

A SYSTEMIC ASSESSMENT OF AN EARLY AUTISM INTERVENTION

A Systemic Assessment of an Early Autism Intervention

Graham Leonard Gauntlett

GNTGRA 002

**A minor dissertation submitted in partial fulfilment of the requirements for the award of the
degree of Master of Arts in Clinical Psychology**

Supervisor:

Dr Nokuthula Shabalala

Faculty of the Humanities

University of Cape Town

2014

Compulsory Declaration

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: _____

Date: _____

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

Author Note

I would like to thank Dr Nokuthula Shabalala for supervising this dissertation and for facilitating access to the University of Cape Town (Psychology Department) Early Start Denver Model (ESDM) participants and their families. In addition, I would like to thank the families and carers of the early start autism study participants for kindly agreeing to participate in this research. Furthermore, I would like to acknowledge their children, most especially those who participated in the intervention. I would also like to acknowledge my wife Belinda Train for her editorial assistance.

Abstract

The early identification of children with autism spectrum disorder is important for effective intervention. Improved diagnostic criteria, a recent move towards a single autism spectrum disorder, increased awareness and an as yet unexplained epidemiological increase have contributed to an increase in the number of children with autism being identified and diagnosed at an early age. This movement towards earlier diagnosis and intervention has coincided with significant developments in the treatment of autism. Early start autism interventions such as the Early Start Denver Model (ESDM) require parents to play an increasingly active role in the form of intervention coach or co-facilitator. Despite this movement towards intensive family-centred interventions, the majority of early autism interventions are evaluated predominantly on the basis of measured impacts on the diagnosed child only. Guided by family systems theory, this study interviewed the parents, family members and carers of a small group of children. These children were taking part in a 12-week ESDM-informed pilot intervention at the University of Cape Town's Child Guidance Clinic (CGC). This study aimed to explore the perceived impact of the intervention on the family system as a whole. The qualitative analysis indicated that having a child participate in the CGC's intervention was considered to have had an impact on the family system. Whilst the analysis revealed that the intervention had an overall positive impact on the family system, there were also negative and stressful impacts, as well as an expression of unmet needs. In light of these findings, further research may be necessary to determine the possible benefits of a more systemic approach to evaluating early autism interventions.

Keywords: Autism spectrum disorder, early autism intervention, Early Start Denver Model, family systems, family-centred interventions, systemic impact.

Table of Contents

Chapter 1: Introduction	1
Background and Rationale	1
Diagnostic Developments	2
Increasing Prevalence	4
Developments in Autism Treatment	6
<i>Neurologically informed Early Interventions</i>	7
<i>Early Interventions</i>	8
Early Start Denver Model (ESDM)	9
Aim of the Current Study	11
Research Methodology	11
Structure of Dissertation	12
Chapter 2: Literature Review	14
Family Systems and Early Treatment	14
A Systemic Understanding of Autism and Autism Intervention	19
Assessment of Early Autism Interventions	26
Systemic Assessment of the Early Start Denver Model	31
Chapter 3: Methodology	33
Aim of the Study	33
Design of the Study	33
Contextualisation of study	35

Sample	36
Process	37
Data Analysis	39
Ethical Concerns	42
Reflexivity	43
Chapter 4: Findings	45
Negative Impact on the Family System	45
Increased Parental and Family Stress	46
Negative Impact on Family Relationships	48
Negative Impact on Family Resources	49
Negative Assessment of Child Functioning	51
Positive Impact on the Family System	53
Positive Impact on Family Resources	53
Positive Interactions with Therapists	54
Positive Impact on Family Relationships	57
Positive Impact on Child Functioning	59
Additional Needs Identified by the Family System	61
Family Need for General Autism Information	61
Community Need for Autism intervention	63
Family Need for Education Pertaining to the CGC's ESDM pilot	65
Chapter 5: Discussion and Conclusion	68
Systemically Orientated Discussion of Main Findings	68
Negative Impact on the Family System	70

Increased Stress on Family Logistics, Resources and Relationships	71
Negative Assessment of Child Functioning	73
Positive Impact on Child Functioning	73
Positive Impact on Family Logistics, Resources and Relationships	74
Positive Impact on Child Functioning	75
Additional Needs Identified by the Family System	76
Conclusion	77
Limitations of the Study	78
Research Conclusions	79
Opportunities for Further Research	80
References	82
Appendix A	98
Appendix B	100

Chapter 1: Introduction

Randomised controlled trials that explore the impact of early autism interventions are extremely limited (Rogers & Vismara, 2008). Whilst several of these studies recognise the important role that family members are required to play in this type of intervention (Aldred, Green, & Adams, 2004; Eikeseth, Smith, Jahr, & Eldevik, 2002), there is limited research on the impact that participation in these early start autism interventions has on the overall family system (Aldred et al., 2004; Moes & Frea, 2002).

The main thesis of this paper is that early autism interventions require parents, families and carers to play an increasingly central role in the implementation of this type of intervention, therefore the impact of such interventions would benefit from a systemically informed assessment process. In contrast, most early start autism intervention assessments focus on changes in the observable functioning of the diagnosed child or diagnosed children. This paper will assess the overall systemic impact of an early start autism intervention, the University of Cape Town (UCT) Child Guidance Clinic (CGC)'s pilot autism intervention, which is based on the Early Start Denver Model (ESDM). This chapter begins with a description of the background and rationale for the study, including a brief overview of the practical, theoretical and empirical factors that informed this study. Following this is a statement of the aims of the study and the research methodology used. Finally, the structure of the study is outlined.

Background and Rationale

The prevalence of autism is increasing and there have been recent diagnostic and treatment developments. These developments include the DSM-5's recently expanded diagnostic

domain for Autism Spectrum Disorder (American Psychiatric Association, 2013), increasingly early diagnosis of the disorder, and a movement towards intensive early treatment interventions (Rogers & Dawson, 2007). One of the unanticipated consequences of these developments has been the increasingly prominent and central role that families and carers are being required to play in such interventions. Despite the significant systemic implications of these developments, the assessment methodologies of early autism interventions such as the ESDM still tend to focus on the diagnosed child, with an emphasis on identifying changes in the observable or reported behaviour and functioning of the child. This issue is explored more fully below.

Diagnostic Developments

Autism was first identified, studied, and documented by Kanner (1943) who described it as a distinct spectrum disorder with varying degrees of deficit. The disorder has continued to be described as a spectrum disorder incorporating a number of diagnostic features such as marked abnormalities or impairments in the domains of social interaction, in receptive as well as expressive communication, in symbolic play impairments and in restricted, repetitive patterns of activities and interests (Rogers & Vismara, 2008).

In the Diagnostic and Statistical Manual of Mental Disorders 4th edition Text Revised (DSM-IV TR) the American Psychiatric Association (APA) differentiated the following autism spectrum disorders: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett's Disorder, and Childhood Disintegrative Disorder (2000).

In a significant development, the APA (2013) proposed and then published in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5), a new diagnosis called Autism Spectrum Disorder (ASD). This disorder incorporates the previously separate diagnoses listed in the paragraph above. The new diagnosis indicates that symptoms of the previous disorders now represent a diagnostic continuum measured from mild to severe, as opposed to symptoms pointing to distinct disorders.

Prior to publication, the proposed DSM-5 recommendations for ASD diagnostic criteria were met with criticism. McPartland, Reichow and Volkmar (2012) evaluated the proposed new criteria for ASD by performing a secondary analysis on a pre-existing early childhood autism study. Their study assessed the implications of the new criteria for children with high-functioning autism, and was highly critical of the new definition and diagnostic criteria being proposed for the DSM 5. Their major concern was that the criteria were too restrictive for cognitively able individuals.

Neurologically informed researchers have also been critical of the heterogeneity of individuals diagnosable according to the DSM-5 criteria (Reiss, 2009). However research aligned to the DSM 5 Neurodevelopmental Disorders Work Group noted that the archived data used in the McPartland et al. (2012) secondary analysis contained too many limitations to be able to adequately assess the new criteria and further indicated that it was too early to assess if the proposed criteria could accurately capture all individuals with ASD (Swedo et al., 2012).

The International Classification of Diseases 10 (ICD-10) (World Health Organisation, 1992) presently classifies autism in a spectrum-orientated manner similar to the DSM-IV TR but

with eight categories instead of the five found in the DSM-IV TR. This means there are now significant differences between the newly released DSM-5, which combines its previously separate spectrum-related disorders into a single Autism Spectrum Disorder and the ICD-10 which maintains its separate autism-spectrum disorder codes. This diagnostic separation may increase further because the beta version of the ICD-11, which is likely to be finalised in 2015, has indicated the inclusion of a ninth category under its autism spectrum, namely Social Reciprocity Disorder (First, 2009). This appears to be similar to Social Communication Disorder, a new and separate disorder introduced in the DSM-5 (American Psychiatric Association, 2013).

These diagnostic changes, which are controversial and potentially confusing for experts, have significant psycho-educational implications for parents and family members, who are now expected to play an expanded facilitation role in early autism interventions.

Increasing Prevalence

As with the diagnostic developments described above, increasing autism prevalence is an important motivator for early start interventions. Although there has been continuous investigation, the exact aetiology of ASD is unknown (Carr, 2006; Lord, Rutter & Le Couteur, 1994). What is known is that a significant number of epidemiological indicators indicate a marked increase in the prevalence of autism, with the most recent figures for Western countries indicating an increase from 3 to 5 out of 10,000 in 1980, to 1 in 150 in 2002, when adjusted for improved autism detection and expanded autism classification (Yeargin-Allsopp et al., 2003). Whilst this trend is currently more notable in developed countries than it is in South Africa, there are indications that this is changing with increased

autism awareness amongst South African health professionals, particularly paediatricians, as well as parents and teachers (Bateman, 2013).

There is currently an estimated shortage of 130 000 special needs education placements for children with ASD in South Africa (Bateman, 2013). The increase in the reported prevalence of ASD in Western countries in recent years is fuelling concern around issues such as overly-inclusive diagnostic criteria, and the possibility of environmental causes triggering specific genetic vulnerabilities (Jepson & Johnson, 2007).

Whilst the issue is controversial, Blaxill (2004) suggests “The available survey literature finds evidence of large increases in (autism) prevalence in both the United States and the United Kingdom that cannot be explained by changes in diagnostic criteria or improvements in case ascertainment.” (2004, p. 536). The reported rate of autism and ASD in the United Kingdom and the United States has increased from less than 3 per 10 000 children in the 1970s, to just under 30 per 10 000 in the 1990s, however this spike has recently levelled off according to a recent study (Taylor, Blick & MacLaughlin, 2013).

According to a systematic review of prevalence studies by Blaxill (2004), despite factors such as the nomenclature as well as the criteria sets that have been used to define autism spectrum disorder having changed over time, these changes are not so great as to prevent a meaningful comparative analysis and they do not explain statistically significant differences in the reported prevalence of autism. The above Blaxill (2004) review has not found significant evidence that the multiple systematic changes in survey methods is able to explain these increases over time. A precautionary approach would therefore suggest that these

increased rates of autism and autism related disorders should be accepted as a statistically significant and concerning public health issue (Blaxill, 2004).

Whilst there is controversy regarding these reported increases in the prevalence of ASD, systematic reviews of Western prevalence studies, and emerging data from developing countries such as South Africa, provide an indication that increased autism rates require urgent public health research and intervention, including interventions that begin in early childhood, such as the ESDM.

Developments in Autism Treatment

Once diagnosed, the outcome for children with autism has, until fairly recently, been poor. Lord et al. (1994) indicate that up to 60% of children diagnosed with autism are unable to lead a completely independent life and that only 4% of diagnosed children reach a stage where their lives are indistinguishable from other typically developing children. In light of the above, a key and encouraging development in the field of autism is an international trend towards the early diagnosis and treatment of autism.

Autism is a life-long disorder that involves deficits in multiple developmental domains including reciprocal social interaction, communication (verbal and non-verbal, including expressive and receptive language), fine and gross motor deficits and delays and restricted, repetitive and stereotyped behaviours and interests, amongst others (Rogers, 1998).

The pervasiveness of autism symptomology has seen a movement towards early, multiple intervention approaches involving multi-disciplinary teams (Rogers & Dawson, 2007). Due to their intensive, all-encompassing nature, parental and carer involvement in these

interventions has become significant, symbolised by terms such as of intervention facilitator and coach, which are now being used to describe the parental role in early interventions (Rogers & Vismara, 2008).

Neurologically informed early interventions

Developments in the treatment of autism have been influenced by advances in the neurological understanding of autism, although it has been suggested that this influence is not as pervasive and cohesive as it should be, and that there is excessive heterogeneity in the diagnosis and treatment of autism (Dawson, Webb & McPartland, 2005; Reiss, 2009). With an increased understanding of both the neurological plasticity of young children's brains and the effect of life and learning experience in shaping brain structure and functioning, it can reasonably be anticipated that early intervention experiences and procedures will contribute to both brain changes and development, as well as behavioural changes (Rogers & Dawson, 2007).

As more knowledge became available, researchers began designing interventions that incorporated emerging information from various fields, such as an increased neurological understanding of the key role played by attachment relationships in infant development (Reebye, 2007). These newer, more integrated interventions also utilised neurological advances to address some of the weaknesses of strictly behavioural type-approaches such as Applied Behaviour Analysis (ABA). They did this by encouraging a style of interaction in which facilitators, including parents, both "capture attention to faces and bodies (social orienting) and then provide extremely clear social and communicative behaviour signals that represent optimum parenting techniques for developing elaborated language, social, and symbolic play, and social initiations from children" (Rogers & Dawson, 2010, p. 13).

The ESDM which informed the pilot project from which the participants for this study were drawn (the facilitators of the above intervention are currently training to become accredited ESDM facilitators), is an example of a more neurologically informed intervention, with an additional focus on earlier and more naturalistic methods which consider social interactions as critical to learning language and communication (Watson et al., 2010).

Early Interventions

Increased understanding of the aetiology of infant development has led to an increase in the early detection of ASD, and this growth in knowledge pertaining to infant development and learning has in turn led to the emergence of promising early intervention models that are specifically aimed at addressing this clearer picture of deficits (Butter, Wynn & Mulick, 2003). Although early diagnosis offers hope for early intervention, which may lead to significant developmental improvements, research on the effectiveness of early intervention is still limited.

