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An Ecological Perspective on Parents' Experiences of Having a Child With Autistic Spectrum Disorder (ASD) in the South African Context.

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Declaration:

A research project submitted in partial fulfillment of the requirements for the degree of MA Community-based Counselling Psychology, in the Faculty of Humanities, University of the Witwatersrand, Johannesburg, 25 November 2011.

I declare that this research project is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.

_____ _____

Signature Date

Abstract:

Autistic Spectrum Disorder (ASD) has traditionally been understood and treated bio-medically. However, bio-ecological and eco-systems theory, as well as a vast body of literature, suggests that ASD has a systemic impact, unique to each context. This study aimed to understand the systemic and ecological experiences of parents' to children with ASD in the South African context with regard to ASD and ASD intervention. Eight parents to children with ASD were interviewed using a semi-structured interview schedule. The data were analysed using deductive thematic content analysis. The study found that, in the South African context, both Indigenous and Western Knowledge Systems impact on parents' experiences of having a child with ASD. It further found that ASD had a systemic impact, and that current ASD intervention failed to target the needs across the system. Lastly, it found that stigma originates from both Indigenous and Western Knowledge Systems, and that information about ASD is of great importance to parents in the South African context.

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Dedication:

To the Giraffe class of 2010, and, of course, to their families.

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CHAPTER ONE: INTRODUCTION

1.1. TITLE

An ecological perspective on parents' experiences of having a child with Autistic Spectrum Disorder (ASD) in the South African context.

1.2. AIMS

This study aimed to gain a broad understanding of parents' experiences of having a child with ASD in the South African context. Various ecological factors impact on the development of neuro-typical children, developmentally disabled children, and more specifically children with ASD (Bronfenbrenner, 1979; Brown & Rogers, 2003; Cuvo & Vallelunga, 2007; Gray, 2002; Mandell, Novak & Zubritsky, 2005; McLeroy, Norton, Kegler, Burdine & Sumaya, 2003; Moes & Frea, 2002; Schopler, 2005; Trickett, 2009). Consequently, these same factors are thought to impact on parents' experiences of having a child with ASD. This is a worldwide phenomenon, but this research focuses particularly on those ecological factors that emerge in the South African context and other similar contexts and developing countries. Therefore, as a precursor to the overarching aim, this study aimed to gain an understanding of what the impact of these ecological factors on parents' experiences encompasses. In relation to this, the study also aimed to gain a more focused understanding of parents' general experiences of public ASD interventions and services, and how their perceptions of these interventions affect their experiences of parenting a child with ASD. It did so, taking into consideration some of the pertinent macro and exo-level factors in the South African context that impact on outcomes of children with ASD, including socio-economic status, public healthcare access, culture, and language (Alexander, 1999; Castro-Leal, Dayton, Demery & Mehra, 2000; Martin & Rosa, 2002; Pillay & Lockhat, 2001; Randall, 2001; Skinner & Mfecane, 2004).

1.3. RATIONALE

Having a child with ASD has been found to heavily impact on the parents' psychological and emotional well-being, with parents often reporting experiences of stress, grief, marital dissatisfaction and low maternal gratification (Bagenholm & Gillberg, 1991; Bouma & Schweitzer, 1990; Holroyd & McArthur,

1976; Marcus, Kunce & Schopler, 2005; Randall & Parker, 1999). Yet, this impact does not occur in a vacuum. The context, as well as the effectiveness of available interventions and services, performs a crucial role in either promoting more positive or negative experiences (Montes, Halterman & Magyar, 2009; Randall & Parker, 1999). This claim is supported by ecological approaches to development, which acknowledge the need to consider individuals within their full context (Bronfenbrenner, 1977, 1979; Greif & Lynch, 1983; Visser, 2007).

The context for parents of children with ASD in South Africa is vastly different from that of more researched, Western contexts, including the United States of America and Britain. In the South African context, poverty and unemployment rates are high and life expectancy is low (Martin & Rosa, 2002; Oosthuizen, 2008; The World Bank, 2011). Additionally, racial inequalities still persist with regards to access to resources and services, as well as in relation to language of services (Alexander, 1999, Jenkins & Thomas, 2000; Randall, 2001). Access to quality healthcare services is low, also largely divided along racial lines (Pillay & Lockhat, 2001; Randall, 2001). Stigma around disease is rampant (Campbell, Foulis, Maimane & Sibiya 2005; Kalichman & Simbayi, 2003; Skinner & Mfecane, 2004), and more pertinently to this study, very few services exist for children with ASD (Jacklin & Stacey, 2010), with only 0.001% of children with ASD in ASD specific schools (Autism South Africa [ASA], 2011).

There is a vacuum regarding research related to the specific experiences of having a child with ASD in the South African context. Experiences cannot be merely assumed equal due to the vastly different contexts impacting on their experiences. An understanding of parents' experiences of having a child with ASD in the South African context is, therefore, clearly warranted. Further, attempts to optimize their experiences can only be made with a full understanding of their context. Therefore, this study aims to provide such an ecological understanding of current experience, possible areas of focus for growth and expansion of services, and a possible basis for further research.

1.4. RESEARCH QUESTIONS

1. What are the holistic experiences of parents of children with ASD of having a child with ASD in the South African context, on all ecological levels?

   1.1 What influence do these ecological factors have on their experiences of having a child with ASD?

2. What are their general perceptions of the available public ASD interventions and services, and how does this influence their experience of having a child with ASD?

3. What are the ways in which the experiences of parents of children with ASD in the South African context are similar or different from experiences of parents in more researched areas, across ecological levels?

