were given the opportunity to review their verbatim interview transcript to ensure that it was an accurate reflection of the interview before it was added to the data pool, as well as being sent a summary of the findings to ensure that the interpretation of the data was representative of their perspectives. Terminology and phrases used by participants during interviews were incorporated into the names of categories and themes, to ensure that the data analysis reflected the participants' voices (for example, the participants in this study used the term 'want' repeatedly when discussing the qualities that they seek in therapists and hence has been used within this paper). Furthermore, a number of direct quotes from participants are provided within each of the categories below, to support and provide transparency regarding the researchers' interpretation of the data. Having the second author review coding at all stages of data analysis ensured that accurate and thorough analysis occurred.

Given that the foundation of methodology for this study is the assumption that knowledge is constructed through the interaction between the researcher and participants, it is important to acknowledge the position of the researchers within this study. The first author is a practicing SLP and researcher, who believes that family-

centered practice should be implemented by therapists when working with children with ASD. The second, third and fourth researchers are experienced researchers and qualified allied health professionals, who also consider family-centered practice to be best practice when working with families of children with ASD.

Results

The findings of this study are presented within two central themes, *Partnership: I need you to give me more than blowing bubbles* and *Effective Therapy: Nobody wants to go to therapy and get nothing out of it*, which together summarize what parents of children with ASD want from therapists. Both themes are presented below, and the core categories within each theme are also examined. A visual representation of the results is also provided in figure 2.
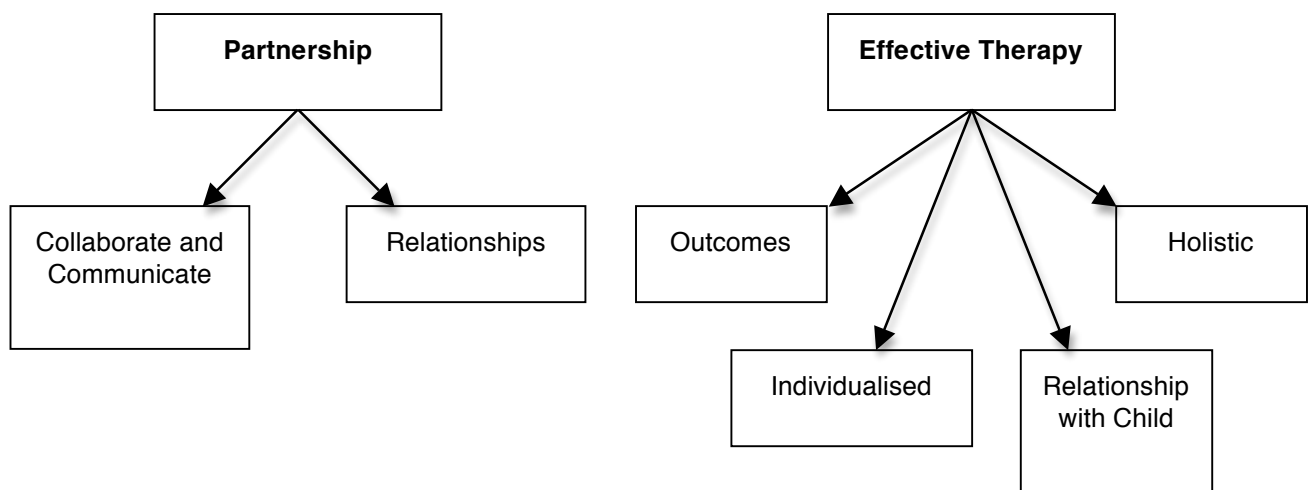
Figure 2. Model representing the themes and categories of the data.

Theme #1 - Partnership: "I need you to give me more than blowing bubbles"

The first theme to emerge from the data was *Partnership*, in which participants described the need for therapists to provide more than just therapy in isolation. Rather, the participants in this study expressed the need for therapists to establish a relationship, and to work in collaboration with parents. Debra recounted

her experience of working with therapists, and her desire for therapists to share information and work collaboratively with her.

> "We've seen I don't know how many speech therapists, maybe about 12 and seriously if I have one more speech therapist that blows bubbles at Henry and taps her chest and says, 'More, you want more?', I'll just go, 'Okay, I need more!'. After four years I need you to give me more than blowing bubbles. And the same with OT. Put him on a trampoline, put him in a ball pit, put him in a hammock. Please tell me what you're doing, please tell me what the goals are, what are you working on? How is this helping? What do you see? Why is he doing that?"

The belief that therapists need to provide more than just therapy emerged consistently from the data in this study, and the theme of *Partnership* evolved as a product of two core categories; '*Collaborate and Communicate*' and '*Relationships*'.

Collaborate and Communicate

The first core category, '*Collaborate and Communicate*', summarizes the need for therapists to work in collaboration with parents and communicate with parents throughout the therapeutic journey, in order to achieve the best outcomes for their children. The participants in this study spoke of their strong belief that therapy should be embarked upon as a joint enterprise, with therapists employing their knowledge and experience, and parents contributing their goals for therapy and knowledge of their child. Hannah recounted an interaction with her son's SLP in which therapy goals and processes were established collaboratively.

> "I did say to her, 'Look, I really want him to talk, it's really important for me that he starts talking, and starts communicating with me in that way', and so that's why, she then went on to suggest sign language, she went on to suggest

flashcards, she went on to suggest that I take photos of everything ... it's great that she suggests these things, and using her experience and what she knows, she's the therapist, if she just lets me know what's next and what will get us to that goal, that's great."

A number of participants, including Alice, identified that it was important for therapists to be experienced, and in particular, to have experience working with children with ASD.

"I suppose, for me, you feel comfortable when they've had a lot of experience, when it seems like they really know their stuff."

However, though experience was considered important, several participants identified open and honest communication as being equally critical. Joanna spoke of the need for therapists to be honest about the scope of their knowledge.

"I want someone who is honest, and that means honest if they're not sure. I actually want somebody to not pretend that they're an expert in a particular area if they're not an expert."

Joanna also identified the value of the information that parents are able to provide to assist with therapy planning and implementation, and expressed frustration that her input was often not considered.