There is, however, evidence that early interventions offer considerable benefits over interventions designed for children of six years and older (Rogers & Vismara, 2008). There is evidence suggesting that intervention before the age of three leads to greater gains in language and communication development, nonverbal communication skills and gesture use (Carpenter, Nagell & Tomasello, 1998), and joint attention and early representational play (Sigman & Ruskin, 1999). Researchers and clinicians are therefore advocating intensive early interventions for infants and young children with autism (Woods & Wetherby, 2006).

Early Start Denver Model (ESDM)

The ESDM is an example of a comprehensive early intervention approach for children with autism, aged 24 to 60 months. The model utilises knowledge from neurologically informed infant development research, such as the importance of relationships for learning (Howe & Courage, 1997). This integrated approach, which goes beyond pure behaviourism, encourages clinicians and researchers to develop individualised learning objectives aimed at improving the development trajectory of young children with autism (Rogers & Dawson, 2010).

According to ESDM intervention founders Rogers and Dawson (2007), autism impedes a child's early interpersonal experience, creating barriers to social-communication development, which leads to a loss of social-learning opportunities. The ESDM and other early interventions seek to stop this negative cascade by providing opportunities for more interactive social relations for most of the child's waking life, in order to develop their interpersonal and symbolic communication, amongst other important objectives (Rogers & Dawson, 2010; Rogers & Vismara, 2008).

Several first-wave early autism interventions or approaches were combined to form the foundations of the ESDM. These approaches include the original Denver model (Rogers & Dawson, 2010), the cascade model of interpersonal development in autism (Rogers & Pennington, 1991), the model of autism as a social motivation disorder (Dawson et al., 2002), and pivotal response training (Schreibman & Pierce, 1993), a natural context teaching approach that is based in applied behaviour analysis and which highlights the child's natural initiative and spontaneity.

The original Denver model saw autism primarily as a failure of social-communicative development and the programme focused on building close relationships with children in order to encourage improvement in communication abilities and social skills development. Core features of the Denver Model that are retained in the ESDM include the use of multiple domain impact measuring; a focus on the level of engagement between child and other; the encouragement of fluent, reciprocal and spontaneous hand gestures, the development of appropriate facial expressions, the use of objects; an emphasis on the development of both nonverbal as and verbal communication; cognitive development pertaining to symbolic and other types of play and the development of a therapeutic alliance with parents, carers and extended family members (Dawson et al., 2010).

Rogers and Pennington's model of interpersonal development (Rogers & Pennington, 1991) proposed that early impairment in imitation and affective sharing disrupted the establishment of bodily coordination and created barriers between carers and infants with autism which interfered with an understanding of the feeling and mental states of both parties. In line with this, one of the fundamental objectives of the intervention is to address critical developmental deficits in the social-emotional-communication domain, within the context of emotionally rich relationships with caring others (Rogers & Dawson, 2010).

Encouragingly there are a number of studies, including reviews of randomised controlled trials, indicating that early interventions such as the ESDM are able to have a positive impact on multiple developmental domains such as the acquisition of language; spontaneous child speech; social-type initiatives and skill-imitation; and parent and caregiver acquisition of therapeutic skills (Rogers & Vismara, 2008; Vismara, Colombi & Rogers, 2009).

Randomised controlled studies demonstrating the effectiveness of autism interventions in this early age group are, however, insufficient (Rogers & Vismara, 2008). In addition, there are insufficient service providers, including researchers and clinicians, with sufficient training and experience to carry out intensive early interventions such as the ESDM (Mahoney & Perales, 2005). It is this lack of service providers, combined with the intensive nature of early interventions, which have contributed to the increasing involvement of parents and caregivers as intervention facilitators, leading to a need to explore the impact of early autism interventions on family systems.

Aim of the Current Study

The above-mentioned developments, such as a new and more inclusive diagnosis of autism, worldwide increases in autism prevalence, and the movement towards the early diagnosis and treatment of autism (with an increasingly central role for families and carers), are bound to have a significant impact on the family and carers of the diagnosed child. However, outcome and assessment studies of these new approaches and interventions tend to be evaluated primarily in terms of the impact on the identified child. This study seeks to add to a growing body of systemically oriented intervention assessment literature, by documenting the perceived impact of an early autism intervention on the families and carers of a group of children participating in an ESDM-informed pilot intervention.

Research Methodology

This paper utilises a qualitative case study as the core methodology. A qualitative case study is an approach to psychological research that facilitates the exploration and understanding of an identified phenomenon within a natural context using one or more data sources (Yin, 2003). In this study an exploratory case study design was used due to the intervention being

evaluated in the absence of a clear set of outcomes and due to the small, clearly identifiable group involved.

The sample used in this study consists of families and carers whose child or children have been diagnosed with ASD, who recently participated in a 12-week early start intervention based on the ESDM model. This intervention is currently being run as a multiple-year research project under the auspices of the Child Guidance Clinic at UCT. The families and carers of eleven children who had recently completed the intervention constitute the primary sample for this study.

The sample size correlated with the single group of children that completed the intervention within the proposed timeline for this study, and met the criteria of a small, clearly identifiable population required for a case study sample. The primary setting for the majority of interviews conducted was the homes in which the families and children lived, these homes were located in a number of different geographical areas of Cape Town. Data was collected in the form of open ended, semi-structured interviews lasting from 45 to 90 minutes. These interviews were then transcribed according to standard research-level protocols and data from these transcripts were subject to a process of thematic analysis.

Structure of Dissertation

Chapter 2 will review the literature on the systemic impact of early autism interventions, with a specific focus on the ESDM. It will also review the literature on the assessment of early autism interventions, and examine attempts to introduce a more systemically informed approach to the planning, implementation and assessment of early start interventions. Chapter 3 will describe the methodological approach used in the research. Chapter 4 will detail the

Chapter Two: Literature Review

Autism prevalence is increasing, and children are being diagnosed at an earlier age. In addition, a clearer understanding of brain development in autism has led to autism interventions beginning at an earlier age and becoming more intensive in nature. This has inevitably required the parents and families of children with autism to play an increasingly central role in these interventions. Nevertheless, the assessment of early start interventions tends to be predominantly focused on the impact of the intervention on the observable functioning and behaviour of the diagnosed child. There appears to be little literature on the overall systemic impact of early autism interventions, particularly in low-income environments. This paper intends to provide a systemically oriented assessment of an early autism intervention based on the ESDM model.

This chapter will present a review of the literature on the impact of childhood autism treatment on families, particularly the systemic impact of early autism interventions. The first section will present a brief overview of family systems and the impact that families have on the treatment and prognosis of their diagnosed children, followed by a review of the literature on the systemic impact and assessment of early start autism interventions, with a specific emphasis on the ESDM.

Family Systems and Early Treatment

An integral approach conceptualizes human interaction as taking place within a morphogenic field consisting in part of both an individual self as well as an inter- relational aspect, with both of these aspects being further divided into an invisible interior and an observable

exterior (Wilber, 2000). A family systems approach is located in the inter-relational domain and it acknowledges both the unseen ways in which families make meaning, as well as the external observable aspects of the family system. Within a systemic approach to children with developmental disability, family systems are seen as constituting a specific type of social system (with disability present), with each of these family systems consisting of a unique combination of individual members, including the identified patient (Bristol, 1985). At its most general level and broadest conception, a family system can be described as including an identifiable number of interacting units or parts, combined with clearly identified relationships between the parts, which serve to create and maintain boundaries between and amongst the various units in the system (Jordan & Powell, 1995). Family systems can also be conceptualized as having a tendency towards integration, with each element affecting the functioning of the whole and being affected in turn by other elements or component members in the family system. It is for this reason that a systems approach is recommended for children with developmental disability (Bristol, 1985).

According to Bowenian and other natural systems theories, the family can also be viewed as an emotional system, and whilst the family's emotional system consists of members of the nuclear household living in the here and now, members of the extended family system, as well as inter-generational and trans-generational influences, are also considered in the family process. A key attainment in the system is the process of differentiation, a process in which family members seek to transcend not only their own emotions, but also those of the family system (Jordan & Powel, 1995).

Whilst the birth of a child will always have an impact on a family, autism is a life-long developmental disability which is typically present at birth and therefore tends to have a

greater impact due to characteristic deficits of the disorder, such as lack of responsiveness, unusual and unexpected responses to the environment and environmental stimuli, gross deficits in verbal and non-verbal communication (Norton & Drew, 1994), and unusual relationships with objects (Overall & Campbell, 1998). Norton and Drew (1994) argue that because autism is a pervasive disability that impacts and affects almost every area of family life, the inclusion of family systems theory into our understanding of the impact of the diagnosis and interventions on the family unit is crucial, as each family member has a role to play and rules to respect. It is thought that the impact of disabilities on a family is similar to the experience of a family death, with families needing to progress through reaction stages such as shock, retreat, and then acknowledgement (Norton & Drew, 1994).

According to Norton and Drew (1994), characteristic problems in autism, such as bonding issues, disrupted early sleep patterns, unpredictable behaviour, extreme responses to changes in routines, and financial challenges are likely to require families to change and adapt to a new reality. Research also revealed that young children with autism have on average been exposed to and tried between seven and nine different therapies and, at any one time, were utilising between four and six (Goin-Kochel, Myers & Mackintosh, 2006).

Behaviour extremes and the extra care required by children with autism can alter the interactions amongst all family members. For example, non-autistic siblings often have to participate in child-care responsibilities, which can lead to negative attitudes towards the affected child (Mahoney & Perales, 2005). Similarly, the family may struggle as it engages with the extent to which its functioning has to adapt to the affected child's difficulties in organising him/herself as well as understanding the way the family environment around them is organised (Swanson & Lock, 2005). According to Norton and Drew (1994) this can result

in multiple hardships ranging from strained relationships, social isolation and increased financial demands due to the stress of having to change goals and activities as well as due to grief about the restricted life opportunities of the impaired child. Increases in parenting stress and elevated depressive symptom scores have been reported among parents raising children with ASD, regardless of whether they are compared to parents raising typically or normally developing children, or to parents of children with other developmental delays (Martinez-Pedraza & Carter, 2011). Because families are seen as systems of interconnected and interdependent members, autism may be thought of as a family problem, rather than as an individual one (Bristol, 1985).

With an increasingly large number of single parent and same-sex households, traditional definitions of families and family systems require constant revision (Walsh, 2003). However traditional nuclear families are still considered the norm in research design (Carter & McGoldrick, 1999). Whilst most family systems research focuses on the impact of the overall family system on an identified child, there is research indicating that it is the parents, their parenting styles and their own attachment styles that have the major impact on child development (Darling & Steinberg, 1993). Research also indicates that children of parents with significant adjustment issues are at greater risk of developing psychological difficulties and that there will be a greater tendency for the symptoms of these children to be maintained by the family system (Carr, 2006; Friedman & Chase-Lansdale, 2002).

Having an understanding of family system functioning is important in the planning, implementation and assessment of early start autism interventions, as there is significant research indicating that families both maintain and also prevent and protect against psychological difficulties in diagnosed children, by either engaging in problem-maintaining

or problem-preventing and protecting interactional patterns (Carr, 2006). Problem maintaining patterns are more likely to be observed in family systems demonstrating traits of disorganisation, marital conflict, and absence of one of the parents (Carr, 2006; Herbert, 2002). Family systems research also indicates that parents inadvertently maintain problematic symptoms by providing intermittent pay-offs for undesirable behaviour (Herbert, 2002). According to Carr (2006), parents and families also impact both positively and negatively on their diagnosed children through coercive and non-coercive interactions, levels of involvement, levels of engagement, consistency of discipline and clarity of communication patterns, with the diagnosed child.

Importantly for this study, research also indicates that mental health problems in diagnosed children can be maintained or protected against and improved, depending on the way in which the family-system engages with health professionals and treatment centres (Imber-Black, 1991). Identified concerns in this regard include denial within the family system regarding the extent of the problem and ambivalence about resolving or improving the symptoms, particularly when there is an outside referral agency involved such as a school and where the family does not feel that they have complete agency regarding participation in an intervention or treatment modality (Carr, 2006; Imber-Black, 1991).

Of particular importance for early start autism studies is research indicating that symptoms are more likely to be maintained by the family system where the parents, caretakers and other family members perceive that there are insufficient resources and routines to improve the problem, and when they are not experienced at forming and maintaining relationships with external treatment providers (Carr, 2006; Reder, Duncan & Lucey, 2004). Providing research support for family-centered early start autism interventions are multiple studies indicating

that parents and families can have a protective and supportive function in the management and improvement of childhood disorders such as autism (Reder, Duncan & Lucey, 2004; Reder & Lucey, 1995; Rogers & Vismara, 2008). The characteristics identified in families that are able to contribute positively to protecting against and improving the symptoms of childhood disorders include: high self-esteem and self-efficacy amongst family members; secure attachment styles; mature defenses and functional coping strategies; protective social and extended family networks; protective day-care and school placements and protective peer-group membership (Carr, 2006).

Recent research by Dawson et al. (2010) has indicated that the optimal amount of therapy for a young child with autism is around 20 hour per week. In an outpatient setting this is usually logistically difficult as well as prohibitively expensive. For this, as well as previously mentioned reasons, family systems play a critical contextual role in maintaining or protecting against the biological and psychological risk factors of the diagnosed child. Increased involvement of the parents and families in early autism intervention has the potential to positively impact on both the treatment and the general functioning of the diagnosed child or children, and to reduce the cost of treatment. Conversely, families also have the potential to maintain or exacerbate their children's conditions and symptoms.

A Systemic Understanding of Autism and Autism Interventions

Parent, family and carer involvement is often a requirement and is considered best practice for early intervention for children with autism (Cridland, Jones, Magee & Caputi, 2014) and it is considered to be an essential component of the ESDM intervention (Rogers & Dawson, 2007). Optimum outcomes for infants and toddlers with the disorder require parents to acquire specific social communication and behavioural skills in order to foster

been diagnosed with ASD, family life is often focussed around the diagnosed child and the impact of the disorder. Despite this, few research studies have been undertaken that document empirically the impact of ASD on families. Although research on the needs of parents, and the effect of the diagnosis on parents has begun to emerge (Grey & Holden, 1992; Schall, 2000), it is evident that a fuller understanding of the multiple impacts of autism on the family is required (Schall, 2000).