1.5. OVERVIEW OF METHODOLOGY

This study has utilized a qualitative approach, located firmly within the interpretivist paradigm. The study made use of self-constructed semi-structured questionnaires to gain the relevant data from eight parents of children with ASD. All participants were sourced from a single, government, autism-specific school located in Johannesburg. The sample was heterogeneous with regards to age, child's age, child's level of functioning, home language, marital status, transport status and monthly income bracket. They were largely homogenous with regards to gender, nationality and race. Transcripts were made of each interview, and analyzed using thematic content analysis, as stipulated by Braun & Clark (2006).

1.6. OVERVIEW OF CHAPTERS:

Chapter One, as outlined above, provides an overview of the study. Here, the aims and rationale for the study are outlined, alongside the research questions. An overview of the methodology used is also provided.

Chapter Two provides an overview of the theoretical framework of the study, namely an ecological approach to development. It provides a detailed description of Bronfenbrenner's Ecological theory, describing the interplay between the micro, meso, exo, macro and chrono systems. It then provides an overview of

Eco-Systems Theory, with a specific focus on system boundaries and feedback loops.

Chapter Three begins with a clinical, biomedical account of Autism Spectrum Disorder. Next a descriptive account of ASD intervention in South Africa across all ecological levels is provided, beginning with the innermost layer of the ecological system and working outwards. ASD interventions are categorized across ecological levels as either biomedical, biopsychosocial and bioecological approaches to intervention. An argument for the need for bioecological approaches to intervention, specifically within the South African context, is made.

The methodology and research design of the study are outlined in Chapter Four. Firstly, the procedure for obtaining a sample is outlined followed by a detailed description of the participants' biographical information. The data gathering tools and general research procedures are then discussed. This chapter then outlines the approach to analysis adopted by the study, as well as a discussion of the various strategies used to ensure trustworthiness. The chapter concludes with a discussion of the ethical considerations.

The results of the study are presented in Chapter Five, both in written and diagrammatic format. Each theme that was induced or deduced from the analysis is presented, and is supported by verbatim quotes from the interview transcripts.

The results written up in Chapter Five are then discussed in Chapter Six, with reference to the literature outlined in Chapters Two and Three. Recommendations on the basis of the findings are made. Here a condensation of the researcher's personal reflexivity over the course of the study is presented, alongside an account of the strengths and limitations of the study. Finally, Chapter Six provides a summary of implications for future research, and concludes the findings.

CHAPTER TWO: THEORETICAL FRAMEWORK
An Ecological Approach to Development

2.1 BRONFENBRENNER'S ECOLOGICAL THEORY

An ecological approach to human development is concerned with the continuous and reciprocal impact of an individual and their environment on each other (Bronfenbrenner, 1977, 1979; Moen, 1995; Rutter, Champion, Quinton, Maughan, & Pickles, 1995). The focus on the influence of the environment distinguishes Bronfenbrenner's theory from the intrapersonal, and distally interpersonal, psychological theories that preceded his (Sallis, Owen & Fisher, 2008). For Bronfenbrenner (1979; Moen, 1995), the environment involves not only the individual's immediate setting, but extends far beyond that. Bronfenbrenner (1977, 1979; Sallis et al., 2008) theorized various nested layers of one's ecological environment, including the microsystem, mesosystem, exosystem and macrosystem. Once acknowledged that development is a "product of interaction between the growing human being and its environment" (Bronfenbrenner, 1979, p.16), it becomes evident that both the person and the environment require equal attention in order to understand development.

The microsystem marks the reciprocal interplay between an individual and their immediate setting, including their home or school, and all the activities and interpersonal relations that exist within this immediate setting (Bronfenbrenner, 1977; 1979). This level involves face-to-face interactions with persons, objects and symbols (Bronfenbrenner, 1995; Goodnow, 1995). Bronfenbrenner (1979) considers one of the innermost ecological levels to be the dyad – a two-person system. Development of any dyad, such as mother and child or husband and wife, is said to be intrinsically linked (Bronfenbrenner, 1979). Yet, third parties, and in fact all other participants in the child's system, can and do also critically influence the individual's development in disruptive or supportive ways (Bronfenbrenner, 1979).

Bronfenbrenner (1977, 1979) saw the mesosystem as a system of microsystems. The mesosystem is, therefore, the interaction between the various settings that make up the microsystem. This may involve the interaction between school and

home, for example. This interaction between school and home is understood to impact on a child's ability to read (Bronfenbrenner, 1979). Like individuals in a microsystem, various contexts can disrupt or support the effectiveness of a context to promote development (Bronfenbrenner, 1979). Factors that promote development are considered to be joint participation, communication and information in each setting about the other (Bronfenbrenner, 1979).

The exosystem is the third layer, which encompasses concrete manifestations of the macrolevel (Bronfenbrenner, 1977; 1979). It is theorized as various social structures that the individual does not relate to directly, but that impact upon the individual's immediate setting (Bronfenbrenner, 1977, 1979; Goodnow, 1995). This will likely include the media, government agencies, resource distribution, parent's workplace, and transport facilities (Bronfenbrenner, 1977).

The macrosystem is the ideology, culture and subculture that shape the concrete world of the individual (Bronfenbrenner, 1977). This will include the "economic, social, educational, legal, and political systems" (Bronfenbrenner, 1977, p.515). Due to the macrosystem, contexts are likely to be more homogenous within one society than between societies (Bronfenbrenner, 1979). For example, socio-economic status, ethnicity and religion may be more similar in families within the United States of America and Kenya than between them. Similarly, these demographics are more likely to be similar within the suburbs of Sandton and Alexandra than between them, despite being neighbouring South African suburbs.