"I want someone to listen to me, because for six years, … we've been with him day and night, and we've got information that can help."

Other participants had encountered the other extreme, whereby therapists would seek information but would not reciprocate in providing information, as described by Fiona.

"I want lots of information. I want lots of information about what they're doing, why they're doing it and how can I see that it's working? … If it's not

working, it's not working. That's okay. But talk to me about well then, what does that mean? Should we keep seeing you? … I want an action plan … I want that, and it's really hard. I find that really hard. I find they want lots of information from you but they're loathe to give you information."

Therapists working collaboratively and communicating openly was firmly established as important by the participants in this study. Moreover, Nicola argued that a collaborative dynamic is not established spontaneously, and that it the responsibility of therapists to facilitate this collaboration.

"I think parents need to - it's important that they are encouraged to have a voice, and that therapists don't take it personally, 'I don't think this is working, or can we do it this way?' ... And therapists encouraging parents to actually do that. Which then empowers the parents to actually feel like they can actually do something with these kids, that they may feel like have no hope."

Relationships

The second core category within the theme '*Partnership*' is the concept of '*Relationships*'. The participants in this study identified the importance of a relationship between parents and therapists being established, and a number of factors that they felt contributed to this. Fiona felt that therapists being willing to make a long-term commitment to working with her child was important in allowing the parent-therapist relationship to develop.

"I want someone who's going to take a long term view … I want to be able to envisage them working with my son for as long as they need to, to reach whatever goals they think they can reach with him … I want to feel like we've got a relationship with them."

One factor that emerged on a number of occasions as contributing to building relationships between therapists and parents was the concept of therapists going *above and beyond*. Ellen recounted the story of the support that a SLP provided to her and her husband after receiving their son's initial diagnosis of ASD.

> "(The SLP) after that first meeting said, 'Look, what evening are you and your husband free? I'm always very concerned for parents that - at this stage they have no support and they don't really know what's happening next, I'll come round for an evening and I will just tell you everything I know and you ask me questions.' So she was an absolute lifeline. … It meant we've got a very good relationship with (her)."

Similarly, Hannah viewed the advice that her son's SLP had provided regarding an occasional care centre as going above and beyond her role as a SLP, but an act that had strengthened her relationship with the SLP.

> "I don't think she had to give me that much information, I really don't. I think really I mean her role is to just assist the speech therapy, but I think it was really handy of her and it was really good of her to give me that advice, because it then made me, really, I don't know, cement the relationship with her I guess in a way."

Another factor identified by participants as contributing to strengthening the relationships between parents and therapists was the concept of *shared values*. Participants reflected that they were better able to work with therapists when they shared like perspectives regarding child development and behaviour management approaches. Michelle recounted her experience of finding a psychologist who shared her philosophy about behaviour management for her sons with ASD.

"She was more on my train of thought as in how to bring them up. Because there's me thinking, I don't know, should I take the stars off? This person said I shouldn't. I think you should. So at least she's telling me what I think anyway, she's just backing me up, which is a good thing for me to hear that I am doing the right thing."

In contrast, Fiona experienced a conflict of values when working with her son's psychologist, which impacted on her ability to establish a therapeutic relationship.

"I thought she was really inappropriate. I thought that the things that she was suggesting that we do around managing our son's behaviour, I would call abusive."

The participants also identified that emotional support offered by therapists was important, not only in terms of establishing and maintaining relationships with therapists, but for their own well-being, as described by Sophie.

"Just the fact they got a little personal sometimes as well, like I remember ringing one of the girls who diagnosed him the next day and she was really nice. She said you know, 'you're upset and maybe you could speak to a psychologist'. Like you know they didn't sort of hesitate to comfort you, and I thought that was a nice thing. Because it's not just about therapy for Andrew. You know, it's about us being mentally able to do it ourselves."

In summary, the participants in this study identified the importance of therapists working in collaboration with families and establishing a therapeutic relationship with parents, in order for the best outcomes for their children to be achieved.

Theme #2: "Effective Therapy: Nobody wants to go to therapy and get nothing out of it"

The second theme that emerged from the data within this study was the concept of *Effective Therapy*. The participants in this study reported that ultimately they want therapists who will deliver effective therapy, and identified factors that they felt needed to be present in order for this to happen. Elka summarized this sentiment, asserting that her measure of a therapist is based on the outcomes of therapy that they deliver.

> "What I'm paying for you to do is get the most out of this therapy session, and if you're going to get the most it, I don't really care how you are and how you're doing, keep doing it. That's definitely would be my thoughts, absolutely. Nobody wants to go to therapy and get nothing out of it, and think the lady's nice or you know, my kid likes them, you know he's not learning anything and he's not being pushed."

The theme *Effective Therapy* is composed of four core categories; *Outcomes, Holistic Approach, Individualized Therapy* and *Relationship with Child*. Each of these four categories is explored in more detail below.

Outcomes

The first core category, *Outcomes*, was central to the concept of *Effective Therapy*. The participants in this study felt strongly that the central role of a therapist was to provide therapy that produces positive outcomes. Debra stated that she was willing to persist with a therapist because the therapist was able to produce results for her child.

> "Now I've got an ABA/VB therapist working with him, getting him to say 'yes' and 'no' and 'I want' and things that we can use around the house and she is making amazing differences with Henry. She's a pain in the neck to

deal with….but she's just the best therapist that we've ever had and she's getting the results."

Similarly, Elka felt that though parents may not initially connect with a therapist, if the therapist is able to prove him or herself by producing outcomes for their child, parents might change their opinion.

"People can only see what sort of speech therapist they like or don't like, and I think it all comes down to whether it's working with your child, to whether you like them or not, you know what I mean? So you might not like them at first, but then you think, 'Hang on a second, this, wow, oh, I like it'."

The participants in this study reported that they wanted therapists to have high expectations and to persist in achieving outcomes with their children, as described by Adriana.

"I suppose if they can pick up on the cues of the child, um, and not you know just give up, because sometimes you know, these kids don't want a bar of them, but if they can still keep trying a little bit, not just give up."