Recent research by Watson et al. (2010) indicates that the specific stressors these parents are exposed to include having to consult multiple professionals before and after getting the autism diagnosis, emotional distress regarding their children's future and the resources that will be needed to support their children. Research also indicates that when children are diagnosed with autism or accepted onto an intervention programme, mothers as the primary special-need carers are at greater risk for psychological and social problems due to feelings of isolation, stress and the challenges deriving from a lack of resources and support (Grey, 2003; Rodrigue, Morgan & Geffken, 1992). It has been reported that mothers of children with autism present with "less parental competence, less marital satisfaction, and less family adaptability...higher levels of disrupted planning, caretaker burden, and family burden...a fewer number of people in their social support system." (Watson, 2010, p. 7).

Grey (2003) indicates that mothers and fathers cope differently with the stress of ASD. From his longitudinal study Grey found that mothers displayed markedly different coping mechanisms, with a greater emphasis on building up social support structures from multiple sources. Fathers on the other hand tended to feel the impact on the family system as a whole, as opposed to feeling it on themselves as individuals. Fathers also placed less emphasis on the creation of social support structures as a way of coping with their stress. In addition,

mothers were more likely to report career stressors as they were unable to return to work or were required to curtail the number of hours that they were able to work. Whilst these stressors tended to improve over the 10-year period of his study, Grey (2002) reported that the one stressor that remained constant was concern about, and planning for, the future of the child or children with autism.

It thus seems that there is a need for more research on the impact of this disorder on the family system as indicated by Watson et al. (2010). Such research should also point the way to finding ameliorating strategies for the above challenges. This is particularly true as families become more and more central to the design and implementation of early interventions. In addition, whilst there is significant evidence that early start ASD interventions can develop and improve multiple-domain trajectories of the diagnosed child (Rogers & Vismara, 2008), both the nature, as well as the intensity, of such early start ASD interventions require significant parental, carer, teacher and family involvement, with both positive as well as negative individual and systemic outcomes (Rivers & Stoneman, 2003; Tonge et al., 2006).

Negative outcomes can be exacerbated by significant but not yet completely understood variances in the long-term outcomes of early start ASD type interventions (Sallows & Graupner, 2005). It is therefore important to gain a greater understanding of the systemic impact of these types of interventions in order to ensure that the nuclear and extended family unit is able to sustain the critical role of intervention coach or facilitator that is an increasingly common requirement in early start autism interventions.

In the majority of early intervention studies, the primary carer trained to implement the intervention was the child's mother (Patterson, Smith & Mirenda, 2012). Whilst there are studies that describe the characteristics of primary carers that participate in early intervention training, Patterson et al. indicate "it is uncertain how frequently and accurately parents are able to identify opportunities for learning in their day-to-day lives when they are taught strategies and skills only in a structured clinical setting. Few studies ...examined the generalisation or maintenance over time of parents' strategy use." (2012, p. 19). These authors suggest that there should be a closer analysis of which elements of an intervention parents are able to maintain at home and that this should then be taken into account when structuring trainings for parents. In addition, it is likely that parents need on-going support, and additional research could shed light on the nature and quantity of the support needed (Patterson et al. 2012).

Despite these limitations, preliminary research indicates that the essential components of early interventions such as the ESDM are teachable to experienced professionals, parents, family members and other carers (Rogers & Dawson, 2007). Encouragingly, research findings on a 12-week ESDM intervention showed the greatest difference in the acquisition of parent and therapist skill was achieved within the first six weeks, with overall skill levels of facilitators above the acceptable intervention levels, resulting in child behavioural gains across areas of development (Vismara et al., 2009). These findings have implications for the 'teachability' of the ESDM as a relatively low-cost intervention that can be implemented in various settings, including those outside the United States where the model was developed, and the model's cross-cultural validity cannot currently be assumed. Another significant point that is highlighted is that although it was unclear what parts of the curriculum were key to developing therapeutic skills in families and novice autism therapists, "the quality of

treatment in a relationship-based, developmentally based intervention model can be quantitatively defined and assessed” (Vismara et al., 2009, p. 123). This is in line with a general approach to developmental interventions that encourages the use of responsive interaction strategies during naturalistic, daily routine interactions with the affected child (Mahoney & Perales, 2005).

For this reason, relationship-focused as opposed to purely behaviour-focused interventions are seen as a priority in helping families deal with the stress of early autism interventions as this can help to enhance and optimise the functioning of infants and young children with autism. There are numerous studies, including a review of multiple randomised controlled trials, showing that comprehensive, relationship-focused interventions can improve children’s cognition, receptive and expressive language, as well as their social and emotional functioning (Rogers & Vismara, 2008; Rogers & Dawson, 2007).

In addition to conducting and facilitating current therapies, parents in the Goin Kochel et al. (2006) study told researchers that they are constantly on the lookout for other therapies. Research is needed to explore the effect on parents of this constant intervention search, involvement and responsibility. According to the fundamental tenets of family systems theory, whatever happens to any individual member of a family, will eventually have an impact on the other members of the family, with the family envisaged and conceptualised as being a single emotional and functional unit (Marshall, Feldman & Sigal, 1989). Few studies could be found that investigated the full systemic impact of intensive, early start interventions on families that have a child or children diagnosed with ASD. One of the reasons suggested for this lack of a systemic focus on early autism interventions is that initial attempts at understanding the aetiological factors implicated in autism suggested that the disorder was

due in part to family, and in particular parental, dysfunction and as a result this early systemic research with its implied blame on the parents was not well received (Spzir, 2006).

Furthermore, research suggests that health professionals that the child with autism is likely to come into contact with tend to focus on biological factors and “unusual social behaviours are not understood as products of social contexts but as by-products of an embodied disorder” (Simon, 2004, p. 260). A major concern in interventions for young children is that the family system may respond to the intervention in ways that do not necessarily support positive, lasting changes in the diagnosed child, due to an upset in the overall family equilibrium (Carr, 2006; Rogers & Dawson, 2007). Despite these types of concerns, there have been a number of recent attempts to provide more systemically focused early autism interventions.

Assessment of Early Autism Interventions

Whilst some of the above-mentioned developments in the field of early ASD detection, as well as the increasingly intensive nature of early autism treatment interventions, have led to greater parental, family and caregiver involvement as active members of the intervention team, the methods for evaluating and assessing the success of these newer interventions are not always reflective of the increasingly systemic nature of ASD early start interventions (Bailey et al., 1986; Flippin & Crais, 2011). The significant increase of parent-inclusive interventions has also led to a renewed call for special training programmes, as well as on-going monitoring and support for caregivers and families implementing parent-focused interventions, and a need to evaluate the overall systemic impact and efficacy of these interventions (Birkin, Anderson, Moore & Seymour, 2004). However, despite an increased focus on parent and caregiver-focused treatment approaches and calls for more systemic

methods of evaluating these interventions, the majority of early autism interventions continue to be patient-focused in their methods of evaluation (Birkin et al., 2004).

Whilst multiple instruments and criteria are used or have previously been used to measure or assess the effectiveness of early start autism interventions, almost all of these methods of assessment have individual changes or improvements in the primary patient or client as their focus. In certain ESDM-type studies for example, the primary mechanism for assessing the intervention includes the individual-focused checklist and adaptive functioning scales (Rogers & Dawson, 2007). Thus, whilst the nature of early autism interventions requires a high level of family input, with multiple systemic components including multi-disciplinary facilitation teams, parents and family members, the primary mechanism for measuring the impact of the intervention is still the diagnosed child (Dawson et al., 2010).

Because young children are embedded in family relationships, if a child is diagnosed with ASD, families are affected in multiple different ways (Martinez-Pedraza & Carter, 2009). A more systemic assessment approach could therefore assist researchers and intervention planners in understanding family functioning variables and the relational dynamics within families, and the impact that these factors have on the intended outcomes of the intervention. One such approach is the systems analysis approach of the impact of early autism and early autism intervention, which specifically focuses on the well-being of different family members, where those families include children with autism, looking at how the well-being of these family members are inter-related (Hastings et al., 2005). There are also several studies (Cassidy, McConey, Truesdale-Kennedy & Slevin, 2008; Hastings et al., 2005; Hastings & Johnson, 2001) documenting the impact on parents and siblings of ASD diagnosed children, who are at increased risk of poor outcomes such as increased stress and

emotional and psychological problems, many with explorative case-study research designs. According to Hastings et al., 2005, p 636) “It is not clear if this putative effect is a direct one or one that is related to the functioning of other family members...general group design studies hide an important reality: family members do not all experience similar effects as a result of being a relative of a child with autism.”

The systems analysis approach further emphasises that it is not only a case of the diagnosed child impacting the other family members, but other family members also have a positive or negative impact on the child with ASD. Research has investigated the influence of family characteristics on the involvement of mothers and fathers in early autism programmes, based on family constructs such as family functioning, social support, marital adjustment, stress and coping, with a ‘functional coping variable’ emerging as an important indicator of positive involvement of both mothers and fathers in early autism interventions, as well as a key mediating variable between parental involvement and healthy family functioning (Gavida-Payne & Stoneman, 1997).

There are indications that parents in treatment groups report less overall stress than parents in control groups, although there can be specific stressors associated with participation in a treatment group (Birnbrauer & Leach, 1993). Studies have reported decreased parental stress as a result of participation in an early intervention for children with disabilities (Lounds, Seltzer & Greenberg, 2007), and Freeman (1997) suggests that the only treatments for autism that have stood the test of time are structured, systemically-informed educational programmes that are specifically geared to the autistic child’s level of functioning, and which stress the importance of taking the family system into account when it comes to structuring and assessing the interventions. Some studies have published findings of negative parental

and family effects as a result of their involvement in early interventions, such as a study indicating that mothers of children involved in early autism interventions exhibited less stress if they had attended fewer, rather than more, early intervention meetings (Brinker, Seifer & Sameroff, 1994). An important early start intervention research finding (Robbins, Dunlap & Plienis, 1991) was that a key success predictor or indicator of early intervention programmes is actually pre-intervention parental stress levels, which can be accurately measured and potentially mitigated against through psycho-education and other pre-intervention protocols. It is important to note that in a South African context, stress is intricately linked with race, class and gender, and for women living in community settings, psycho-education may not be enough. The importance of family stress levels was an indication as to how a more systemically informed approach could start to inform the actual interventions. According to Hastings and Johnson (2001)

It is crucial to understand more about the factors associated with parental stress in families associated with intervention for their children with autism. Information about these variables will help to inform support interventions for parents and these, in turn, would hopefully have a positive impact on early intervention outcomes for children with autism and other developmental disabilities. (p. 328)

Models based on generic stress and coping frameworks suggest that family resource factors such as coping strategies and levels of social and educational support, moderate the effects of autism on parental stress as does the families perception of the stressor (Papageorgiou & Kalyva, 2010). Hastings and Johnson (2001) further posit that although early intervention families are placed under an increased strain, belief in the efficacy of the treatment may help to reduce parental strain. The data from systemically oriented research suggests supportive pre- and post-intervention programmes reduce stress, and that the depression and stress

associated with the extreme, continuous care-giving requirements of children with autism, responds well to interventions such as psycho-education and support groups (Hastings & Johnson, 2001).

Harris and Wishart (2003) stress that siblings need to be adequately informed about their sibling's illness and about the nature and requirements of the early start autism intervention, so as to prevent unhealthy worry or speculation. Furthermore, they reported that involvement in intensive, home-based early autism interventions resulted in more drawbacks than benefits for families if the benefits were measured over time, although the stress levels of these families did not always increase. The research concluded with an appeal for professionals facilitating home-based interventions to consider the multiple needs of the entire family, with minimum disruption to family life where possible.

Freeman (1997) also suggests that before beginning an early autism intervention, parents should question how the perceived failure of the treatment might affect their child and family because families often find themselves in a crisis when they have spent all their financial and emotional resources on a programme that has not resulted in a 'cure', or met other possibly inflated expectations.

Further research into assessing the impact of early interventions on families looked at issues such as the confusion and uncertainty created in families when they receive a diagnosis of ASD for one of their children (Skellern, McDowell & Schluter, 2005), as this process is often directly or indirectly linked with a subsequent early autism intervention. The importance of family involvement in the assessment of communication-focussed early autism interventions has also been identified as important (Koegel, 2000), as has the importance of assessing

parent training in early interventions in terms of gains in language function and behaviour improvement, and the importance of professionals obtaining the views and perceptions of parents with regards to the process of autism diagnosis and treatment (Osborne & Reed, 2008). The need for systemically informed research designs that enable holistic conclusions about the overall effectiveness of parent and carer-implemented early interventions has also been identified (McConachie & Diggle, 2007), including the sustainability over time of parent training, and the importance of including this factor when assessing the success of early autism interventions.

Systemic Assessment of an Early Start Autism Intervention

The specific aim of this study is to systemically evaluate how families and caregivers participating in a CGC pilot early autism intervention based on the ESDM model, experienced the impact of their participation in the intervention, thus expanding the intervention's predominantly child-focussed evaluation methodology, which would be congruent with the systemically oriented nature of this type of intervention.

The need for early identification and early, intensive intervention in children with autism is now well documented, leading to a better prognosis and a reduction in secondary emotional and behavioural problems for the child (Rogers & Vismara, 2008). The ESDM brings together a combination of some of the most promising developments in the treatment of ASD, integrating two of the most successful approaches to treating neurodevelopmental-type disorders, namely Applied Behaviour Analysis and Pivotal Response Training, coupled with the latest knowledge in neurology and developments in infant learning (Rogers & Dawson, 2010).

In conclusion, despite a high level of involvement for parents, carers and other family members in intensive home-based interventions, the present methods of assessing the success of these interventions remain focussed on the diagnosed child, with little attempt to formally incorporate systemically informed assessment protocols.