A later addition to Bronfenbrenner's ecological model is the chronosystem (Bronfenbrenner, 1994). The chronosystem encompasses all changes and consistencies over time, across all other levels of the ecological system (Bronfenbrenner, 1994). It, therefore, encompasses changes over time throughout the individual's life, as well as historical changes in government policy, political systems, and more. An important example of the influence of the chronosystem in South Africa is the change from the Apartheid government to the current democratic government.

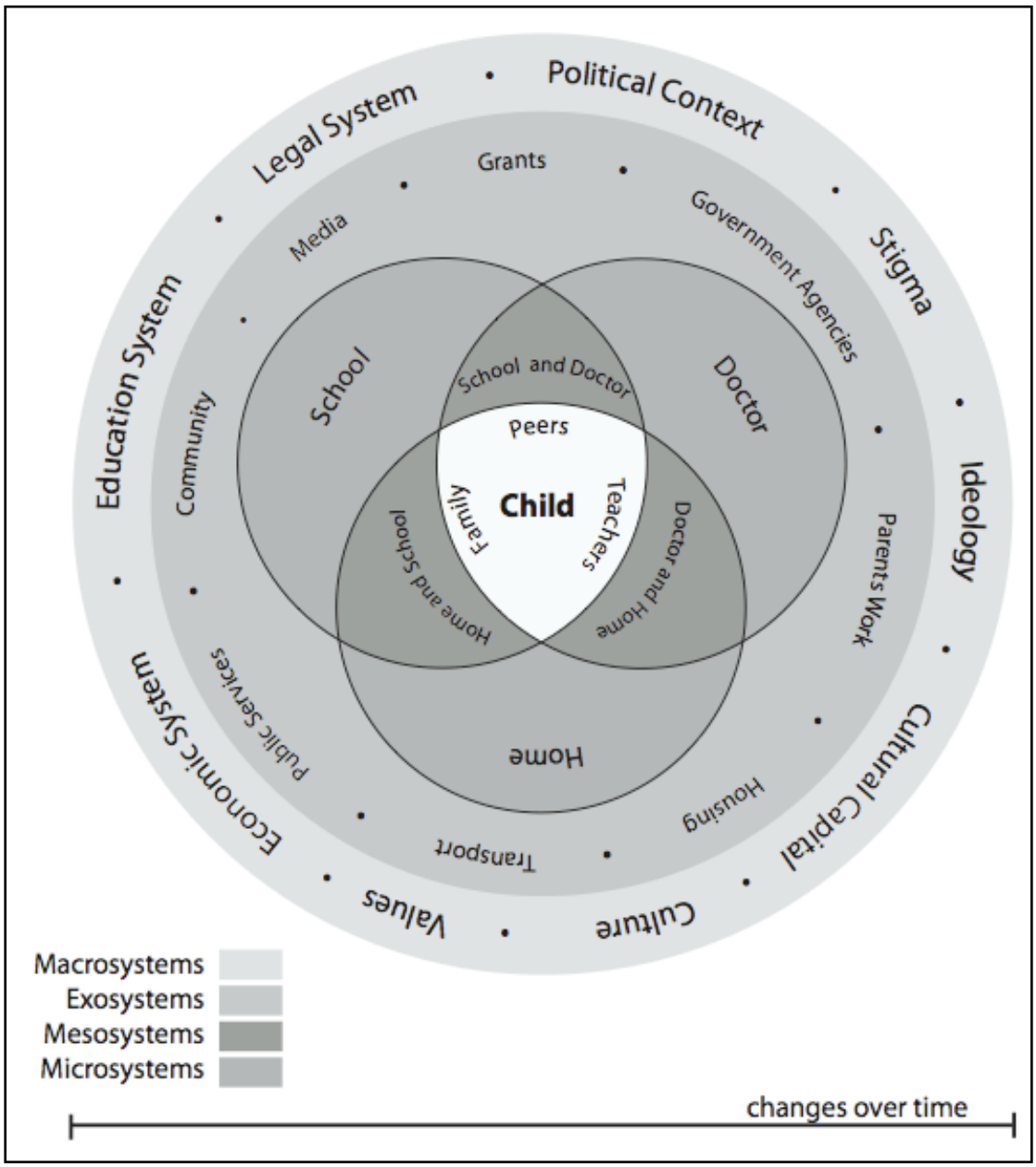


Figure 2.1: Bronfenbrenner's Ecological Model

While Bronfenbrenner's theory strongly argues that environmental factors impact developmental outcomes, it did not ignore the role of biology. Bronfenbrenner and Ceci (1994) developed the bioecological model of development, acknowledging that genetic material interacts with the environment to determine developmental outcomes. It is argued that developmental outcomes will be optimal when both genetic material and environment are optimal (Bronfenbrenner & Ceci, 1994).

Bronfenbrenner's bioecological model and understanding of the reciprocal impact of various ecological levels on one another, is not only useful for understanding development. The model also provides a useful framework for developing effective interventions for psychopathology and mental illness. Healthcare interventions based on the bioecological model are comprehensive and multileveled, as opposed to targeting only the individual using psychotherapeutic intervention (Sallis et al., 2008). Interventions based on the model also redirect the focus of intervention to prevention of risk factors, in contrast to psychotherapy's more reactive approach (Rutter et al., 1995).