Holistic Approach

Though the participants in this study considered producing outcomes as an important measure of whether therapy was effective, there were additional factors that participants perceived as important in contributing to effective therapy. The first of these factors was a holistic approach to therapy. The parents spoke of the need for therapists to consider the overall needs of their child. Fiona recounted a story of when her son had a meltdown during an occupational therapy group, and her disappointment that the therapist did not acknowledge her son's behaviour, but rather focused only on his fine motor skills.

"How can you support him with his pencil grip if you're not addressing the fact that his pencil grip is so weak that he becomes so distressed by it that he's ruining the room? How can you ignore that and still keep talking about his muscles in his fingers?…You're only looking at a tenth of the picture, to me. You're not looking at that big picture."

Additionally, the participants in this study wanted therapists to consider their children in a broader context than just therapy sessions. Joanna reported feeling frustrated when a psychologist failed to acknowledge that her son's behaviour in a therapy session might not be an accurate representation of the behaviour she was dealing with home.

"She was really nice, but then, when met with Nicholas, (she was) going, 'This is fine'. You're left going, but hang on a second, you're giving him one-on-one attention. Yeah, it's fine. If I could do that for my life and if he could have everybody in his life give him one-on-one attention doing exactly what he wants, I would be (fine) too."

Individualised Therapy

The participants in this study also perceived the need for therapy to be individualized in order for it to be effective. The participants, including Hannah, felt that it was important for therapists to understand the specific needs of their child, and to tailor their therapy approach to suit their child's needs.

"That they understand my child, that's huge for me, that they understand Jacob. And they're willing to work with Jacob at the pace that he's at and the way that he is. That for me is really, really important. And not that Jacob's just another number, or just another client."

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Likewise, Joanna asserted that she wanted therapists to provide therapy addressing her child's specific needs.

> "I want someone to actually address him, look at him and don't assume that he needs social skills training because he's on the spectrum… It just makes no sense to me, because people who are professionals surely need to know that one thing that you know about autism is that kids are all different. So, for me, I just want somebody to address his issues."

Relationship with Child

Finally, the participants in this study reported that it was important their child liked and had a relationship with their therapists, as described by Hannah.

> "I'd like them to be able to have that sort of bond I suppose with them, that they're a therapist and client, but yeah, I just like to see that bond as well. That they are working, and it's working for Jacob."

In Sophie's experience, when her son didn't have a good relationship with his therapist, this made it difficult to continue with a therapy program.

> "Sometimes Andrew just doesn't like someone. If their voice is too loud or - so that kind of slants how you feel about them. We did have one person…he didn't like and that was always a trial."

Overall, all the participants in this study maintained that achieving positive outcomes for their children was the most important quality that they wanted in therapists. However, the participants also recognized that there are qualities that facilitate these outcomes being achieved.

Discussion

Within this data exploring what parents want from therapists, two central themes emerged: the concept that parents and therapists need to work in *Partnership*

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to achieve therapy outcomes, and the factors that parents believe should be present in order for *Effective Therapy* to be implemented. One of the interesting findings that emerged from this study was the value that the participants placed on therapists achieving positive outcomes for their children, above all other factors. In previous studies (Bachner et al., 2006; Caroll, 2010), parental satisfaction has been reported to be higher where therapists work in collaboration with parents. While it is certainly the case that the participants in this study want to work in collaboration with therapists, it is also the case that they placed more value on whether the therapist was able to produce positive outcomes for their child. Moreover, the participants in this study were willing to sacrifice other factors, for example, having a therapeutic relationship with the therapist, if they perceived that their child was making progress. A similar finding was reported by Auert et al. (2012), which examined parents' experiences of accessing evidence-based SLP services for their children with ASD. Although some of the participants in the study expected therapists to implement evidence-based practice, other participants did not believe this was critical, as long as their child made progress in therapy (Auert et al., 2012). Thus, parents consider the ability of therapists to produce positive outcomes for their children with ASD to be very important.

This is not to say that the need for therapists to work in partnership with parents should be disregarded, because in actual fact, the participants in the current study considered a situation in which they were working in partnership with therapists and effective therapy was delivered to be ideal scenario. However the participants in this maintained that partnership alone is not enough, which is understandable, given that the aim of intervention for a child with ASD is to develop a specific skill or behaviour. Therefore, the challenge for therapists from a clinical perspective is being able to work in partnership with parents while achieving the positive outcomes, which

are valued so highly by parents. Not only has this been identified by the participants in this study as the way in which they want to work with therapists, but the literature also cites family-centered practice, in which collaboration occurs regarding service planning, delivery and evaluation, as best practice when working with families of children with disabilities (Carpenter & Russell, 2005; Hanna & Rodger, 2002). The experiences of the participants in the current study and previous studies (Auert et al., 2012) however indicate that despite having been established as best practice, not all families feel that they are working in collaboration with their child's therapists. The reasons for this may be wide and varied (e.g., expectations of family, therapists' level of experience), and further research into the barriers that prevent therapists from working in collaboration with parents of children with ASD would be beneficial. Regardless of the cause, the findings of this study would indicate that further support of trainee therapists, including SLPs, with regard to the implementation of family-centered practice would be beneficial. It is potentially the case that though therapists acknowledge the importance of collaboration with parents (Watts Pappas, McLeod, McAllister & McKinnon, 2008), specific practices implemented by therapists may not consistently embody this approach. Offering trainee therapists increased opportunities to practice implementing family-centered practices, and specifically how to work in coloration and communicate with parents of children with ASD, may facilitate therapists to transfer the principle of family-centeredness from theory to practice.

Another strategy to the implementation of family-centered practice is for therapists to routinely use goal setting and specific outcome measures in collaboration with parents during initial intervention planning. Measurement tools such as Goal Attainment Scaling (Kiresuk, Smith & Cardillo, 1994) offer therapists a means by which to measure progress due to intervention (Schlosser, 2004). Furthermore,

measurement tools can serve as an initial point of discussion in which parents identify their goals for intervention, and therapists explain the steps in achieving these goals. Alternatively, formal and informal measures specific to each discipline can be implemented to measure outcomes from therapy programs (e.g. progress record of an ABA program). Incorporating outcome measurement tools as part of standard practice within intervention planning fosters collaboration, with therapists and parents working together towards a specific positive outcome for the child.