Chapter Three: Methodology

This chapter describes the methodology that is used in the study. It begins with an outline of the aims of the study, and is followed by a description of the study design. The study is then contextualised. After this the sample and sample size that was utilised, the data collection process, the interview process, and the data analysis are detailed. The chapter concludes with an exploration of the critical issues of ethics and reflexivity.

Aim of the Study

The aim of this study was to investigate the perceived impact on their family systems of a 12-week intervention for young children with autism. The study involved a group of 11 children involved in the pilot project of an early autism intervention based on ESDM principles. The facilitators of the pilot project were clinical psychologists currently completing ESDM training requirements. The exploration of the impact on the family system was selected as a way of expanding on the typically child-focussed methods of early start autism intervention evaluations. The study also provides feedback to the clinical team at the UCT Child Guidance Clinic that is piloting the ESDM project, both with regard to the perceived impact of the intervention on the family system as well as parental perceptions regarding the diagnosed child's post-intervention functioning. This chapter presents the methodology used to achieve these stated aims, beginning with a description of the case study design of the project and the qualitative approach adopted.

Design of the Study

This is a case study exploring the impact of an intervention for children under the age of six years, who have been diagnosed with ASD. According to Yin (2003), case studies can be

categorised as explanatory, explorative, or descriptive and this study has been identified as exploratory in nature. Case study designs are useful for a deeper exploration of a particular issue, with Stake (2000, p. 436) reporting that case studies are common and describing the case as a “functioning specific” which in the social sciences tends to consist of a system, whether the system is the individual child or the family. Thus the case study design was selected because it offered the best way of exploring the perception of how an intervention impacted on a system. This study is interested in how an autism intervention affects a family system because, according to Stake (2000), the family system has a patterned, usual way of being, with parts that interact and respond to events and phenomena in particular ways. In order to maximise the understanding of this phenomena, multiple families were selected to be part of this case study. The study is not however considered to be a multiple case study (which would require individually reporting on each of the individual families involved) but is rather a single study of the systemic impact of the intervention on a small, clearly identified population.

A case study design enabled the exploration of differences in perception within the families involved in the pilot project. This provides a deepening of the understanding of how families are being affected by the intervention, in contrast to other early start autism assessments, which are mainly interested in how the functioning and behaviour of the diagnosed child is being affected. In case studies involving multiple-participants, it is important that all the participants have an event and or phenomena of interest in common (Baxter & Jack, 2008). To this end this exploratory study involves a small and clearly identifiable population group.

As is common to case studies, there is no clear, single set of outcomes that can be measured. It has been suggested that propositions are necessary elements for the development of a

conceptual framework that guides the research (Baxter & Jack, 2008) and in this study, the major proposition is that as autism interventions such as the ESDM become implemented more intensively, and at an earlier age, and as parents and carers inevitably become more integral to the implementation of the intervention, these intervention will have an increasing effect on the family system as a whole. Omitting to investigate this impact or perceived impact on the family system would prevent the clinical interventionists and researchers from developing a fuller understanding of the intervention outcomes on the identified child, including crucial issues such as the long-term sustainability of such outcomes.

The decision to use a qualitative research approach was motivated by the lack of a single clear set of outcomes that could be measured: the descriptive, open-ended nature of qualitative research is suited to the exploratory nature of this study, which has not received significant previous research interest, and whose outcomes are thus largely unknown. Typical methods for collecting qualitative data include interviews, focus groups, and open-ended type questionnaires. In this study data was collected in the form of semi-structured interviews, using guiding questions to ensure all areas of interest were covered (see Appendix A).

Contextualisation of the Study

This study is a pilot project of partners from different disciplines and fields, including the Red Cross Children's Hospital, Autism Western Cape (a non-government organisation supporting families with autism) and the UCT Psychology Department's Child Guidance Clinic. The Child Guidance Clinic, which is a post-graduate training clinic, provides assessment and therapeutic services to children and adults. The ESDM is an internationally developed early start autism intervention that is currently being utilised in a number of different countries, and the above intervention based on ESDM principles is currently being

piloted for the first time in South Africa. The interventionists that are implementing the project are doing the intervention in part-fulfilment of their certification as formally recognised ESDM practitioners. This intervention is currently being run as a multiple-year research project, with children participating as individual members of a small group, with no joint interactions between the various group members and their families. This South African pilot intervention was standardised and run by two internationally trained clinical psychologists, with the outcome of the intervention being evaluated in terms of individual improvements to the identified child participants, according to a standardised intervention protocol. Subsequent to the main intervention, each child participated in a limited number of follow-up sessions.

Sample

The sample used in this study consisted of 10 families with one or more children who have been diagnosed with autism, and who had recently participated in a 12-week early start autism intervention. Because of the interest in how the intervention impacted on the system, immediate and extended family members who were available and willing to participate were interviewed. A total of 16 family members and carers were interviewed. Demographically this group consisted of nine mothers, six fathers, a grandparent and an older niece. With the exception of the niece who was eighteen years old, and the grandparent, all the participants fell into the 25 to 45 year age group. One fell into the group classified in a South African context as 'white', two into the group classified as 'black' and 12 into the group classified as 'coloured'. Geographically, two families lived in 'previously disadvantaged' township locations; one in a traditional 'middle class' suburb and the rest of the families lived in

families had two children with autism, the others had one child with this diagnosis, and most had at least one other child.

Encouragingly, several of the fathers interviewed had taken the primary support role in the intervention, despite international research indicating that it is difficult to persuade fathers to become effectively involved in early autism interventions (Flippin & Crais, 2011).

Process

Permission to conduct the interviews was given by the senior member of the professional clinical team that is presently supervising the ESDM based intervention under the auspices of the UCT Psychology Department, and ethical approval for the study was requested and received from the University of Cape Town Psychology Department. Prior to the interview the nature of the research was explained, and a request was made for the participants to sign a consent form (Appendix B).

Data was collected in the form of open-ended, semi-structured interviews lasting from 45 to 60 minutes. These interviews were then transcribed according to standard research-level protocols, and all interviews were conducted in English with the option of an interpreter present (although this option was not requested by any of the participants).

The majority of participants were approached whilst they were attending the post-intervention sessions that were part of the follow-up protocol. Other participants were contacted telephonically. During the initial engagement, the aims of the study were explained, and it was clarified that their participation in the intervention did not require them to take part in the

study. Family members of ESDM based intervention participants that indicated that they were interested in taking part were then offered a choice of times and locations in which the interviews could be conducted, and these appointments were confirmed prior to the interview date.

The interviewer initially provided a more detailed explanation of the intention of the study and indicated what the possibilities were of the participants receiving eventual feedback from the process. Following this, the participants were provided with consent forms, and they were given adequate opportunity to read through the forms and ask questions regarding confidentiality, interview recording, and other issues, if these had not been fully understood. The majority of interviews were conducted in the homes where the 11 children who participated in the study lived. These homes were located in a number of different geographical areas in Cape Town, including previously disadvantaged areas. The housing varied from brick and mortar housing to pre-fabricated structures. Interviews were usually conducted in a private or semi-private manner in the sitting room, and lasted approximately 45 minutes. Some interviews were conducted at the Child Guidance Clinic for logistical reasons. It was hoped that these settings would provide relative familiarity and privacy, which have been shown to be supportive of in-depth interviews (Babbie & Mouton, 2006). However, it is possible that the clinic location could have had implications for what participants felt they could and could not say, as they may have associated it with the CGC intervention and therefore felt restricted from providing critical feedback. Similarly, the semi-private nature of several of the home interviews could also have restricted the nature of the feedback.

The interviews were conducted and recorded and an opportunity was provided at the end for participants to reflect on the process. All interview recordings were stored safely for reasons of confidentiality. The interview data was then transcribed verbatim, into a number of separate interview documents, which were password protected. These documents were printed out in service of the data analysis process detailed below. Printed hardcopy documents were stored in a secure location to further protect confidentiality as per the signed confidentiality agreements.

Data Analysis

Data from these transcripts were subject to a process of thematic analysis. Although thematic analysis is considered by some researchers to constitute an unclearly demarcated and not fully acknowledged process of qualitative analysis (Braun & Clarke, 2006), it is nevertheless a valid method of identifying and analysing data patterns, and then reporting on them (Braun & Clarke, 2006). It is a way of minimally organising and describing a data set in rich detail, with the potential for going deeply into, and interpreting various aspects of a research topic, and it is widely used within and beyond psychology (Boyatzis, 1998; Roulston, 2001).

Qualitative approaches, by definition, are extremely diverse, as well as nuanced and complex. Thematic analysis has been identified as one of very few skills that is shared across the multiple domains of qualitative analysis, and is generally located within major analytic traditions (such as the grounded theory tradition), rather than being seen as a specific approach in its own right (Braun & Clarke, 2006; Holloway & Todres, 2003). However there is significant scope for thematic analysis to be considered as a valid research method in its own right, being a flexible and useful research tool that is capable of providing a rich, nuanced and detailed account of data (Braun & Clarke, 2006). The absence of concise

guidelines for thematic analysis is a problem because it lends itself to the 'anything goes' critique of qualitative research. According to Foster and Parker (1995, p. 2004), the "analysis of the material is a deliberate and self-conscious artful creation by the researcher, and must be constructed to persuade the reader of the plausibility of an argument."

A number of decisions have to be taken at the beginning of a study underpinned by thematic analysis, starting with what constitutes an identifiable research theme. In this study a theme was regarded as that which captured something important about the data in relation to the overall research aims, representing some level of patterned response or meaning within the overall data set. A further methodological requirement was the development of a rich thematic description of the entire data set and the subsequent identification of themes using a bottom-up or inductive method of thematic analysis (Frith & Gleeson, 2004). This meant that the themes would be strongly linked to the data set, as opposed to being driven by a specific theoretical or clinical interest. Similarly, a decision was made that the research themes would be identified at a semantic or explicit level (Boyatzis, 1998) and the researcher would not look for anything beyond what each participant said on a surface level.

The process of analysing the data consisted of an initial phase of familiarisation with the data set through a process of a rigorous orthographic transcription of the interview material, and subsequent immersion through repeated active reading of the transcripts. At this point there was an initial familiarity with the depth and breadth of the content, including a preliminary search for and noting of meaning and patterns. This methodology was in accordance with suggested best practice for thematic analysis (Braun & Clarke, 2006). Following this first phase, a list of ideas was generated. The next phase involved the production of initial codes from the data sets, which was done manually. Codes identify a feature of the data set that

appears interesting, and refers to “the most basic segment or element of the raw data or information, that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63). Although the final results and discussion of the themes was informed by family systems theory, the coding was strictly data rather than theory driven and conformed to a realist-type epistemology. During this phase all data extracts were coded, then collated together within each code.

The third phase focussed on the specific identification of the research themes and began when all interview transcripts had been coded and then collated. This phase refocuses the thematic analysis at the broader level of themes, rather than the data level of codes, and involves sorting the various codes into potential themes (Braun & Clarke, 2006). A thematic map was used to provide a visual representation of these potential themes. Some initial codes went on to become themes whilst others formed sub-themes or were discarded. This process was reviewed several times in order to allow for depth and nuance to emerge. The fourth phase involved reviewing the potential themes. Patton’s (1990) dual criteria for judging thematic categories, namely the need for both internal and external heterogeneity, were considered here. The fifth phase consisted of evaluating the validity of individual themes in relation to the overall data set, as well as evaluating whether the themes reflected the meanings evident in the data set as a whole. The sixth phase involved defining and naming the themes by identifying the essence of what each theme involved and by subsequently identifying sub-themes within the main themes.

The last phase of the thematic analysis involved the final analysis and write-up of the above identified themes, a task which was described by Braun and Clarke (2006) as telling the complex and nuanced story of your research data, in a way that conveys the merit and

validity of your analysis, as well as providing a sufficient number of relevant data extracts to demonstrate the prevalence of the theme or sub-theme. These extracts need to be embedded within an overall analytic narrative that goes beyond surface description of the data and makes an argument in relation to the overall research question and research aims. The terms F and P were used to differentiate participants within each theme (ie. F1, P1 indicates Family 1, Parent 1)

Ethical Concerns

The ethical concerns of this study related primarily to the process of gaining informed consent for the interviews and dealing with the issue of confidentiality, particularly as the interviews were being recorded. To this end consent forms were provided and adequate opportunity was given for these to be read and for questions to be addressed. The consent forms addressed multiple areas of possible concern including the study purpose and process, possible risks and benefits, voluntary participation and confidentiality (see Appendix B). Participants then signed the consent forms.

Prior to this, ethical clearance for the study was requested and granted by the supervising research institution. A further ethical concern regarding the study was the significant logistical arrangements and time commitment that was requested of the families involved. Many of the interview participants were living in a resource-challenged environment, and there was an ethical question around how much of the participant's time and resources could be asked for, considering they had already made a significant commitment to the autism intervention itself. To this end a commitment was made to participants to share the essence of what was learned from this study with them, in the form of written feed-back. Where interview participants incurred travel costs, these were reimbursed as per the practice for the

CGC autism intervention. A final ethical concern was around the emotional impact that the study could have on interview participants, as parents and family members often found it emotionally challenging to discuss their children's disabilities, and found it especially difficult to discuss their own difficulties regarding their diagnosed children. To this end a considerable effort was made to ensure that the interviews were conducted in a confidential and supportive space. It was made clear from the outset that participation in the study was voluntary and would in no way impact on participation in the CGC autism intervention.

As far as methodological rigor was concerned, there is much debate as to whether specific criteria such as Lincoln and Guba's criteria for trustworthiness are applicable to qualitative research (Shenton, 2004). It was noted however, that according to Shenton (2004), the trustworthiness of a research study is considered important to evaluating its worth, and that trustworthiness involves establishing credibility (truthfulness), transferability (of contexts), dependability (consistency and repeatability) and confirmability (freedom from bias). In this regard, all efforts were made through the use of regular supervision and oversight, to ensure that the findings met the above standards for methodological rigor.