Ecological theory is considered to be the most robust theory of psychological development, and is commended for its ability to incorporate intrapersonal and interpersonal theories within its framework. Ecological theory is also highly commended for its positive impact on reforming interventions and increasing their efficacy through its multilevel conceptualizations of development and intervention. One noted criticism of ecological theory, however, is that, despite acknowledging the interaction between variables on different levels, the theory fails to account for how these influences occur. (Sallis et al., 2008).

2.2 ECO-SYSTEMS THEORY

Bronfenbrenner's ecological model is best extended and elaborated on from within the framework of eco-systems theory. Eco-systems theory is frequently considered a social work theory, yet has its roots firmly in psychological theory (Greif & Lynch, 1983; Rothery, 2001). The theory is a merger of ecological theory, discussed above, and psychology's general systems theory, which is commonly used in psychotherapy to understand family functioning and

psychopathology (Greif & Lynch, 1983; Rothery, 2001). However, eco-systems theory moves away from general systems theory in its acceptance of the concept of multiple realities (Visser, 2007). Like Bronfenbrenner's ecological theory, eco-systems theory allows for the conceptualization of the reciprocal impact of both individual and environmental factors on development and functioning (Rothery, 2001).

From an eco-systems theory perspective, both the individual and the various levels of their environments are defined as systems (Greif & Lynch, 1983). Systems are thought to exist in a hierarchy, with systems nested in each other (Greif & Lynch, 1983; Visser, 2007). Systems can contain subsytems, or be embedded in larger supersystems (Greif & Lynch, 1983; Visser, 2007). Each system has a boundary, giving it its unique identifying features (Greif & Lynch, 1983). For example, boundaries distinguish one community from another, or one subsystem from another. More specifically, they may distinguish the parental and sibling subsystems from one another, or the work from the family subsystem. Boundaries can be open and flexible, allowing for the free flow of input and information, or rigid and closed, restricting the flow of information (Rothery, 2001). Optimally, systems need to be permeable, yet sufficiently well defined, forming a balance on a spectrum between opened and closed (Rothery, 2001). Permeable boundaries allow for influence from and interaction with other systems (Greif & Lynch, 1983; Visser, 2007). From an eco-systems framework it is argued that all systems are permeable or open to some degree, impacted on by the environment (Greif & Lynch, 1983; Visser, 2007).

Due to their permeability, systems are thought to receive input from the environment, such as energy and information, which then becomes used in the functioning of the system (Greif & Lynch, 1983). The system responds to the environment in the form of an output, which acts as an input for the environment (Greif & Lynch, 1983). A constant flow of input and output is necessary to ensure that the system continues to function, and like with Bronfenbrenner's ecological theory, implies the reciprocal impact of individual and environment on each other (Greif & Lynch, 1983; Rothery, 2001). It also

implies a circular nature of causality, as opposed to linear causality (Rothery, 2001).

It is the permeable boundaries of open systems, and the constant flow between systems, that allows for growth and change (Visser, 2007). Feedback loops are inputs that serve either to maintain equilibrium in the system (negative feedback) or to promote change (positive feedback) (Greif & Lynch, 1983; Visser, 2007). Changes in one part of the system are thought to affect the whole system (Greif & Lynch, 1983; Visser, 2007). When a person enters a new environment they are thought to alter that environment through their mere presence in it (Grief & Lynch, 1983; Visser, 2007). Feedback loops can be represented graphically as follows:

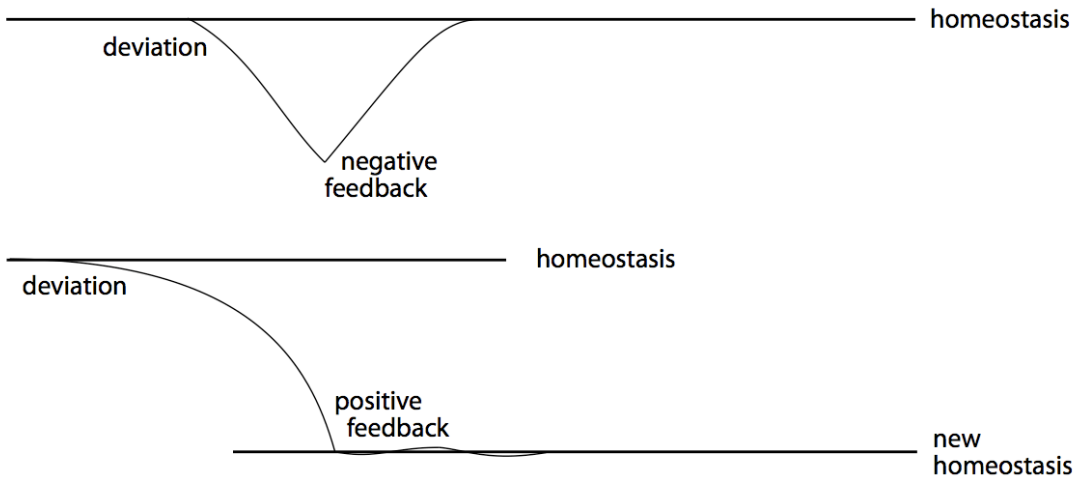


Figure 2.2: Feedback Loops

A graphic representation of the flow of input and output between systems, and their impact on each other can be seen in the Figure below. The figure represents the flow of information between the child and parental subsystems within the family system. Behaviour from the child acts as an output from the child subsystem and an input for the parental subsystem. This behaviour elicits feedback from the parental subsystem, which acts as an output from the parental subsystem and an input for the child subsystem. Positive feedback from either the child or parent leads to a new homeostasis, while negative feedback maintains the original homeostasis. It is important to note, however, that circular

causality is implied, and that, as seen in the Figure, no beginning point with regards to the flow of input and output is noted.