Participants in this study also identified the need for therapists to communicate honestly and openly, and to share the reasoning behind their clinical decision-making. The participants felt it was important that they understood the necessary steps to achieve therapy goals, and how therapy activities were targeting specific goals. This finding once again supported the results of the study by Auert et al. (2012), in which participants had identified open communication as an important skill for therapists to possess. Interestingly though, the participants in the current study wanted therapists to be open and honest in particular when therapy wasn't achieving the desired outcomes. This is perhaps a more difficult conversation for therapists to have with parents, but is something that the participants in this study valued equally as much as communicating about therapy when positive outcomes were being achieved. Thus, it is important for therapists to be able to engage in reflective practice, and to be able to give parents open and honest feedback about all aspects of a child's progress and participation in a therapy program.

Clinical implications

The participants in this study considered therapists being able to produce positive outcomes for their child to be very important. This highlights the need for therapists to work collaboratively with parents to set and measure therapy outcomes.

The participants in this study also spoke of the need for therapists to explain their clinical reasoning, so that parents are able to develop a greater understanding of their child's ASD. Thus, therapists should allow time during therapy sessions to allow for discussion of the child's progress with parents and trainee therapists should be supported to develop skills in collaborating with families and other professionals.

Limitations

As is often the case with qualitative research, the results of this study cannot be generalized beyond the participants who were involved in this study. This is especially the case given that convenience sampling was implemented within this study, meaning that there is a potential that the participants who opted into this study had particularly strong opinions regarding the topic under investigation. Furthermore, the participants' perspectives were based on experiences in one region, and service provision can vary significantly across the county and internationally. However, the current study provides a useful insight into these parents' perspectives on the qualities that they want in therapists, and in particular the value that parents may place on positive outcomes being produced as a result of therapy input.

Future research

This study only considered the perspectives of parents relating to the qualities that they want in therapists. It would be useful therefore for further research to not only explore the perspectives of therapists, but also to observe parent-therapy interactions, to determine if the perceptions of parents and therapists are reflected in their interactions. The results of the current study also indicated that there might be some potential barriers to therapists working in collaboration with parents. It would be beneficial to explore this further, and more importantly, to consider potential strategies to overcome barriers and support parent-therapists collaboration. Finally,

given the emphasis that the participants in this study placed on achieving outcomes, it would be useful to explore in further detail parents' perspectives on therapy outcomes, and specifically, what level of change they consider necessary to continue with a therapy program.

Conclusion

The findings of this study, exploring what parents of children with ASD want from therapists, led to the emergence of two core themes; *Partnership* and *Effective Therapy*. The first theme reflected parents desire to work in partnership with therapists, and the need for therapists to collaborate and communicate openly, as well as forming a relationship with parents. The second theme reflected the participants' want for therapists to provide effective therapy that produces positive outcomes for their children, and the features that parents perceive as needing to be present in order for effective therapy to be delivered. The participants in this study reflected that working in partnership with therapists to deliver effective therapy is the ideal scenario, however there was also a sense from the participants in this study that they were willing to settle for therapy where other factors may not be present, as long as it produces positive outcomes. Thus, it can be argued that it is the responsibility of therapists to facilitate a partnership with families in order to deliver effective therapy, armed with the knowledge that working in collaboration with parents not only increasing parental satisfaction, but can improve therapy outcomes.

Acknowledgements

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Appendix 7: Original Article (currently under review in "Child: Care, Health & Development")

"The Early Intervention Trap": The Impact of the Early Intervention Message on Parents of Children with Autism Spectrum Disorder.

Abstract

Background There is strong evidence that early intervention can improve the outcomes for children with autism spectrum disorder (ASD), and consequently, the importance of early intervention has been widely promoted to families of children with ASD. However, the impact of the early intervention message on parents of children with ASD has not been widely examined.

Methods This study used qualitative methods to explore the impact of the early intervention message on parents of children with ASD. Semi-structured interviews were undertaken with 14 participants from 12 family units to explore the impact of the early intervention message on parents of children with autism spectrum disorder. Thematic analysis was undertaken on the data.

Results Three central themes were constructed following data analysis: (1) parents' initial perceptions of early intervention following their child's diagnosis with ASD, (2) the consequences (both intended and unintended) of the early intervention message, and (3) parents' perspectives on life after early intervention. The results of this study indicated that parents were acutely aware of the importance of early intervention, and though this provided parents with hope immediately post-diagnosis, it also placed pressure on parental decision-making regarding which intervention approaches to access for their children with ASD.

Conclusions The results of this study highlighted the importance of carefully considering how health messages, specifically the importance of early intervention, are communicated to families of children with ASD. Furthermore, the findings of this study also highlight the need for allied health professionals to communicate openly with parents about the anticipated outcomes of early intervention programs.

Introduction

Early intervention has been found to significantly improve the outcomes for children with ASD (Eldevik et al., 2009; Roberts & Prior, 2006), and consequently, the importance of early intervention is a powerful and widely accepted health message, which has shaped health policies and service delivery models. The term 'health message' refers to a persuasive message designed to influence behaviour within the field of healthcare (Gallagher & Updegraff, 2012). Within this paper, the term 'early intervention message' is used to refer to the widespread promotion of early intervention as being critical in improving the outcomes for children with ASD with the aim of engaging families with early intervention services.

Given the significant evidence regarding the effectiveness of early intervention (Eldevik et al., 2009; Roberts & Prior, 2006), promotion of early intervention to families of children with ASD is logical and effective in encouraging parents to participate in early intervention programs (Daniel et al., 2009). There does however need to be careful consideration about how health messages are communicated to populations of parents, given that there is the potential for inadvertent harm if health messages are misinterpreted (Lawless et al., 2014; Rossi et al., 2013).