Reflexivity

Alvesson and Sköldbberg (2000) describe reflexivity as the interpretation of interpretation. Reflexivity requires the researcher to attempt to be aware of the impact that he or she is having on the research process and particularly the research outcomes (Steedman, 1991). It has been suggested that in the social science field everything is interpretation and that inherent in qualitative research is the understanding that it is not possible to remain outside of the subject matter being studied (Denzin, 1994). Reflexive research therefore requires the researcher to continually reflect on how his or her involvement is influencing the research. A

reflexivity issue that was specifically focused on was the fact that the interview participants were still involved in the follow-up phase of the autism intervention that they were being asked to evaluate. This could have potentially impacted on what they felt safe to share regarding the impact of the intervention, with possible concerns that a negative assessment would have an impact on their continued or future involvement with the CGC autism intervention. This was mitigated against by reinforcing the issue of confidentiality, and providing assurances that the results would be presented in a way that insured anonymity for the participants. Another reflexivity issue that was taken into consideration was the fact that I was a 'white' researcher from a 'middle-class' socio-economic background, who was interviewing primarily 'black' families, from a 'working-class' socio-economic background, and consideration was given as to whether this would impact on what the participants chose to share with me regarding their experience. It was possible that they would see me as an 'authority figure' and that this would influence their responses. This possibility of bias was mitigated against by attempting to ensure that participants felt as safe as possible, usually in their own homes, and by conducting the interviews in as neutral and professional manner as possible. This process of reflexivity was constantly attempted during this study and was actively discussed during regular supervision meetings.

Chapter Four: Findings

In this chapter I will present the main findings that emerged from the thematic analysis that was conducted on the semi-structured interviews, which constituted the initial data for the study. The study sought to gain insight into the systemic impact of an early start intervention for children who had been diagnosed with autism. The findings are presented in the form of the main themes that emerged from the data analysis. Whilst some of the themes correlate with the focus of the interview questions, new topics and insights that emerged during the process have also been integrated into the findings. These themes are discussed in greater detail in the following chapter. A total of seventeen family members were interviewed, all of which were family relations of the eleven children that constituted the ESDM based pilot project group. A copy of the interview format is available in Appendix B. The interviews were conducted in April and May 2012, several months after the ESDM based intervention had been completed. The majority of the interviewees were adults, and one was a child.

The findings of the semi-structured interviews fell broadly into three themes, each with a number of sub-themes. The three main themes pertaining to the intervention were: negative impact on the family system; positive impact on the family system and additional needs identified by the family system.

Negative Impact on the Family System

One of the broad themes that emerged from the interview process was that, although all family members interviewed felt that the intervention clearly had an overall positive impact,

participation in the ESDM based pilot project had also impacted on the family in a negative way.

These concerns are dealt with in the sub-themes of increased parental and family stress; negative impact on family relationships; negative impact on family resources and negative assessment of child functioning.

Increased Parental and Family Stress

The pervasive and life-long nature of autism means that parents and families of diagnosed children are often required to participate in multiple interventions, which requires constantly establishing new treatment routines and relationships. Several participants spoke of the logistical and relational stress that this involves, which is often exacerbated by a heightened need to be protective of their children. Some of the parental stresses were primarily logistical, with one mother who was not familiar with the area saying:

“I think maybe it was the stress of driving up and down.” (F1, P1)

and another who lived in an informal settlement, and who was required to use public transport provided another perspective on this sub-theme:

“Yes, just the transport, you know the delays of the transport in the mornings.” (F2, P1)

Other stresses were more relational than logistical. One mother described her first visit to the clinic as stressful:

“In the beginning it was a bit stressful.” (F3, P1)

“I did not know what to expect.” (F3, P1)

She went on to indicate that this initial stress reduced considerably after the first session. In the same way that starting a new programme could be stressful for the family system, knowing that the programme would end produced a different but related stress. One very involved father expressed this poignantly, saying:

“It made him (IP) happy to be here and to see her (his primary therapist).” (F4, P1)

“The negative part is that it is over.” (F5, P1)

He then discussed the constant stream of beginnings and endings that both his son and he had had to learn to deal with, regarding the multiple services that they had utilised to date.

A similar but related theme was the stress induced by the fact that parents and family members were usually required to play differing roles in the intervention. Due to resource constraints, the intervention usually involved one parent. This has implications in terms of the fact that early start interventions are parent-coaching models, ideally requiring the participation of all family members. Participants expressed this in several ways:

“Yes, mostly I work during the day, so I haven’t had much of an opportunity to participate as much in it. And there was one Saturday morning where I got to sit in on the session.” (F6, P2)

“No, X was always there (at the sessions), I think X is actually the better parent, I think, out of the two of us in that sense, with the patience, with trying to understand what he’s saying, trying to communicate with him.” (F7, P2)

‘His father doesn’t do a lot of activities away from the home... generally I could say I’m his sole caregiver because his father doesn’t really participate in every single day’ (F8, P1)

Some of the above comments also hint at the level of stress that participation in autism interventions, such as the CGC early start autism intervention, can place on relationships between family members and carers, which is the next sub-theme. This is exacerbated by the fact that several parents were involved in multiple interventions simultaneously.

Negative impact on family relationships

Parenting a child can be stressful, and having a child with a disability such as autism is known to increase the level of relational stress in family systems (Raina et al., 2005). This stress can be exacerbated by the added commitment of an intervention, particularly early start interventions that bring the intervention into the home. Several of the participants spoke loyally and movingly of the impact that autism and interventions such as the ESDM based pilot project have had on their families. One mother spoke of how her perceived lack of support regarding her intervention participation put strain on her relationship:

“I think it was actually more strain (on my relationship with my partner), because I had to be somewhere every day.” (F1, P1)

“I don’t really have, you know, the support, and it was kind of crazy.” (F1, P1)

This increased strain was not limited to parents; several mothers and fathers spoke of the impact of the intervention on their other children:

“I think they think that X (IP) gets away with a lot of things that they (siblings) would never have gotten away with.” (F2, P1)

“Everything that we do revolves around X (IP). I told my husband, you know it’s coming to the holiday, and we (must) take K (sibling) out to the cinema. Take him out so he can know we make time for him as well... so that he does not feel left out.” (F3, P1)

As can be seen from some of the above comments, the strain of participating in interventions that encourage home-based facilitation can have a stressful impact on family relationships. This emotional strain can also extend to a strain on the financial and economic resources of the families concerned, as discussed in the next finding below.

Negative Impact on Family Resources

Early autism interventions are intensive in nature (Rogers & Dawson, 2007), and families are required to transport their children to and from interventions, usually during work hours. This can have a significant impact on job security and income production. One mother described having to reduce her working hours in order to facilitate multiple interventions, which

resulted in time and money constraints that prevented her from being able to afford previously cherished activities such as going to the gym. She elaborates:

“Yes, it has (a negative impact), because it did have, it does have an impact on my working hours, and that’s where the impact comes... in my salary as well.” (F1, P1)

“So, now I’m working (less) there’s a loss of income, but if I had to pay someone to take T (IP) here, to do that, it’s you know, it’s not going to work.” (F2, P1)

Some of the parents interviewed expressed gratitude at having understanding employers; others were not as fortunate. As several frustrated breadwinners put it:

“To me it is actually a bit of a problem because, you know, the boss is always like...you can’t always take time off.” (F3, P1)

“And, especially you only do this during the week, so having to arrange for a work (absence), to be gone for two to three hours, travelling and coming back and staying there.” (F4, P1)

One self-employed father describes the overall impact on family resources:

“No, definitely, you know we’re struggling all the time, you know, we’re always caught up between what we want to do, and what we need to do, and what we have to do, and for me, personally, sometimes it’s difficult you know, and to juggle all of them, you know, it’s crazy.” (F5, P1)

The findings above provide insight into some of the indirect consequences that participation in the intervention had on participants, with the last quote in particular highlighting the economic impact of the intervention on the whole family. However, their concerns were not limited to themselves and general family functioning, they also spoke of their concerns regarding the more direct impact of the intervention on their autistic children and their child or children's overall behaviour and functioning, which is the next sub-theme of the research findings.

Negative Assessment of Child Functioning

In the same way that involvement in early interventions for children with disabilities can be stressful for the parents on a general level, it can also be stressful with regards to the perceived and hoped for success of the intervention in improving child functioning (Raina et al., 2005). Intervention participation brings an almost inevitable level of frustration as parents try to mediate their sometimes desperate hope for significant improvement with a more realistic assessment of what can actually be achieved. This problem is often exacerbated by a lack of understanding of the disorder, which will be discussed later. A mother who did not directly participate in this intervention but who was involved in another simultaneous intervention expressed her frustration in this way:

“I’m going to be honest. I feel more positive when I come from speech classes, because...I can see, okay, here’s some improvement.” (F1, P1)

Another parent who has participated in multiple interventions spoke to her initial exasperation:

“I got frustrated during the middle (of the course), because I felt he (IP) had her (therapist) round his finger.” (F2, P1)

Another participant who had less experience with autism interventions stated:

“I think, you know, the one thing ... is how long it takes to achieve progress.” (F3, P1)

“For me, it (a workshop) would have been more effective than, you know, these sessions.” (F4, P1)

Other concerns that families spoke to regarding the negative impact of the intervention on their child related to the intervention’s requirement for changes in the daily routine which are particularly difficult to manage for children with autism and their families. One mother whose child had to be taken out of school for the sessions provides insight:

“Routine is broken, and he (IP) wouldn’t go back to school – there’s always a negotiation, every time we leave – ‘I’m not going to school’, and then you must enforce (going back).” (F5, P1)

Of course, changing routines means creating new ones, as one father explained:

“He’ll (IP) scream if I didn’t go to KFC afterwards, after the sessions, he would. He got in the routine of UCT, KFC, then go home.” (F6, P1)

In this instance, the family decided the best strategy was to just get him the take-away.

In addition to the somewhat negative and stressful impacts listed above, there were also a number of discussions regarding the intervention that were more positive in nature, which will be addressed in the next major theme of the findings, below.

Positive Impact on the Family System

The identified theme with the highest number of coded responses was that pertaining to the perception that participation in the programme was a positive experience, suggesting that participation in the ESDM based intervention had been a positive experience for the extended family system. This main theme emerged from several sub-themes, such as the positive impact on family resources; positive interactions with therapists; positive impact on family relationships and positive impact on child functioning.

Positive Impact on Family Resources

Although negative findings related to the impact on the resources of families participating in the CGC intervention were reported above, parents also spoke with gratitude regarding the intervention's impact on the family's finances and other resources. Many participants spoke about their gratitude that the programme was made available free of charge, including the coverage of transport costs. This was important as many of the parents were struggling financially. Because of the multiple deficits that characterise autism, many of the children had to receive other interventions that the family had to pay for, which was an added burden on top of normal daily family living expenses. As one father put it:

“Yes, that’s why we jumped at the chance (of a free intervention) when we found it.”

(F1, P1)

Others expressed similar sentiments:

“With the speech (classes) and things like that, if you don’t have a medical aid...yes, then it becomes very expensive.” (F2, P1)

“Yes, the thing is, I think, with autism it’s like ...it’s very difficult to find support, to find (free) activities, so it’s been useful.” (F2, P2)

Participants spoke about other aspects of the programme that they were grateful about, one of them being the high quality of the interactions that they had with the Child Guidance Clinic therapists.

Positive Interactions with Therapists

A significant positive impact theme identified from the interview data pertained to the nature and quality of the interactions that primary parents and carers had with the clinical staff of the Child Guidance Clinic. Parents expressed surprise at how well their socially challenged children took to and interacted with clinic staff:

“You know, to (therapist), he (IP) was a person, that, she is very open and she was easy to work with him. Like I said, he took to her quite quickly, where otherwise he would rather be playing by himself.” (F1, P1)

A father expressed similar sentiments:

“I was surprised that he would go to (therapist), and on the Tuesday, he looked forward, you know, to actually see (her).” (F2, P1)

“I think the part where he was actually mixing with an outsider, I think that was a good thing.” (F2, P2)

Others commented positively on the clinic, support staff and the therapists:

“I’d say the environment also played a role. The, you know, the health setting.” (F3, P1)

“Before he was a zombie child, it’s just amazing, and the therapist he worked with, he actually built a relationship with her. U (IP) hasn’t had a relationship with anyone other than my husband and myself.” (F3, P2)

“He became friends with (therapist), now he’s engaging with his brother, and it’s just amazing!” (F4, P1)

“So to be able to ask a therapist (therapist 1) or (therapist 2), and for them to be able to give us an answer was like awesome, because so far there were no one that we could ask what we could do...from, you know, like an educated background.” (F4, P1)

Parents and caregivers also stressed that they had not just appreciated the staff, but learned from them as well. They indicated that watching the therapists interacting with their children had helped them to learn, not only specific parenting techniques relating to children with autism, but also some basic parenting lessons, which they had obviously been struggling to learn. It was clear that their lack of these parenting techniques had had a negative influence on child behaviour and family stress levels. Parents had observed the way that clinic staff interacted with their child, and then replicated and reinforced what they had observed at home. One mother spoke with amazement, expressing her gratitude at learning some key parenting skills:

“And, watching (therapist), the way she engages with U and that he actually understood also gave us, you know, like a light bulb moment that we can say no, and we can discipline him, and it’s fine, and he actually picked up so much, his behaviour calmed down. It was just awesome training, really.” (F5, P1)

Others parents and family members interviewed echoed this theme:

“That was really, really (helpful) because they took the time out, to ask me, so how are things? And then I would say, oh you know, he’s touching his private part, and then she would say, oh, do you know what, that is actually normal for a young child.” (F6, P1)

“And also, I noticed they gave him options, we’ve never ever given, because we say ‘you do what I say, you don’t get a choice.’ ...like you just see his little eyes shining, he’s like, oh, I have a choice in life! And that was amazing, it built his self-esteem.”

“...and then, I’d say, I learned a lot – they taught me certain things, you know? And, taking, maybe taking one toy at a time, or playing and trying to get him to do a repetition of colours, or repetition of shapes and sizes, and that learning I brought home, and then we practice it at home.” (F7, P1)

“But, yes, like I said, it didn’t make me feel at all useless. What I learned from there, and saw how they do things, it was more of an empowering thing, so you could come home and teach them or use that method here.” (F8, P1)

“It actually made me feel that I’ve actually...it made me feel more helpful, you know, sometimes as a father, you know, with autistic children, because you (now) have to play a certain role.” (F8, P1)

“Having to practice those things actually made me feel, you know, I have a purpose, I actually have a role.” (F9, P1)

“It was very helpful, because it’s actually the first intervention that R was in. It was the first course that I was in, to see how to assist my child.” (F10, P1)

In addition to expressing their appreciation for the positive relational experiences that they had with staff at the clinic, many also spoke of how involvement with the intervention had improved overall family relationships.