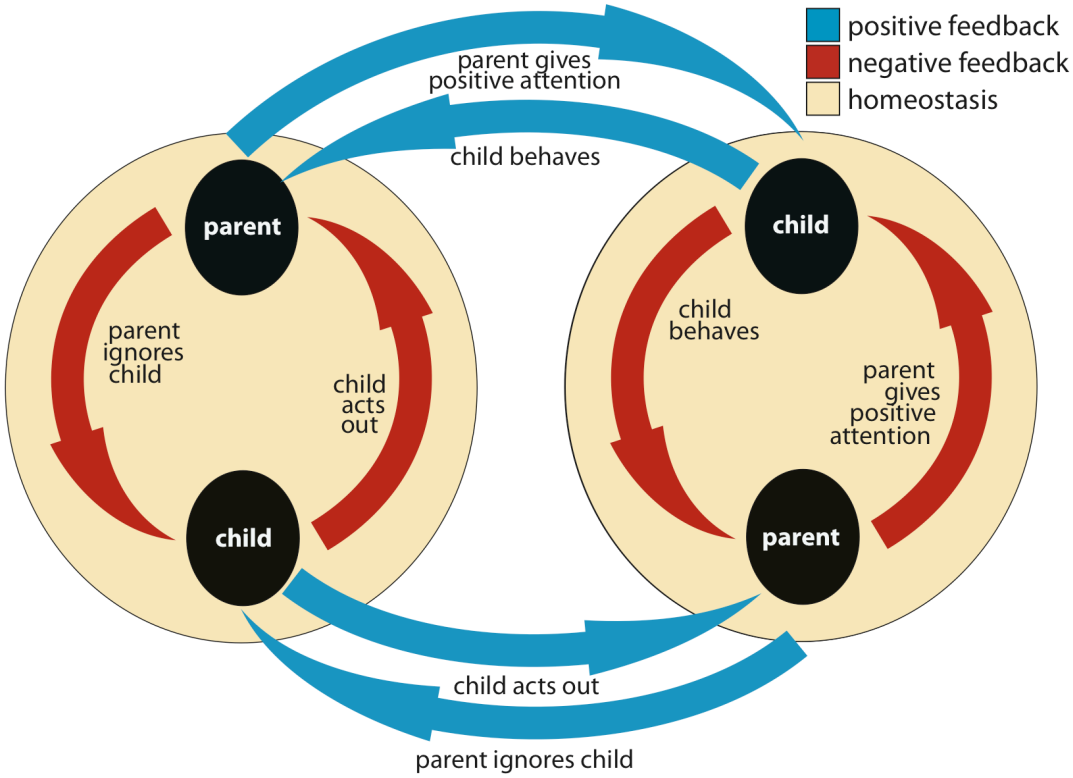


Figure 2.3: Flow of Input and Output

While eco-systems theory acknowledges the impact of systems on each other, their understanding of this impact is not deterministic. Eco-systems theory subscribes to equifinality, a concept which notes that a system can reach the same end state through various paths (Greif & Lynch, 1983; Rothery, 2001; Visser, 2007). Further, it also subscribes to multifinality, acknowledging that similar situations can lead to different outcomes (Greif & Lynch, 1983; Rothery, 2001; Visser, 2007). Power dynamics are also acknowledged, noting that balances between individuals and their environments may be unequal with regard to influence, often at the expense of the individual (Greif & Lynch, 1983). For example, the South African Apartheid government provided South African citizens classified as "Black"[1] with minimal influence over the development of the

[1] Within the South African context, "Black" refers to all non-white races, including African, Coloured and Asian populations.

environment, while allowing the environment to heavily influence the development of "Black" citizens.

Despite the impact of nested systems on one another, all systems have some structures, elements and patterns of relating that are somewhat enduring (Greif & Lynch, 1983). For example, individual reactions to events and cultural understandings are relatively enduring and can influence outcomes (Visser, 2007). Each system has a unique past, present and future, that will affect outcomes (Greif & Lynch, 1983). Energy is also considered to be used within a system, to maintain it and adapt it to its environment (Greif & Lynch, 1983). Therefore, systems increase in complexity over time, showing development (Greif & Lynch, 1983).

An eco-systemic approach is useful for gaining an expansive understanding in assessment and evaluation (Greif & Lynch, 1983). Eco-systemic approaches also broaden our focus for intervention, from focusing only on the individual to a focus that includes the environment (Greif & Lynch, 1983). Similarly to Bronfenbrenner's ecological theory, from an eco-systemic approach, interventions are conceptualized as needing to address various levels in order to facilitate substantial change (Visser, 2007).

CHAPTER THREE: LITERATURE REVIEW

3.1 INTRODUCTION

This study will argue for the need for an ecological understanding of parents' experiences of having a child with ASD in the South African context. In order to do so, clinical understandings of ASD, which align with the biomedical model, will be presented first. Subsequent to this, current clinical approaches to autism intervention will be discussed, highlighting the shift from a biomedical to biopsychosocial approach to ASD intervention. This paper will then argue that neither approach is sufficiently all-encompassing, and will, therefore, outline ecological and eco-systemic approaches to development and intervention. From the framework of the bioecological model of development and intervention, this paper will highlight pertinent socio-contextual factors in South Africa. Lastly, it will argue for the need to consider the impact of these pertinent socio-contextual factors on parents' experiences of having a child with ASD, as well as on the parents' general experiences of public ASD services and interventions.