Based on the high uptake of early intervention services (Carter et al., 2011), it is reasonable to conclude that parents of children with ASD have received the early

intervention message. There has, however, been limited investigation into the broader impact of early intervention as a health promotion strategy on parents of children with ASD. In a review of post-diagnosis support for families of children with ASD, parents reported that they were acutely aware of the need to intervene early, with delays in accessing intervention adding to their distress post-diagnosis (Valentine et al., 2010). It has also been reported that parents of children with ASD want to commence intervention as quickly as possible, and are concerned about the 'time wasted' in searching for an ASD diagnosis (Altiere & Von Kluge, 2009), thus placing pressure on parents to access early intervention services. Participating in early intervention has also been reported to support parents to cope following their child's ASD diagnosis (Grey, 2006). Thus, it can be concluded from previous studies that the early intervention message may increase parental anxiety or help parents to cope following their child's ASD diagnosis. Overall though, parental perspectives regarding the early intervention message remain relatively unexamined.

Current Paper

The data presented within this paper emerged from a larger study examining how parents of children with ASD make decisions about which intervention approaches to access. The first stage involved the construction of an interview guide. The second stage was a larger constructivist grounded theory (CGT) matrix study. Constructivist grounded theory is a qualitative research methodology, in which theory is constructed through interactions between the participants, the researcher and the phenomenon of study (Charmaz, 2006). In order for this to occur, an iterative research process is implemented, in which initial data collection and analysis shapes subsequent data collection and analysis and therefore the researcher is open to the ideas and experiences of the participants relating to the phenomenon under investigation. One

of the categories that emerged from the early interviews in the CGT study was the influence of parental understanding of therapy on decision-making, and specifically, how parents' perceptions of early intervention influenced decision-making. Thus, the decision was made by the research team to pursue this topic in subsequent interviews. The aim therefore in exploring this topic was not to present a substantive theory, but rather to explore parents' perspectives the early intervention message. Consequently, thematic analysis was undertaken on this subset of data, whereby the coded data relating to the impact of the early intervention message on parents was examined for patterns and themes (Braun & Clarke, 2006). Figure 1 provides an overview of how the subset of data presented within this paper fits within the larger CGT study.
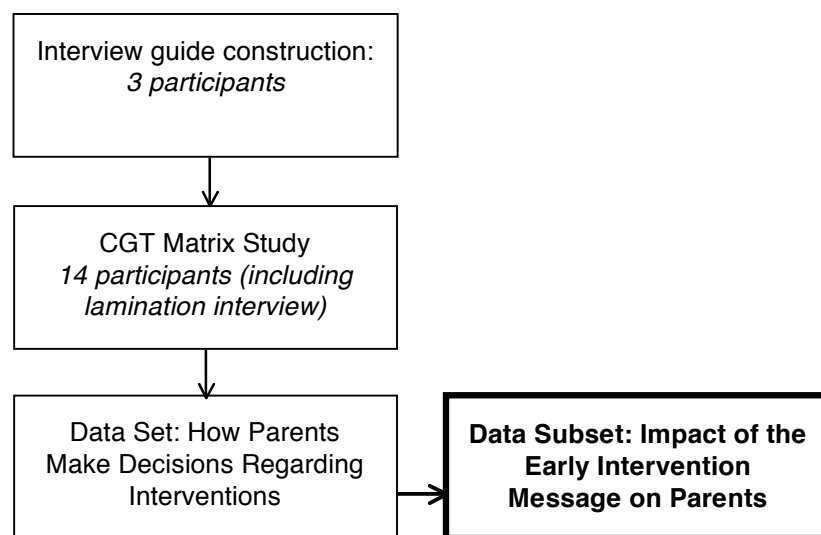

Figure 1. Research process.

Methods

Ethics Statement

This study was approved by the Southern Adelaide Clinical Human Research Ethics Committee in South Australia.

Participants

Participants for both stages of the study were recruited from public and private ASD service providers in South Australia. The eligibility criterion for this study required that parents had a child diagnosed with autism[7] in the last five years. Three female participants were recruited into the first stage of the study and 14 participants (11 women and three men) from 12 family units were involved in second stage of the study. All 17 participants had male children with autism, with ages varying from 2 years, 0 months to 11 years, 3 months. Convenience sampling was implemented and therefore the participant sample was not balanced for sex, age or any other demographic attributes. Tables 1 and 2 provide a summary of the key participant demographic information for the first and second stages of the study respectively.

Table 1. Key participant demographic information for Stage 1 participants.

Participants	Highest level of completed education (mother)	Child's gender	Child's age at diagnosis	CARS[a] score at diagnosis
Jane	University degree	Male	2;3	43
Marjorie	Secondary school	Male	4;0	N/A
Rachael	University degree	Male	5;2	30.5

Table 2. Key participant demographic information for Stage 2 participants.

Participants	Highest level of completed education (father)	Highest level of completed education (mother)	Child's gender	Child's age at diagnosis	CARS[a] score at diagnosis
Elka	Trade qualification	Trade qualification	Male	3;6	46
Adriana	Trade qualification	Diploma	Male	2;10	39
Michelle	Trade	Diploma	Male	8;10	39.5

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[7] At the time of data collection, the DSM-V diagnostic criteria had not been released, and therefore autism existed as a sub-diagnosis of ASD.

	qualification				
Ellen & David	University research degree	University degree	Male	1;8	34.5
Nicola	Trade qualification	Diploma	Male	N/A	N/A
Debra	University degree	University degree	Male	1;8	32
Hannah	University post graduate diploma	University post graduate diploma	Male	1;10	33
Fiona	Diploma	University degree	Male	4;6	N/A
Deepak	Research higher degree	University degree	Male	5;3	45.5
Sophie	Trade qualification	Secondary school	Male	3;0	31.5
Alice	Diploma	Diploma	Male	8;5	N/A
Joanna & Russell	Trade qualification	University degree	Male	3;6	N/A

[a] Childhood Autism Rating Scale (Schopler, Reichler, DeVellis & Daly, 1980)

Stage 1: Interview Guide Construction

The first researcher met individually with three parents of children with ASD (who were not involved in the subsequent semi-structured interviews) to assist with the development of an interview guide. Participants were asked to generate questions that they felt would allow them to share their experiences with decision-making. The questions were compiled and grouped into broad categories (e.g. journey to diagnosis, deciding on interventions, experience with interventions). The interview guide was reviewed within the research team and no amendments were made. Topics covered within the semi-structured interview included: getting a diagnosis, selecting intervention approaches, support available for decision-making and changes in decision-making over time. A copy of the original interview guide is included as an appendix.