Positive Impact on Family Relationships

Participants spoke about the stress that having a child with autism and participating in the ESDM based intervention had placed on family relations, but they also spoke of the positive impact that the intervention had on parental and family relationships. One husband and father said:

“In terms of our relationship, we are much closer as a couple.” (F1, P1)

Other parents said:

“So I think although it has down sides, it actually...it’s actually strengthened our relationship.” (F2, P1)

“It created an opportunity to spend a little more time together...for us to relate on any level at this point is fantastic.” (F3, P1)

These positive impacts extended to other family members. One mother had this to say about the positive impact on her children:

“Definitely. U (IP) never used to share and they didn’t really bond as brothers, they were like two separate people walking past each other in the house. They engage, they chase one another now...U (IP) went to fetch two sweets and he handed one sweet over to his brother. He’s never done that and they’re actually acknowledging one another now.” (F4, P1)

“He (IP) was aggressive, he was so aggressive, but now he’s fine. He’s so kind to him (sibling).” (F5, P1)

“So far as R (sibling) and him (IP) are concerned, there’s been a marked improvement there and it’s a day-by-day thing we see every day – better and better.” (F6, P1)

Consistent with an improvement in sibling relations, family members attested that participating in the programme had improved relationships with extended family members and family friends, including grandparents, cousins and child carers. Some of the comments were:

“It’s just been so positive through the whole family. It didn’t just stop with myself and my wife, you know, and the kids, it just went on and on, you know...this just reintroduced them into the family again as autistic children.” (F7, P1)

“...when I started the Denver module, my mother and I were not on good terms, we recently started speaking again and she was telling me how amazing (the improvements were), U using language, S making eye contact. So that was actually quite positive because she could see the difference in my kids.” (F8, P1)

In addition to the positive impact on the families, another positive theme that emerged from the interviews was that of family-observed improvements and observations regarding the improved functioning of the child participant in the intervention, as reported below.

Positive Impact on Child Functioning

A potentially significant finding in the study is that whilst parents and family members spoke at length about the impact of the intervention on overall family functioning, they also had a

lot to say about the positive impact that they perceived the intervention as having on the behaviour and functioning of their autistic child. Parents spoke movingly and often with deep appreciation about these changes. Some participants spoke to both the impact on the family and their diagnosed children:

“Yes, look, I don’t think I could ever say anything negative about the Denver programme, right, because as far as we understand Denver and what it’s done for kids, you know, it’s been positive all the way, you know. And not just for our kids, for the complete family, whether it’s my brother, or sisters, or my parents, because they actually...it’s been a case where the one just taught the other, you know.” (F1, P1)

Another family member who was a consistent primary carer spoke about where she felt the impact of the intervention had been:

“I think it was more changing him (IP), most probably, than (in) the whole family.”
(F2, P1)

Others shared their thoughts and observations on just their children. A mother with two autistic children on the programme had this to say:

“I actually saw more of an improvement with my older son U (IP1) than S (IP2), although U is moderately to severely autistic, and S is a little more high functioning. Both are non-verbal, but U started speaking through the Denver model, so that was like awesome.” (F3, P1)

“More and more he could express his behaviour, in words, (rather) than shouting and screaming.” (F4, P1)

“It’s helpful, because he’s got, he’s got other words. He was not talking at all when we came here. So now there are a few words, 10 to 20 words he knows, yes.” (F5, P1)

“It’s amazing that, you know, when he goes to the other therapies...they pick up things and sooner or later they forget it, you know, but it’s been a while, and there are things that actually stuck, you know, and he just seems to be more playful than what he used to be.” (F6, P1)

“I’ve only got positive things to say about it, and it has only helped my child and helped me and helped my family.” (F7, P1)

In addition to the positive and negative findings reported on, above, many families reported experiences pertaining to needs that they had identified regarding their participation in the intervention.

Additional Needs Identified by the Family Systems

Another major theme identified in the interviews could most simply be described as unmet needs pertaining to participation in the early start intervention. Although these needs-focussed issues that were raised by interviewees were neither negative nor positive, this did not mean that they were expressed with any less passion or eloquence; in fact discussions on

these issues were often highly energised. Of these needs, the most commonly referenced was regarding the issues of the need for more autism education.

Family Need for General Autism Information

A common theme in the interviews, which was spoken to with equal measures of frustration and enthusiasm, was the need for autism education and information, for both the immediate family and carers, as well as for the extended family and the community. Notable in the interviews was the widely differing level of knowledge about autism and the ESDM intervention amongst the participants. A single mother spoke with anguish on her general lack of understanding:

“Yes...I also don’t know about it, like really about the autism – I don’t know really about it.” (F1, P1)

Whilst there were several requests for general information on autism, it was the issue of their child being diagnosed with a spectrum disorder that had clearly left many parents confused, and this was prior to the official recognition of ASD. Some of the questions were as follows:

“What I don’t know, sorry to interrupt, I want to know is, he’s been that known as a child that’s on the spectrum. Where on the spectrum he is, we don’t know.” (F2, P1)

“No, that is a good one to know, like what do you do with a child that’s on the spectrum, that’s what I need to know? Does it change?” (F3, P1)

“Yes, what spectrum is he? What was the aim of that towards? I don’t know, does it change? Does it stay the same?” (F4, P1)

“The diagnosis was done with Dr S. That’s where he was taken to, to be diagnosed. Yes, what spectrum is he?” (F5, P1)

Clearly there is a need for accurate information regarding the implications of having a child diagnosed with a spectrum disorder. In addition to this need for general knowledge, there were requests for more autism information for extended family and community members.

Community Need for Autism Education

In the same way that immediate family members expressed a need for specific information for themselves, a clear sub-theme was the need for more general information regarding autism and autism interventions expressed in relation to extended families and geographic and cultural communities, as evidenced in previous studies (Baron-Cohen, Tager-Flusberg & Cohen, 1993). This was an issue where the words and the number of responses below hopefully convey some of the passion that this topic, which was not in the original questionnaire, unexpectedly engendered:

“There’s a lot of awareness that needs to be done in the family, in the house...she, my mother-in-law, is telling me last week that the people on the other side of the house were saying there’s nothing wrong with him (IP)...my family, my parents, hasn’t accepted it yet.” (F1, P1)

“My parents told me that I am a bad parent...the radio station had a programme on autism awareness, one man said his child (with autism) could now speak and recite Koran, so my parents are thinking, if that child can recite Koran, why can't your child speak more, you know. What are you doing?” (F2, P1)

“That's the biggest problem. The family members don't understand it (the autism interventions), my son, they say we spoil him too much...you know where I come from they are always cultural, so they say I must go to those witchdoctors.” (F3, P1)

Some parents suggested that they wanted to become more active in educating their families and communities. One suggestion that was made by some parents and family members was for a week-end educational workshop before or during the programme, to which family and community members could be invited, as well as for parents who would not be directly involved in the sessions and parent coaching activities:

“Actually, what I would like to know is how can I get people to understand what autism really is about. The same problem also with the community, they also don't understand my son.” (F4, P1)

“And at the moment you obviously would not know what to say...and then maybe if you had a bit more information...even just sharing your personal experience I think would be useful (over the radio in Khayelitsha).” (F5, P1)

“Yes, like if there could be a day workshop ...then I’d say yes, I don’t think getting involved like, you know, being there for every session is as effective as perhaps a day programme with lots of theory and discussion and that.” (F6, P1)

Although there were many requests for education and awareness raising for families and communities, one parent expressed that she did not think that anyone would ever understand her experience unless they were in a similar situation:

“I’m the one and they’ll never understand, okay. Never. You can’t explain it to somebody else that doesn’t, has never experience being with an autistic child, and how they are, and they’ll never understand (my child).” (F7, P1)

In addition to more general information, participants requested more information about the CGC’s pilot programme.

Family Need for Education Pertaining to the CGC’s ESDM pilot intervention

Parents and immediate carers not only expressed a need for general autism information, but they also expressed the need for more specific information about the ESDM programme itself, including aims, methodology, post-intervention evaluation, follow-ups and sustainability. of the model:

“Why would you ask the child to put the puzzles together? What was your scoring aim like, or what were you testing?” (F1, P1)

“You see, what I need to also understand is I don’t know much of the programme that he was on, and I need to know what was the aim of him (it)...what is the motive behind the whole thing?” (F2, P1)

“I must say that I am not too familiar with all the different treatment models; if you speak to...if you say we’re doing the Denver model, I don’t see it as a model.” (F3, P1)

Other parents wanted to know more about the follow-up process, indicating concerns around sustainability:

“So, I want to know, what was the aim? What were you people actually looking for...and more importantly, with the help that he has been getting, and the progress that he has been making, how do we then take that and carry on? Going forward.” (F4, P1)

“My thing is, what is the next step? So, that cycle came to an end after 16 weeks...so what now?” (F5, P1)

Other participants inquired eagerly about the assessment process, results and feedback:

“What I am looking for is did you see an improvement in him? Because you assessed him, you did the programme with him...besides me, did you see an improvement in him?” (F6, P1)

The findings reported above provide a clear indication of the impact that participation in the CGC early start autism intervention had on the families and caregivers involved. The results showed that the intervention had significant impacts on the participants, and that these impacts were both positive and negative in nature, and that they encompassed both the impact of the intervention on the families, as well as the impact of the intervention on the diagnosed child or children.

The findings also elicited a third category, which was more neutral in nature, and related to perceived needs that the participants articulated during the course of the interviews, which pertained to their participation in the intervention, but which could not be categorised as being either positive or negative in nature.

The systemic impacts documented above are usually not captured in a conventional early start autism intervention, and they will be discussed in more detail in the following chapter.

Chapter Five: Discussion and Conclusion

This chapter examines and discusses the main findings that emerged from the study's thematic analysis, which was based on the study participants' semi-structured interviews. It attempts to convey an understanding of the participant's responses, and where appropriate refers to recent research. The chapter starts with a systemically oriented discussion of the findings, and is followed by a more general discussion correlating with the main themes that were identified in the previous chapter on findings. Due to the relatively small sample size, the nature of the discussion will be tentative in nature, and open to alternative interpretations. The interview structure provided an opportunity for the participants to address issues that had not been addressed previously, and the results and discussion will reflect this. The chapter will conclude with a reflection on the research process, some comments on the limitation of the study, as well as research conclusions and opportunities for further study

Systemically Oriented Discussion of Main Findings

The main themes that emerged from the data identified by the process of thematic analysis described in Chapter 3 and reported on in Chapter 4, can be broadly categorised into three main themes, namely that a theme that participation in the ESDM based pilot project had a negative impact on the family system (such as increased family stress); a theme that participation in the ESDM based pilot project had a positive impact on the family system (such as an increased family cohesiveness); and a theme that participation in the ESDM based pilot project elicited additional needs identified by the family systems (such as a need for more information on autism).

The described impact of having a child participate in the ESDM programme, as indicated by

the thematic analysis and findings, is in accordance with the basic propositions of family systems theory. One of the central concepts of this systems approach is holism, a concept that suggests that family systems engage in an integrally organized way in order to carry out the daily challenges and tasks of life (Wilber, 2000), and that they also adjust in order to accommodate various developmental needs and challenges within the family system, including the development of strategies to meet the needs of individual members and the family as a whole or group (Anderson & Sabatelli, 1999).

A systems perspective therefore focuses on the connectedness in terms of both the interrelation and interdependence of the components of the system. This interrelation and interdependence can be seen in the themes of this paper which indicate clearly that participation in the ESDM based pilot project impacted not just on the autistic child, but on the family system as a whole. Participants spoke eloquently and movingly on the impact that autism and the intervention has had on relationships with partners, siblings and extended family members, and accommodations they had to make such as less time together.

The concept of interdependence and independence is implicit in discussions focusing on the nature of the family system and the way that the system organises around, and adapts to, changes and disruptions. Individual family members and the sub-units that comprise the family, extended family or community system, are mutually influenced by and mutually dependent upon each other (Whitechurch & Constantine, 1993). This primary concept is now firmly embedded in clinical models that are emerging from a family systems perspective, and the study findings seems to bear evidence of this in the themes that emerged, with the thematic analysis indicating that virtually all members of the family had been mutually influenced by one another, with both positive and negative effects. Examples from the study

include instances such as siblings feeling left out due to the extra attention on the participating child, and parents responding by feeling guilty then attempting to accommodate the sibling response by organising special activities for the siblings. Related to the systemic concept of holism and hierarchies is that of boundaries (Wilber, 2000), which regulate the flow of people and information into the system and within the sub-systems, and the themes in this study provide an insight into the boundaries of the families and extended families that participated in the study. The study indicates that some family systems are more open and accommodating to peripheral members, such as the CGC study facilitators (and their approach), whilst others are more closed and rigid. Families also spoke of a healthy mourning of the loss when the intervention ended, saying how hard the ending was for their child, with others frustratingly questioning levels of follow-up.

Because it is the main focus of autism interventions, parents and family members interviewed on the impact of participating in an autism programme tend to focus on the impact that the intervention has had on the autistic child. The ESDM based intervention, however, was not conceived as a standard 'expert-delivered' intervention, but described as being a systemically informed model utilizing the family as co-facilitators (Rogers & Dawson, 2010; Rogers & Dawson, 2007). This orientation towards the family can be seen in the findings which indicate that involvement in the ESDM has had an impact, not just on the identified child, but on the entire family system. Examples of this were present in parents' descriptions of how the intervention had facilitated increases in family cohesion. The various issues that emerged will now be discussed below.