3.2 CLINICAL, BIOMEDICAL UNDERSTANDINGS OF AUTISM

Autism is a pervasive developmental disorder, characterized by social and communicative problems, as well as the presence of atypical, repetitive behaviours (American Psychiatric Association, 2000; Sadock & Sadock, 2007). The disorder is considered developmental in nature, in that impairments relate to a contrast with the capabilities of a neuro-typical (non-autistic or otherwise non-disordered) child (Ozonoff & Rogers, 2003). Individuals with autism are commonly referred to as displaying a triad of impairments, namely: impaired social interactions, impaired communication, and rigid repetitive behaviours and interests (Sadock & Sadock, 2007; Wing, 1997).

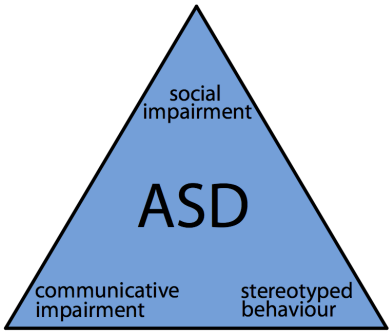


Figure 3.1: Triad Of Impairment

On initial discovery, autism was thought to be a very categorical disorder, but clinicians have since realized that it can have a range of potential manifestations (Ozonoff & Rogers, 2003: Schopler, 2001; Wing, 1997). Autism is now considered a spectrum disorder, with individuals displaying features along a continuum of autistic inclination (Ozonoff & Rogers, 2003; Wing, 1997). Nowadays, autism is more commonly referred to as Autism Spectrum Disorder (ASD) (Ozonoff & Rogers, 2003). Some conceptualizations note three spectrums, one for each of the triad of impairments (Schopler, 2001). An individual with ASD may fall at a different place on the spectrum with regards to each of the three impairments (Schopler, 2001).

Reports on ASD prevalence from earlier this decade suggested that between 0.3 and 0.6% of children fall on the spectrum (Chakrabarti & Fombonne, 2005; Sadock & Sadock, 2007). More recent surveys found that prevalence was closer to between 0.5 and 1% of children (Nassar et al., 2009; Rice, 2009). This equates to one child being born with ASD everyday in South Africa (ASA, 2011), if international rates of mental illness are assumed equal in South Africa (Pretorius-Heuchert & Ahmed, 2001). The increase from earlier to later studies is largely attributed to improved diagnostic abilities and assessment methods (Nassar et al., 2009; Rice, 2009). The disorder is about 5 times more prevalent in males than females (Rice, 2009; Sadock & Sadock, 2007).

3.2.1. IMPAIRED SOCIAL SKILLS

As noted above, children with ASD largely act in socially inappropriate ways, seen most obviously in a common lack of eye-contact, and struggle to play with other children (Ozonoff & Rogers, 2003; Sadock & Sadock, 2007). They have very rigid, concrete ways of thinking, consequently struggling with "theory of mind", and finding it difficult to gauge others' motivations or emotions (Murray-Slutsky & Paris, 2000; Sadock & Sadock, 2007). People with ASD, therefore, lack the ability to be empathetic (Sadock & Sadock, 2007).

3.2.2. IMPAIRED COMMUNICATION

While many children with autism are able to remember and formulate words, they struggle to understand their meaning, to use the words to formulate meaningful speech, and to use speech in the right context (Murray-Slutsky &

Paris, 2000; Sadock & Sadock, 2007). Expressive skills normally far exceed receptive skills (Murray-Slutsky & Paris, 2000; Sadock & Sadock, 2007). Echolalia, the repetition of speech or words out of context, is common (Murray-Slutsky & Paris, 2000; Wilkinson, 1998). Some children with autism will repeatedly produce strange, nonsensical sounds, showing no intent to use them for communication (Sadock & Sadock, 2007; Wilkinson, 1998). Pragmatic and non-verbal communication skills, such as facial expressions, turn taking and choice of topic, are also largely absent (Murray-Slutsky & Paris, 2000; Wilkinson, 1998).

3.2.3 STEREOTYPED BEHAVIOUR

Children with ASD frequently engage in behaviours that are inappropriate (in nature or frequency) for their age, and which contradict social norms (Randall & Parker, 1999; Sadock & Sadock, 2007). Repetitive, inappropriate motor movements can include toe-walking, hand-clapping, hand-flapping, finger-flicking, whole-body rocking, spinning and jumping (Murray-Slutsky & Paris, 2000; Ozonoff & Rogers, 2003). These behaviours, which are exceptionally difficult to stop, commonly inhibit the child's ability to learn (Randall & Parker, 1999). Exploratory play, as well as symbolic, imitative and abstract play is normally absent (Sadock & Sadock, 2007).

3.2.4. OTHER COMMON BEHAVIOURAL CHARACTERISTICS

In addition to the main triad of impairments, other abnormal behavioural characteristics are also common in children with ASD. One such characteristic is instability in mood and affect (Sadock & Sadock, 2007). Sudden, seemingly unwarranted outbursts of crying or laughing are common (Sadock & Sadock, 2007). Vestibular-seeking behaviour is also common, resulting in behaviour such as spinning and swinging, as noted above (Sadock & Sadock, 2007). Children with ASD also generally struggle with change and transition (Sadock & Sadock, 2007). Lastly, another common behavioural characteristic of people with ASD is an over or under reaction to sensory stimuli, commonly towards pain, smell and sound (Sadock & Sadock, 2007). This characteristic of hypo or hyper sensory reactivity was, at the time of writing, being considered for inclusion in the criteria for ASD in the DSM-V (American Psychiatric Association, 2011).