Stage 2: Data Collection

The first researcher conducted semi-structured interviews using the interview guide established within the first stage of the study. On average, interviews ran for 60 minutes, though interviews where two parents were involved ran longer. At the conclusion of the semi-structured interview, participants were asked to complete a questionnaire to collect demographic information, as well as information regarding the interventions implemented with their child (see appendix). Following each interview, the first researcher also recorded observations and field notes to add depth to data analysis.

The interview guide was updated after each semi-structured interview, allowing key topics to be explored in further detail. In this study, the influence of the early intervention message on decision-making was frequently raised during initial interviews, which was therefore explored in more detail during later interviews. Data collection continued until 14 participants had been interviewed. At this point, data saturation was achieved, whereby no new insights or information was raised. Fourteen participants are considered to be an adequate sample size to achieve data saturation in qualitative research (Francis et al., 2010).

Stage 2: Data Analysis

The initial interview audio recordings within the larger CGT study were transcribed verbatim into Microsoft Word and de-identified, with pseudonyms allocated to participants and family members. Once the 14 interviews had been undertaken, thematic analysis of the subset of data relating to the impact of the early intervention message was undertaken. Initial coding was applied to the subset of data relating to the impact of the early intervention message, which was then reviewed by the second author to ensure that the coding had accurately captured the meaning of the data. The initial coding was refined, and categories of data and potential themes began to

emerge. A mind map was generated to represent the potential categories and themes of data and was discussed within the research team. Key phrases and terminology used by participants were used to label themes and categories, and categories and themes were finalized. The participants were sent a summary of the results of the larger CGT study for the purposes of member checking. None of the participants requested any changes to the data. Refer to table 3 for a representation of the process of thematic analysis.

Table 3. An example of data coding and refinement of themes.

Quote from participant	'We're losing time here', to me it was critical to get in somewhere as soon as I could.
Initial Code	Feeling time pressure
Category	Influencing decision-making
Theme	Consequences of the EI Message

Credibility

In order to increase the credibility of this study, data triangulation occurred, whereby semi-structured interview and questionnaire data were combined with the researcher field notes and observations to enable credible conclusions about the data to be constructed. Additionally, participants were given the opportunity to review their verbatim interview transcript to ensure that it was an accurate reflection of the interview before it was added to the data pool. Terminology and phrases used by participants during interviews were used to represent categories and themes and a number of direct quotes from participants have been included within the reporting of the results, to support and provide transparency regarding the researchers' interpretation of the data.

Results

Data analysis resulted in the construction of three central themes relating to the impact of the EI message of parents. Each theme will be explored below in further detail. A visual representation of the central themes is provided in Figure 2.
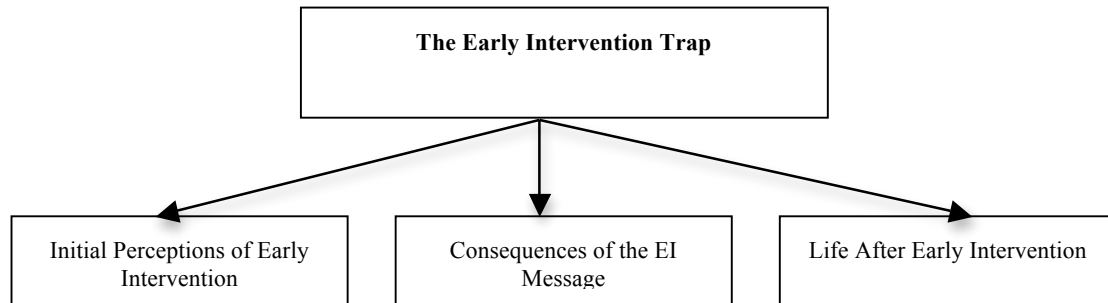
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│ of Early           │ │ the EI            │ │ Intervention          │
│ Intervention       │ │ Message           │ │                       │
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Figure 2. Visual representation of central themes

Theme #1: Initial Perceptions of Early Intervention: "Everyone was Just Saying It All the Time"

All the participants within this study reported that they were aware of the importance of early intervention, indicating that the EI message had well and truly been communicated to the participants in this research. Parents in this study reported that numerous medical and allied health professionals repeatedly had emphasized the importance of early intervention.

> Everyone was just saying it all the time, every therapist, you know, 'Early intervention, early intervention.'

Moreover, the parents interviewed had developed an understanding of why early intervention is important, stating that early intervention can change the outcomes for children with ASD. Michelle, the mother of three children with ASD, reported that though there are differences in the abilities of her children, the impact of early intervention could not be underestimated.

> I recognize they're all very different, but also that you can certainly make a big difference of early intervention and just having belief.

Nicola, who also had three children on the autism spectrum, reflected on her own perception that early intervention would be able to influence the outcomes for her children, and preparing her children for the future had been a motivating factor in implementing early intervention programs.

> Yeah, especially at an early age. You think, 'I should get it all done now ready for the future.

These parents' constructions of the importance of early intervention were somewhat influenced by their own perceptions of the cause and course of ASD. Several participants reported the importance of early intervention due to neural plasticity in the early years.

> I think it's really important while their brain is forming.

Alternatively, Deepak held the strong belief that the MMR (measles/mumps/rubella) vaccination had caused his child's ASD. He believed that biomedical interventions would be able to cure his child but that early intervention would only be effective up until the age of seven.

> The theory say [sic] that the curing period is up to seven years old.

While not every parent in this study believed that early intervention would be able to cure their child, the perception that ASD interventions needed to be implemented as early as possible was common amongst the participants in this research.