Negative Impact on Family System

Whilst the majority of research on early autism interventions focuses on the observed impact

of the intervention on the autistic child, the finding of interventions having a negative and stressful impact on the family system has been documented in a smaller body of literature (Cridland et al., 2014; Hastings & Johnson, 2001). In some studies parents articulated concerns around logistics and resource allocation regarding participating in the project (Hastings & Beck, 2008), although there is research indicating that family involvement in a pre-intervention stress-reduction programme can reduce these concerns (Bitsika & Sharpley, 2004). There is also research documenting the impact of intervention participation on resource allocation for the family, in which carers seen to make sacrifices when allocating resources to interventions (Hastings & Beck, 2008). There was very little research documenting the impact of interventions on low-income participants in developing countries. Participants in this study seemed to feel comfortable discussing negative and stressful responses of the intervention on themselves and their families, possibly because they felt that the overall impact of the ESDM based intervention was positive, especially for their autistic children. The researcher was also clear about his lack of direct involvement in the project, and the high level of confidentiality regarding the interview data. Some of the negative issues family members described are discussed in the sub-themes below.

Increased Stress on Family Logistics, Resources and Relationships

The issue of increased stress on parents and families was raised by a large number of participants. Parents indicated that the everyday stresses of parenthood are often exacerbated by the experience of having an autistic child. The pervasive and life-long nature of the disorder means that parents are often required to engage in a number of autism-related services, often simultaneously (Rogers & Dawson, 2010), and parents spoke to the stress of constantly beginning new interventions and the stress of having to end them. These interventions, including participation in the ESDM based project placed parents under stress

regarding practical issues such as logistical arrangements. Intensive, early interventions are usually planned in developed countries, and do not necessarily take into account the challenges faced by participants in developed countries. An example of this was participants who complained about the reliability and scarcity of public transport, with one single mother having to change her mode of transport twice in order to get to the clinic, needing to leave well in advance of the session.

The intervention was also described as having a negative impact on job security and income production, with families describing the difficulty of having to take time off of work with a net loss of productivity and income. This is a critical issue as parents often described a double-bind type of situation in which the costs of intervention services placed them under financial strain, and required them to maximize their income, yet the timing and nature of the services often impacted negatively on income production. This is particularly serious in a country such as South Africa that offers little in the way of economic and social support for families with autistic children, and where the unemployment rate is high, and the consequences of endangering one's employment are significant. In addition to negative impacts on family logistics and resources, relationships in the family system also suffered, with some participants pointing to a loss of closeness and cohesion in the family. Some parents who were the 'involved one' in the intervention reported feeling unsupported, with and the less involved one feeling left-out and untrained regarding the home-based component of the ESDM based intervention. This separating out of roles is potentially problematic considering that early start interventions encourage full participation from all family members.

Positive Impact on Family System

The study participants spoke of the many significant impacts that participating in the early start autism interventions had had on both the overall family system, as well as the positive impacts on their identified child or children.

Positive Impact on Family Logistics, Resources and Relationships

Participants spoke about the numerous positive impacts of the programme, including the value of the intervention as a parental learning experience. Whilst it is potentially challenging for parents to observe trained professionals interact with their children in ways that appear to be more effective than their own interactions, (Remington et al., 2007), the overall perception amongst parents and caregivers in this particular study was that it was a positive and empowering experience.

Parents indicated that one of the most positive aspects of the ESDM based intervention had been the warm interactions that the families had with the therapists, and how they had learnt a great deal, including some basic parenting lessons. The fact that the interventionists are highly qualified and experienced clinicians could account for the high quality of these interactions, and it is possible that the nature of autism is such that some parents are reluctant to utilise standard parenting techniques such as firm discipline, even when they have used these techniques effectively on their other children. For example, one sibling described how his younger autistic brother was allowed to get away with anything, unlike himself at that age. Involvement in the intervention was also described as having an overall positive impact on family relations, such as parental cohesiveness, which can be expected when a family shares a generally positive experience.

Parents also spoke with surprise and gratitude at the fact that such an intensive, high quality intervention was offered at no charge, with transport costs covered. This also spoke to the great need for parents with autistic children to be able to access services at no charge, and the burden that participation in multiple service interventions places on the family. This also speaks to the pervasive and life-long nature of the disorder, and the need for these types of services to be provided in low-income communities.

Positive Impact on Child Functioning

Another significant and positive sub-theme that emerged from the family interviews spoke to improvements in functioning and behaviour in the identified child participant in the intervention, echoing findings from previous early intervention studies. (Vismara & Rogers, 2010; Warren et al., 2011). Although this study was designed to assess the overall impact of the intervention on the family system, it was clear from the responses that the participants had noted with enthusiasm the specific impacts of the intervention on their autistic children. One possible reason for this is that positive changes in the behaviour and functioning of their autistic children has a positive influence on the entire family. Families reported improvements in almost all the domains affected by autism such as social communication and restricted interest. These findings will be passed on to the intervention team, and it was significant for the purposes of this study that there was a high correlation between the perceived impact of the intervention on the autistic child, and the perceived impact on the overall family system.

Overall, the majority of responses by the family members were positive about the ESDM intervention, and participants expressed gratitude for the opportunity that this study afforded them to reflect on their participation, and on the impact of the intervention on their families.

Additional Needs Identified by the Family Systems

This theme references issues that the families felt had arisen as a result of the intervention but which could not be categorized as having an overall negative or positive impact on the system, such as the need for further education. This need for further education has been identified in previous systemically oriented evaluations of early autism interventions (Freeman, 1997; Mahoney, Kaiser & Girolametto, 1999).

In this study parents expressed specific requests for more information on autism in general, and on specific issues such as 'where on the spectrum is my child?' Another common question in the study was 'where was my child on the spectrum before the intervention, and where are they now?' This has been previously identified as a common area of confusion for parents of children with autism (Skellern & McDowell, 2005), and this confusion may well increase with the new autism classification in the DSM-5. In the same way that immediate family members expressed a need for specific information for themselves, a clear sub-theme was the need for more general information regarding autism and autism interventions, which was expressed in relation to extended families and various geographic and cultural communities.

This need for greater community education has been evidenced in previous studies (Brunner, 1993). The discussions on this topic was amongst the most passionate, with more than one participant describing how exposure to autism through their children, had motivated and inspired them to contribute in some way to increasing the level of community awareness around autism. This need was also expressed in relation to extended families, whose comments to participants regarding their autistic child were often painful ones along the lines

of 'there is nothing wrong with this child, you must be firmer with them'. Family comments were also possibly biased by genetic inheritances, with one mother being told by a great aunt, that her child had also not spoken until he was seven and this was normal. This need of families for some form of meaning making regarding their life experience can be very beneficial for the family (Wilber, 2000). Some parents made specific suggestions about how they wanted to become more active in educating their families and communities.

One suggestion that was made by some parents and family members was for a week-end educational workshop before or during the programme, to which family and community members could be invited, including the parent who would not be directly involved in the sessions and parent coaching activities. This correlates with research indicating that parental and family benefit from the intervention is greater for members who actively participate in the intervention in some way (Zager, Wehmeyer & Simpson, 2012). Family members also communicated the need for more information regarding the aims, methods and assessment of the ESDM intervention, and this would form part of the recommendations to the intervention teams. This family need for more intervention information is understandably common to participants in more systemically oriented autism programmes such as the ESDM (Rogers & Dawson, 2010).

Conclusion

On reflection it was a privilege to have had an opportunity to meet and work with the therapists and families that participated in both in the ESDM based intervention, as well as this study. This study has potential implications for the role of ESDM interventions in South Africa, and could provide valuable feedback to the ESDM based interventionists who were

involved in the pilot project. The study does however have limitations. The first part of this conclusion will focus on these limitations, and the next section will draw together the outcomes of the research findings.

Limitations of the Study

The original group of children in the ESDM based intervention was relatively small, and I was not able to interview all their family members for this study, mostly due to logistical difficulties. Although the study looks at the impact of the intervention on family members as a whole, the participants largely consisted of parents and grandparents, which is not an ideal representation of all family sub-systems.

Due to parental time constraints, the interviews, which took place at the clinic, were not always as long as would ideally have been possible, and some participants seemed reluctant to allocate more time to an intervention that had already been a strain on their family resources. The fact that interviews were conducted several months after the intervention could have impacted on the participant's ability to accurately recall the perceived impact of the intervention.

Although confidentiality was stressed and efforts were made for the interviews that took place in private homes to be as private as possible, the level of sharing may well have been compromised by a lack of privacy. It was also not clear to what extent participants were able to differentiate myself from the CGC's ESDM based intervention implementers, although attempts were made to convey this on numerous occasions.

Language of the participants was also a consideration, and a limitation of the study was that the interviews were not always conducted in the participant's home language. The semi-structured nature of the questionnaires was designed to allow for open-ended and unanticipated responses, however it also has the potential to lead participants in directions they would not necessarily have chosen to go and this may have impacted on the themes that emerged in the findings.

Research Conclusions

There appears to be a clear movement in the field of autism, towards treating children more intensively and at a younger age. This trend has been driven by numerous factors including an ability to diagnose autism at a younger age, as well as neurological developments emphasising the importance of this type of approach with reference to neuro-plasticity and developments in the field of infant and child learning.

As this movement towards early, intensive interventions, such as the ESDM, progresses, it has become clear that a greater role is required from parents and family members if the intensive nature of the intervention is going to be adhered to. The intervention is no longer separate from daily family and home activities, but has now become integral to them. We know from family systems theory this additional input and responsibility is going to have significant impacts on all the members of the family system, and that if the impacts are considered to be too great for the system as a whole, then the system in the form of the parents and other family members will potentially defend against the changes required by the intervention.

The results from this study seem to indicate that participation in a 12-week ESDM based pilot

study did have significant impacts on the family system, even though this intervention did not constitute a full intensity early start intervention in terms of what it required the parents to facilitate in the home environment. The impacts on the family fell into three main themes, namely negative impacts, positive impacts, and needs identification. Families also differentiated between the impact on the family as a whole, and the impact on the autistic child.

Whilst the overall tone of the participants was positive, with many references to improvements in child and family functioning, there were also sufficient negative concerns regarding the impact of the intervention, and these could be taken into consideration when planning future interventions, with special emphasis on the type of issues that most affect low-income families, such as unreliable transport infrastructure.

On a more global note, it became clear from this study that the movement towards family-focused early autism interventions such as the CGC's pilot ESDM based intervention, could benefit from a corresponding movement to systemically informed methods of intervention assessment.

Opportunities for Further Research

There appeared to be limited research on the systemic-impact of early start autism interventions, particularly research that utilised best practices such as random controlled trials and there would thus appear to be an opportunity for further research in this area. Another potentially rich area of research would be to explore more deeply the desire expressed by participants to become involved in educating their extended families and communities

regarding autism, and the potential individual and communal benefits of these meaning-making and psycho-social activities

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, V.A.: American Psychiatric Association.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.). Washington, D.C.: American Psychiatric Association.
- Aldred, C., Green, S. & Adams, C.C. (2004). A new social communication intervention for children with autism: Pilot randomized controlled treatment study suggesting effectiveness. *Journal of Child Psychology and Psychiatry*, 45, 1420-1430.
- Alvesson, M., & Skoldberg, K. (2000). *Reflexive Methodology: New Vistas for Qualitative Research*. London: Sage.
- Anderson, S. A., & Sabatelli, R.M. (1999). *Family interaction: A multigenerational developmental perspective* (2nd ed.). Boston: Allyn & Bacon.
- Babbie E., & Mouton, J. (2006). *The practice of social research*. Cape Town: Oxford University Press.
- Bailey, D., Simeonson, R., Winton, P., Huntington, G., Comfort, M., Isbell, P., O'Donnell, K., & Helm, J. (1986). Family-focused intervention: A functional model for planning, implementing and evaluating individualised family services in early intervention. *Journal of Early Intervention*, 10(2), 156-171.

- Baron-Cohen, S., Tager-Flusberg, H., & Cohen, D.J. *Understanding other minds: Perspectives from autism*. Oxford: OUP.
- Bateman, C. (2013). Autism – Mitigating a global epidemic. *South African Medical Journal*, 103 (5), 276-277.
- Baxter, S., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 14(4), 544-559.
- Bayatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, C.A.: Sage.
- Birkin, C., Anderson, A., Moore, D., & Seymour, F. (2004). Evaluating the efficacy of parent-focused interventions for autism: How do we know what will work? *Australian Journal of Early Childhood*, 25(1), 42-47.
- Birnbrauer, J., & Leach, D. (1993). The Murdoch early intervention programme after two years. *Behaviour Change*, 10(2), 63-74.
- Bitsika, V., & Sharpley, C.F. (2004). Stress, anxiety and depression amongst parents of children with ASD spectrum disorder. *Australian Journal of Guidance and Counselling*, (14), 151-161.

- Blaxill, M.F. (2004). What is going on? The question of time trends in autism. *Public Health Report*, 2004, 119(6).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brinker, R., Seifer, R., & Sameroff, A. (1994). Relations among maternal stress, cognitive development, and early intervention in middle and low SES infants with developmental disabilities. *American Journal of Mental Retardation*, 98(4), 463-480.
- Bristol, M. (1985). Designing programmes for young developmentally disabled children: A family systems approach to autism. *Remedial and special education*, 6(4), 46-53.
- Butter, E.M., Wynn, J., & Mulick J.A. (2003). Early intervention critical to autism treatment. *Pediatric Annals*, 32 (10), 677-684.
- Carpenter, M., Nagell, K. & Tomasello, M.(1998). Social cognition, joint attention, and communicative competence from 9 to 15 months of age. *Journal of Child Development*, (63) 4, 1-143.
- Carr, A. (2006). *The Handbook of Child and Adolescent Psychology (2nd Ed.)*. New York. Routledge.

Cassidy, A., McConkey, R., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum disorders: the impact on families and the supports available to them. *Early Child Development and Care*, 178(2), 115-128.

Cridland E.K., Jones, S.C., Magee, C.A. & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism Journal*, 18 (2), 108-118.

Dawson, G., Webb, S.J., & McPartland, J. (2005). Understanding the nature of face processing impairment in autism: Insights from behavioural and electrophysiological studies. *Developmental Neuropsychology*, 27(3), 403-424.