3.2.5 INTELLECTUAL FUNCTIONING

It has been argued that around 70% of children with autism display mental retardation, with only 20% displaying normal, nonverbal intelligence (Chakrabarti & Fombonne, 2005; Sadock & Sadock, 2007). Children with autism largely score lower on IQ items of verbal sequencing and abstract reasoning, while showing strength in their visuo-spatial and rote memory skills (Mesibov, Shea & Schopler, 2004; Sadock & Sadock, 2007). Their main cognitive deficits lie in their lack of ability to organize and integrate information, filter out extraneous information, think in abstract ways, and understand emotion (Mesibov et al., 2004; Murray-Slutsky & Paris, 2000). However, counter arguments exist which claim that the majority of children with ASD are in fact not mentally retarded (Chakrabarti & Fombonne, 2001). Rather, the complexity of distinguishing general impairments and impairments specific to ASD has led to an underestimation of their intellectual abilities (Chakrabarti & Fombonne, 2001). Further, some children with autism possess savant abilities, or splinter skills, that they perform beyond the ability of their peers (Sadock & Sadock, 2007).

3.2.6 COURSE AND PROGNOSIS

The disorder is lifelong, but severity of symptoms can decrease with appropriate and early intervention (Marcus, Garfinkle & Wolery, 2001; Ozonoff & Rogers, 2003; Randall & Parker, 1999; Sadock & Sadock, 2007). Outcomes are most promising for children with higher IQs and communication skills (Ozonoff & Rogers, 2003; Sadock & Sadock, 2007). Communication and social behaviour are the two symptomatic areas that demonstrate the most positive change, but rigid and repetitive behaviours do not seem to improve (Sadock & Sadock, 2007). Despite improvements through intervention, around 66% of people on the spectrum will be dependent or semi-dependent on care from others (Ozonoff & Rogers, 2003; Sadock & Sadock, 2007).

3.3 BIOMEDICAL APPROACHES TO AUTISM INTERVENTION

As noted above, the severity of ASD symptoms can decrease with appropriate and early intervention (Marcus, Garfinkle & Wolery, 2001; Ozonoff & Rogers, 2003; Randall & Parker, 1999; Sadock & Sadock, 2007). The focus of treatment for children with ASD is commonly threefold, focused on the triad of

impairments – to increase pro-social behaviour, decrease odd behavioural symptoms, and to improve communication (Ospina et al., 2008; Sadock & Sadock, 2007). The ultimate aim of such interventions is to improve the child's ability to integrate into schools, help them develop meaningful relationships and increase independent living for adulthood (Sadock & Sadock, 2007).

Earlier and more commonly-used clinical approaches to autism can be seen as falling within the biomedical model of disease, which conceptualizes disease purely in relation to biological variables and focuses intervention at the individual, ignoring the role of the psychological and social (Engel, 1977). While there is no medication available to reduce or relieve the core triad of impairments (Sadock & Sadock, 2007), various other treatment strategies have, therefore, been developed. Some approaches include Applied Behavioural Analysis (ABA), Treatment and education of Autistic and related Communication handicapped CHildren (TEACCH), Picture Exchange Communication Systems (PECS), Makaton, object play, pony therapy, the squeeze machine, the Gluten-free Casein-free (GFCF) diet and even intravenous secretin (Bondy, 2001; Elder, 2008; Lightdale, Heyman & Rosenthal, 1999; Ospina et al., 2008; Schopler, 2001; Walker & Armfield, 1981; Yoder & McDuffie, 2006). Some have been extremely controversial (Elder, 2008; Lightdale et al., 1999; Ospina, et. al, 2008), while others have been found to be highly effective (Bondy, 2001; Ospina et al., 2008; Ozonoff & Rogers, 2003; Walker & Armfield, 1981).

One common treatment approach used to assist in the development of communication in children with ASD is Makaton (Walker & Armfield, 1981). Makaton is normal, grammatically correct, spoken language with accompanying signs and symbols, taught according to normal developmental stages (Walker & Armfield, 1981). The visual media and logical structure of the signs has proven to be quite helpful in encouraging expressive communication and understanding in an array of people with communication difficulties, including children with ASD (Lal, 2010; Walker & Armfield, 1981). Attitudes towards Makaton are becoming more favourable (Sheehy & Duffy, 2009).

PECS (Picture Exchange Communication System) aims to encourage spontaneous functional communication in children with ASD by positively reinforcing it, and to help direct this communication towards a communicative partner (Bondy, 2001; Bondy & Frost, 1993). It involves exchanging pictures of a desired object, for example food, for the actual object (Bondy, 2001; Bondy & Frost, 1993). Various studies have noted the efficacy of using PECS with children with ASD (Anderson, Moore & Bourne, 2007; Bridge & Carter, 2007; Carr & Felce, 2007; Howlin, Gordon, Pasco, Wade & Charman, 2007), yet limitations around generalizability and resources are noted (Bondy, 2001; Fillipin, Reszka & Watson, 2010).

ABA is a common form of intervention used with children with ASD, and relies largely on positive reinforcement - rewards for desired behaviour (Bijou & Baer, 1978; Keenan, Kerr & Dillenburger, 2000). Rewards must be accurately timed, promptly following the desired behaviour (Bijou & Baer, 1978; Keenan et al., 2000). ABA can also be used to help extinguish problem behaviours, by removing reinforcers gained from inappropriate behaviours, while continuing to reinforce more appropriate ones (Keenan et al., 2000; Zeiler, 1978).