> Because the younger they are that we start, the better it is. That's what they keep telling me. So it's great that we got in really, really early. And so you can't waste time, you've just gotta do it.

Many families in this study also reported that in order for early intervention to be effective, a high intensity therapy program was critical. In the case of one participant,

information communicated through mainstream media about early intervention contributed to the development of this perspective.

> Just I guess the idea in the media that the more therapy a child gets the better he will be, and the earlier you do it the better off, so I was motivated by doing as much as we could and as early as we could.

Though the parents in this study had developed an acute awareness of the importance of early intervention, at the same time, parents reported feeling the pressure of early intervention.

> One of the things that's really difficult…because there's the belief now that if you have early intervention, it can make such a huge difference… I'm constantly thinking, but they say that if you get it right, you can make such a huge difference to his life. What if I get it wrong?

This gives rise to the second theme of this study; the consequences of the early intervention message.

Theme #2: Consequences of the EI Message: "The Window of Opportunity"

The promise of early intervention improving the outcomes for children with ASD certainly offered hope to families in this study, especially immediately post-diagnosis, as recounted by Debra.

> People said, "He's so young"…I think he was about 20, 22 months when he was diagnosed. You know, "You're lucky that you've got it so young" and "You can get fantastic early intervention" and so I guess I was just thinking, "Well, we'll get the intervention and it's all going to be all right."

It is possible however that emphasizing the importance of early intervention for children with ASD inadvertently conveyed another message to parents that

participated in this study; that the stakes are high, and the consequences of a wrong decision can be critical.

> You're kind of very conscious at times … he's young, his mind's developing, you want to get it right, you don't want to start on the wrong track and then have to do something else. So that does put pressure on you and does put pressure on us, you know.

The pressure that the parents in this study reported to felt to make the right decision was immense, and though they appreciated the opportunity to access intervention services, some parents feared the consequences of making the wrong decision.

> It can be very stressful. It's not like we're not grateful for all the services and the funding. It's fantastic that he's got access to help him with some of these things. But along with that comes a lot of baggage.

Though the parents in this study reported feeling incredible pressure to make the right decisions with regard to selecting ASD interventions, they also did not want to be uninformed when it came to the importance of early intervention. Rather, the participants requested increased professional support when making such important decisions.

> I think that it's important that we know that. I'm not saying, don't tell parents that it's important, but to say how important it is, and then to be left with this.

Parents in this study reported that as a result of the pressure of early intervention, their decision-making was influenced. A sense of urgency overlaid parental decision-making regarding interventions for the families that participated in this study. Many of the parents in this study reported that they were unwilling to wait for services, given that they believed that intervention needed to be implemented as early as

possible in order for it to be effective. To this end, some parents selected intervention programs based purely on availability.

> Well, you've given me this diagnosis, it's all about early intervention, and now you're telling me I'm going to have to wait 12 months? What's going on? That was a bit stressful. So my experience was basically the first one who rang back to say, "Look, I can fit you in", and it was within a week…and that's pretty much, we just went there because she could fit us in.

Some parents felt that they had no time to research the different intervention options, given the perceived need that intervention had to be implemented as soon as possible.

> I think it would have been better if we'd just took two, three, four months to absorb the diagnosis and do all the research and try and be a bit calmer and a bit more strategic and systematic about the way that we approached things and kind of set out a bit of a plan. There was never a plan."

Other participants had similar experiences, where their decision-making regarding which interventions to access was influenced by the perceived need to have intensive therapy, as opposed to just accessing therapy to address their children's specific needs.

> You do think you've got to have all these appointments all week, you know, early intervention. So it is a bit of a trap like that.

Furthermore, the pressure these participants reported to make the most of the early intervention window of opportunity meant that they were unwilling to wait for outcomes from therapy programs. Many of the parents in this study reported that they preferred to frequently change therapists and intervention programs, rather than risk wasting time on therapy they perceived to be ineffective.

We're going to spend six months, and if they haven't got it after six months, well maybe we'll change. Six months is an incredibly long time to spend on something that may not actually work.

Parents in this study reported that there could be another unintended consequence of the early intervention message if early intervention does not achieve the promised outcomes. As established, the parents that participated in this research strongly believed that early intervention could change the outcomes for their children and they felt pressure to make the right decisions in order to achieve these outcomes. Consequently, if children did not make the gains that parents were expecting, there was the potential for these parents to take the blame for a perceived lack of early intervention outcomes.

I still feel like we've failed Henry. I still feel like we didn't - we didn't do enough.

This sense of failure is perhaps another unintended consequence that could be occurring as a result of parents feeling the pressure of early intervention. It also gives rise to the final theme of this study; life after early intervention.

Theme #3: Life After Early Intervention: "What happens once the early intervention is finished?"

Although some parents in this study reported feelings of guilt when early intervention programs did not achieve the desired outcome, other parents reflected that with time and in retrospect, their perspective on early intervention had changed. With increasing acceptance of their child's ASD diagnosis, parents felt the pressure to undertake intensive early intervention reduce.

We thought we could make him normal. So that was probably the initial goal. Because you're thinking maybe if we do this and this… But after a while we

could see that, when you finally accept it's a lifelong problem, I think that's

when you calm down a bit.

Over time, some of the parents in this study developed more realistic expectations about the outcomes that could be achieved from early intervention.

But early intervention really is designed to make these kids more normal. Is

there a way of early intervention, of being able to be just as impacting, without

the focus being making them more normal? Because the reality is they're on

the autism spectrum. They're never going to be normal.

Although the parents in this study had been well and truly been made aware of the importance of early intervention, they generally had no expectations of or hope for therapy beyond the early years. In some cases, parents were surprised to find that therapies implemented once their children were older were more effective than early intervention programs had been.

I feel like everybody talks about early intervention but I don't even know that

the money we spent with therapies that we did in those early days helped

Henry. I think it was almost too early. Now his speech is starting to develop,

now the therapy is starting to have effects. ... It's like they have to get to a

point where they are starting to get a little bit of language and they are starting

to kind of work things out a little bit. So then you kind of can build on that.