Dawson, G., Munson, J., Estes, A., Oosterling, J., McPartland, J., Toth, K., Carver, L., & Abbot, R. (2002). Neurocognitive function and joint attention ability in young children with autism spectrum disorder versus development delay. *Journal of Child Development*, 73(2), 345-358.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model, *Pediatrics*. 125, e17-e23.

Denzin, N.K. (1994). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.

Drew, A., Baird, G., Baron-Cohen, S., Cox, A., Slonims, V., Wheelwright, S., et al.

(2002). A pilot randomised control trial of a parent training intervention for pre-school children with autism: Preliminary findings and methodological challenges. *European Child and Adolescent Psychiatry*, 11, 266-272.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioural treatment at school for 4-7 year olds children with autism: A 1-year comparison controlled study. *Behaviour Modification*, 2002, 49-68.

First, M.B. (2009). Harmonisation of ICD-11 and DSM-V: Opportunities and challenges. *The British Journal of Psychiatry*, 109, 382-390.

Flippin M., & Crais, E. R. (2011). The need for more effective father involvement in early autism interventions: A systematic review and recommendations. *Journal of Early interventions*, 33(1), 24-50.

Freeman, B. (1997). Guidelines for evaluating intervention programmes for children with autism. *Journal of Autism and Development Disorders*, 27(6), 641-651.

Frith, H., & Gleeson, K. (2004). Clothing and embodiment: Men managing body image and appearance. *Psychology of Men and Masculinity*, 5, 40-48.

Gavida-Payne, S., & Stoneman, Z. (1997). Family predictors of maternal and paternal involvement in programmes for young children with disabilities. *Journal of Child Development*, 68 (4), 701-717.

Goin-Kochel, R.P., Mackintosh, V.H., & Myers, B.J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Journal of Autism*, 10(5), 439-451.

Grey, D.E., & Holden, W.J. (1992). Psycho-social well-being among the parents of children with autism. *Journal of Intellectual and Developmental Disability*, 18 (2), 83-93.

Grey, D.E. (2002). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual Development Disability*, 27(3), 215-222.

Grey, D.E. (2003). Gender and coping: the parents of children with high-functioning autism. *Social Science and Medicine*, 56(3), 631-642.

Harris, K.R., & Wishart, J.C. (2003). The Son-Rise Program for autism: an investigation into family experiences. *Journal of Intellectual Disabilities*, 47(5), 291-299.

Hastings, R.P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based interventions for their young child with autism. *Journal of Autism and Developmental Disorders*, 31(3), 327-336.

Hastings, R., Kovshoff, H., Ward, N., Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.

Lounds, J., Seltzer, M., & Greenberg, J. (2007). Transition and change in adolescents with autism: Longitudinal effects on maternal well-being. *American Journal of Mental Retardation*, 112(6), 401-417.

McPartland, J.C., Reichow, B., & Volkmar, F.R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. *American Academy Child Adolescent Psychiatry*, 51, 368-383.

Mahoney, G., Kaiser, A., Ginolametto, L., MacDonald, J., Safford, P., & Spiker, D. (1999). Parent education in early intervention: A call for renewed focus. *Topics in Early childhood Special Education*, 19(3), 131-140.

Mahoney, G., & Perales, F. (2005). The impact of relationship focused intervention on young children with autism spectrum disorders: A comparative study. *Journal of Development and Behavioural Paediatrics*, (26), 77-85.

Marshall, M., Feldman, R. B., & Sigal, J. J. (1989). The unravelling of a treatment paradigm: A follow-up study of the Milan approach to family therapy. *Family Process*, 28(4), 187-193.

Martinez-Pedraza, F., & Carter, A. (2009). *Autism Spectrum Disorders in young children*. *Child Adolescent Psychiatry*, 18(3), 645-663.

- McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: A systematic review. *Journal of Evaluation in clinical Practice*, 13(1), 120-129.
- Moes, D.R. & Frea, W.D. (2002). Contextualised behavioural support in early intervention for children with autism and developmental disorders. *Journal of Autism and Developmental Disorders* 32, 519-533.
- Murius, M., Webb, S., Greenson, J., & Dawson, G. (2000). Resting state cortical connectivity reflected in EEG coherence in individuals with autism. *Biological Psychiatry*, 62L, 270-273.
- Norton, P., & Drew, C. (1994). Autism and potential family stressors. *American Journal of Family Therapy*, 22(1), 67-76.
- Osborne, L., & Reed, P. (2008). Parent's perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12(3), 309-324.
- Overall, J.E., & Campbell, M. (1998). Behavioural assessment of psychopathology in children infantile autism. *Journal of Child Psychology*, 44, 708-716.
- Patterson, S.Y., Smith, V., & Mirenda, P. (2012). A systematic review of training programmes for parents of children with autism spectrum disorder: single subject contributions. *Journal of Autism*, 16(5), 498-522.

- Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.
- Papageorgiou, V., & Kalyva, E. (2010). Self reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders*, 4, 653-660.
- Raina, P., et al. (2005). The health and well-being of caregivers of children with cerebral palsy. *Journal of Pediatrics*, 115 (6), e626-36.
- Reebye, P. (2007). Attachment theory in clinical work with children: Bridging the gap between research and practice. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 16(4), 186-187.
- Reiss, A.L. (2009). Childhood developmental disorders: An academic and clinical convergence point for psychiatry, neurology, psychology and pediatrics. *Journal of Child Psychology and Psychiatry*, (50), Issue 1-2, 87-98.
- Reminton, B., Hastings, R., Korshoff, H., Espinosa, F., Brow, T., Alsford, P., Lemaic, M., & Ward, N. (2007). Early intensive behavioural intervention: outcome for children with autism and their parents after two years. *A.J. Mental Retardation*, 112(6), 418-438.
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383-393.

- Rodrigue, J.R., Morgan, S.B., & Geffken, G.R. (1992). Psychosocial adaption of children with autism, Down syndrome, and normal development. *Journal of Autism and Developmental disorders*, 22(2), 249-263.
- Robbins, F., Dunlap G., Plienis, A. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*, 15(2), 173-184.
- Rogers, S.J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology*, 27, 168-179.
- Rogers, S.J., & Vismara, L.A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child Psychology and Psychiatry*, 37(1). 8-38.
- Rogers, S. J., & Dawson, G. (Eds.) (2007). *The Early Start Denver Model*. New York: Guilford.
- Rogers, S.J., & Dawson, G. (2010). *Early Start Denver Model for young children with autism*. New York: Guilford.
- Rogers, S.J., & Pennington, B.F. (1991). A theoretical approach to the deficits in infantile autism. *Development and Psychopathology*, 3, 137-162.
- Sallows, G. O., & Graupner, D. (2005). Intensive behavioural treatment for children

with autism: Four-year outcomes and predictors. *American Journal of Mental Retardation*, 110(6), 417-438.

Schall, C. (2000). Family perspectives on raising a child with autism. *Journal of Child and Family Studies*, 9(4), 409-423.

Schreibman, L., & Pierce, K. (1993). Achieving greater generalisation of treatment affects in children with autism: Pivotal response training and self-management. *The Clinical Psychologist*, 4, 184-191.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22(2004), 63-75.

Sigman, M., & Ruskin, E. (1999). Social competence in children with Autism, Down Syndrome and other developmental delays: A longitudinal study. *Monographs of the Society for Research in Child Development*, 64(1), 1-114.

Simon, G. (2004). Therapy with families with a child who has a diagnosis of aspergers syndrome. *Human Systems Journal of Systemic Consultation and Management*, 15, 257-275.

Skellern, C., McDowell, M., & Schluter, P.J. (2005). Diagnosis of autistic spectrum disorders in queensland: Variations in practice. *Journal of Pediatrics and Child Health*, 41(8), 413-418.

- Smith, T., Groen, A.D., & Wynn, J.W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 105:269–285.
- Stake, R.E. (1995). *The Art of Case Study Research*. Thousand Oaks, CA: Sage.
- Steedman, P. (1991). *On the relations between seeing, interpreting and knowing*. In *Research and Reflexivity*. London: Sage.
- Spzir, M. (2006). Tracing the origins of autism: A spectrum of new studies. *Journal of Environmental Health Perspectives*, 114(7), 412–418.
- Swanson, T.C., & Lock, R.H. (2005). Provide structure for children with learning and behaviour problems. *Intervention in School and Clinic*, 40(3), 439-451.
- Swedo, et al., (2012). Commentary from the DSM-5 Workgroup on Neurodevelopmental Disorders. *Journal of The American Academy of Child and Adolescent Psychiatry*, 51, 347-349.
- Taylor, B., Blick, J., & MacLaughlin, D. (2013). Prevalence and incidence rates of autism in the UK: time trend from 2004–2010 in children aged 8 years. *British Medical Journal Open*, 3 (10), 2019.
- Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. (2006).

Effects on parental mental health of an education and skills training programme for parents of young children with autism: A randomised controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(5), 56-1-569.

Van Ijendoorn, M.H., Bakermans-Kranenburg, M.J., & Swinkels, S.H. (2007). Autism attachment and parenting: a comparison of children with autism spectrum disorder and non-clinical children. *Journal of Abnormal Child Psychology*, 35(5), 859-870.

Vismara, L.A., Young, G.S., Stahmer, A.C., Griffith, E.M., & Rogers, S.J. (2009). Dissemination of evidence-based practice: can we train therapists from a distance? *Journal of Autism Development Disorder*, 39(12), 1636-1651.

Vismara, L.A., Columbi, C. & Rogers, S.J.(2009). Can one hour per week of therapy lead to lasting changes in young children with autism. *Autism*, 13(1), 93-115.

Warren, Z., McPhectes, M., Sathe, N., Foss-Ferg, J., Glasser, A. & Venstra-VanderWeele, J. (2011). A systematic review of Early Intensive Intervention for Autism Spectrum Disorder. *Pediatrics*, (1542), 2011-0426.

Watson, R., Lanter, E., McComish, C., & Poston Roy, V. (2010). Enhancing the communication development of toddlers with autism spectrum disorders. *Journal of Cognitive and Behavioural Psychotherapies*, 4(2), 179-201.

Walsh, F. (2003). Family resilience: a framework for clinical practice. *Family Process*, 42(1), 1-18.

- Warren, Z., McPheetes, M.L. , Sathe, N., Foss-Feig, J.H., Glasser, A., Veenstra-Vanderweele, J. (2011). A systemic review of early intensive intervention for autism spectrum disorders. *Evidence Based Mental Health*, 14(4): 102.
- Whitchurch, G., & Constantine, L. (1993). *Systems Theory*. In sourcebook of family theories and methods: A contextual approach. New York: Platinum Press.
- Wilber, K. (2000). *Integral Psychology*. Boston: Shambahla Publications.
- World Health Organisation (1992). *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD 10)*. Geneva: WHO.
- Woods, J., Wetherby, A. (2003). Early social interaction project for children with autism spectrum disorders beginning in the second year of life. *Topics in Early Childhood Special Education*, 26, 67-82.
- Yeargin-Allsop, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., Murphy, C. (2003). Prevalence of Autism in a US Metropolitan Area. *The Journal of The American Medical Association*, 289 (1), 49-55.
- Yin, R. (2003). *Case study Research: Design and Methods* (3rd ed.). Thousand Oaks, CA: Sage.

Zager, D., Wehmeyer, M.L & Simpson, R.L. (2012). *Educating students with autism spectrum disorders: Research based principles and practices*. New York: Routledge.

Appendix A: Provisional Interview schedule Parent perceptions of the impact of an Early Start Denver Model on Family Systems

Questionnaire

1. Please describe your family and the role that family members played in the intervention.

2. Please describe your role in the intervention, and your experience of that role.

3. Please provide a brief description of the impact that participating in the Early Start Denver Model intervention at the University of Cape Town has had on you personally.

4. Please provide a brief description of the impact that participating in the Early Start Denver Model intervention at the University of Cape Town has had on your family and on family relationships, and family functioning.

5. How did the intervention impact on carers and extended family members.

- 6.. Please provide a general description of the impact that participating in the Early Start Denver Model intervention at the University of Cape Town has had on your diagnosed child.

6. Please provide a brief description of the impact that participating in the Early

Start Denver Model intervention at the University of Cape Town has had on your diagnosed child's ability to Communicate.

7. Please provide a brief description of the impact that participating in the Early Start Denver Model intervention at the University of Cape Town has had on your diagnosed child's Playing Style and Personal Independence.

Appendix B: Consent to participate in a research study: Parent perceptions of the impact of an Early Start Denver Model on family systems

Dear Interviewee

Study Purpose

You are being asked to participate in a research study being conducted by myself; a clinical psychology masters student from the University of Cape Town. The purpose of this study is to explore the perceived impact that having a child involved in an Early Start Denver Model (ESDM) has on the family. You are being asked to participate in this study as the parent or primary carer of a child participating in the abovementioned autism intervention.

Study Procedure

If you decide to participate in this study you will be asked to engage in an interview that should take approximately 60 minutes. The interview will address questions relating to your perceptions of the impact that participating in the ESDM intervention has had on your diagnosed child, and the rest of the family including yourself. All information will be strictly confidential and your name will not appear in any report.

Possible Risks and Benefits

There are no known risks to participating in this study. It is hoped that this study will contribute to our understanding of the impact that early start autism interventions have on the family and new ways of supporting parents and other family members with children diagnosed with autism.

Alternatives and Voluntary Participation

Participation in this research is entirely voluntary and is not a requisite for continued involvement in the ESDM intervention. You may choose not to answer certain questions, or to discontinue with the interview. Alternatively you may choose not to participate.

Confidentiality

Information pertaining to this study and your name will not be kept with the interview data. All identifying information will be kept in separate locked cabinets and only accessible by the researcher. Any reports or publications will not contain any information identifying you.

Questions

Any study-related questions should be directed to the following researchers:

Graham Gauntlett 079 0522967

Nokuthula Shabalala 021 650 3435

If you have any concerns about the way the study was conducted, please feel free to contact the Department of Psychology at the University of Cape Town on 021 650 3435.

I have read the above and am satisfied with my understanding of the study, its possible benefits, risks and alternatives. My questions about the study have been answered. I hereby voluntarily consent to participate in the study as described, and I agree that the conversation may be recorded.

Signature of participant Date

Name of participant

Witness