The parents in this study recognized that the developmental age of the child had the ability to influence the effectiveness of therapy programs, and that the child's readiness and ability to participate in therapy developed with time.

Early intervention is great, but I believe that if that then was done between the

ages of 5 to 8, you'd get so much more out of it then you would of between

the age of 4 to 7 … because I'm getting more from him now, then what I was

> then. He was prepared to listen, he was prepared to learn, he can sit down and look at you, he gives you complete eye contact now, he wasn't giving you anything back then.

This sentiment reflects the need to explore whether services should develop a broader primary focus than just early intervention. Though the parents that participated in this study came to discover that there was hope for life beyond early intervention, they felt that services did not reflect this. Parents reported that the networks of support that were available during the early intervention stage were not accessible once their children started school.

> I must say that's the thing that when Andrew went school, like I now feel completely alone. Like there's nobody you can talk to. … I kind of wish they would give a little bit more support for kids at school.

In prioritizing early intervention services, the belief that early intervention is the only hope for children with ASD, though misguided, could be inadvertently reinforced. The parents in this study believed that services needed to change to reflect that there is life and hope beyond early intervention, with one parent commenting

> I would like more awareness about … what happens to the children after all the money has run out and once they get to school and once the early intervention is finished?

Discussion

The participants in this study revealed an acute awareness of the importance of early intervention, which placed pressure on parental decision-making. Though not intended, this was the inadvertent outcome of the early intervention message for the parents in this study. A similar phenomenon was observed in a study of infant mental

health promotion (Lawless et al., 2014), where participants were acutely aware of the importance of infant mental health promotion, referencing the 'window of opportunity' and critical period of brain development in the early years, and the role of parents in achieving these outcomes. However, similar to the current study, there was a reported misinterpretation of the health promotion message, with parents being viewed as risks to their children's development. One of the sociological critiques of health promotion is that there is a risk of 'victim-blaming', in which health promotion efforts inadvertently blame individuals for their poor health, rather than looking more broadly at the structural conditions that have contributed (Green, 2008). Within the context of the current study, it is possible that with health promotion efforts focused on the early intervention message, which seemingly shifts the responsibility for intervention outcomes onto parents, broader issues relating to funding, support and access to early intervention services have been overlooked. Rossi et al. (2013) also raised concerns about communicating risk information to parents of children with ASD, given the potential for inadvertent harm to be caused to the recipients of this information, and advised caution in how this information was communicated. The results of the current study also indicate that further exploration regarding how information about early intervention is communicated to parents of children with ASD is required, given that there is the potential for this information to negatively impact on parents.

This study highlighted the pressure that these parents feel with regards to early intervention, which is an important finding given that higher levels of stress and mental illness are frequently reported with regards to parents of children with ASD in comparison to parents of children with other developmental disabilities (e.g. Estes et al., 2009; Hayes & Watson, 2013). There are a number of factors that likely

contribute the stress of raising a child with ASD (e.g. challenging behaviour, impact of ASD on the daily functioning), but the current study identifies the pressure added by the early intervention message as another possible contributor. Though further research into the impact of the early intervention message on parental well-being is required, the results of this study highlight the need for consideration of increased professional support for decision-making.

The importance of early intervention was frequently communicated to families in this study by medical and allied health professionals, and therefore participants reported that they had extremely high expectations of early intervention and engaged in early intervention services in the hope of achieving improved outcomes, without necessarily having a clear understanding of what the outcomes would be. The challenge therefore, for medical and allied health professionals, is to communicate with families regarding specific outcomes, instead of speaking broadly about the benefit of early intervention. This is not an easy task, given that the specific outcomes for children with ASD are difficult to predict, particularly in the early years. However, if medical and allied health professionals are able to provide parents with more concrete outcomes and assist families to set measurable goals for intervention programs, particularly at and around the time of diagnosis, the pressure of early intervention may reduce. Ultimately though, in order for professionals to be able to make meaningful and specific recommendations to families, further research into the characteristics that indicate the children will respond to specific intervention programs in required. Furthermore, if predictors of success with intervention programs are more clearly determined, parents could be provided with more realistic expectations of intervention programs.

Limitations

As a qualitative methodology was implemented, the results of this study cannot be generalized to the broader population. This is especially the case given that convenience sampling was implemented within this study, meaning that there is a potential that the participants who opted into this study had particularly strong opinions about the topic under investigation. Furthermore, the participants' perspectives were based on experiences with one particular funding model, and service provision and supports can vary significantly across the county and internationally. However, the current study provides a useful insight into the perceptions of the participating parents on early intervention and the potential impact of the early intervention message on parents of children with disabilities.

Future Directions

Further research regarding the impact of the early intervention message on parents of children with ASD within different contexts is required, particularly given across different service delivery and funding models. In order to gain a deeper understanding regarding the impact of the early intervention message, it would also be beneficial to investigate the perspectives of medical and allied health professionals.

Conclusion

The results of this study, which explored the impact of the early intervention message on parents of children with ASD, indicated that the participants in this research were acutely aware of the importance of early intervention and had clear beliefs about what early intervention should involve. While the concept that EI can improve the outcomes for children with ASD offers hope, it also can place pressure on parents to

make the right decisions with regard to which intervention programs to implement, which as a consequence has the potential to influence parental decision-making. The parents in this study reported the need for increased support with decision-making, and for services to continue beyond the early intervention period. The findings of this research indicate that further exploration regarding how the early intervention message should be communicated to parents, and how services need to support families of children with ASD, would be beneficial.

Key Messages

- Parents of children with ASD are acutely aware of the importance of early intervention.

- Parents feel significant pressure to make the right decision with regard to early intervention programs and concerned about missing the 'window of opportunity' for early intervention.

- Parental decision-making with regard to intervention programs is influenced by their perception that intervention needs to be implemented as quickly and an intensively as possible following diagnosis.

- Parents had few expectations of life following early intervention and the potential for therapy to be effective beyond the early years.

- There is a need for careful consideration regarding how the importance of early intervention is communicated to parents of children with ASD.

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