Children with ASD respond better to more structured environments (Schopler, Brehm, Kinsbourne & Reichler, 1971), which are found to reduce anxiety, stimulate learning (Olley, 2005; Sadock & Sadock, 2007), make the child's world more predictable and concrete, and therefore, make it less overwhelming and confusing (Mesibov, Shea & Schopler, 2004). This is the cornerstone of the TEACCH programme (Mesibov et al., 2004; Schopler, 2005). Structure is applied to the physical structure, day's schedule and daily tasks (Mesibov, Schopler & Hearsey, 1994; Mesibov et al., 2004; Murray-Slutsky & Paris, 2000; Olley, 2005). This is implemented in very "visual" ways, helping them to understand sequencing, serving as a constant reminder of present and upcoming activities, and making instructions more comprehensible (Mesibov et al., 1994; Mesibov et al., 2004; Schopler, 2005). Research supports claims of the effectiveness of visual schedules and the removing of visual distractions (Dettmer, Simpson, Myles & Ganz, 2000; Duker & Rasing, 1989; McClannahan & Krantz, 1998).

Biomedical Intervention	Biomedical Target Area	Main Tenets/Theoretical Framework
Makaton	Impaired Communication	Behaviour Modification
PECS	Impaired Communication	Behaviour Modification, Visual Aids
ABA	Full Triad	Behaviour Modification
TEACCH	Full Triad	Structure and Visual Aids

Table 3.1: Overview of Main Biomedical Interventions

3.4 BIOPSYCHOSOCIAL APPROACHES TO AUTISM INTERVENTION

While the above, more biomedically-oriented approaches to intervention are still commonly used with children with ASD, to effective ends, there has been a positive shift towards a more biopsychosocial approach. The biopsychosocial model of disease adopts a psychological and social focus for intervention, and was formulated in reaction to the inadequacies of the biomedical model (Engel, 1977; 1980; Kiesler, 1999). The shift can be evidenced, for example, through the shift in the role of parents in ASD intervention. Historically, parents have taken a backseat to professionals in prioritizing intervention strategies (Randall & Parker, 1999). However, it has since become commonplace to include families in the intervention process, with a focus on parent-training, collaborating and advocacy training (Marcus, Kunce & Schopler, 2005; Sadock & Sadock, 2007; Schopler, 2005). While the inclusion of families is a positive shift for ASD interventions, the process is not yet perfected. Some parents have expressed high dissatisfaction with the services they are provided (Montes, Halterman & Magyar, 2009). Others reported finding doctors, social workers and psychologists far less helpful than teachers and family members (Randall & Parker, 1999). Further, attending parent training is very time intensive (Sadock & Sadock, 2007), and therefore, not always a viable part of treatment.

Not only are families being included in the child's intervention, but there has also been a shift to include the family as the point of intervention (Marcus et al., 2005). Support and psychotherapy for parents is recommended (Sadock & Sadock, 2007), as research suggests that autism is one of the most stressful disorders for families to cope with, and will affect many areas of the family's life (Bagenholm & Gillberg, 1991; Bouma & Schweitzer, 1990; Holroyd & McArthur, 1976; Marcus et al., 2005; Randall & Parker, 1999). More specifically, having a child with ASD has been found to negatively impact parents with regards to mother's attachment, maternal gratification, parenting competence and marital

satisfaction (Higgins, Bailey & Pearce, 2005; Hoppes & Harris, 1990; Randall & Parker, 1999; Roudrigue, Morgan & Geffken, 1990). Further, receiving a diagnosis of ASD is often experienced like a death, with parents mourning the loss of the expected perfect child (Ellis, 1989; Randall & Parker, 1999). Parents of children with ASD also report poorer sleep quality and lower quantity of sleep than parents of typically developing children (Meltzer, 2008). Research also shows that the psychosocial functioning of siblings is strongly affected in families of a child with ASD (Bagenholm & Gillberg, 1991; Gold, 1993; Howlin, 1988).

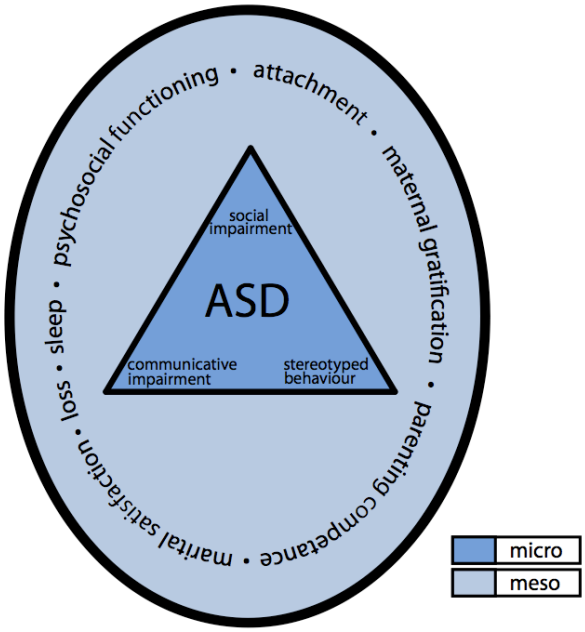


Figure 3.2: Ecologically Represented Target Areas of Biopsychosocial Intervention

As noted in the literature above, there has been a clear shift in the conceptualization of ASD and ASD intervention, towards the biopsychosocial model. However, despite a more holistic approach to intervention, studies show huge dissatisfaction from parents with current ASD interventions (Kogan, Strickland, Blumberg, Singh, Perrin, & van Dyck, 2008; Montes et al., 2009). Despite the shift, one international study found that families of children with ASD were less likely to receive family support services than families of children with other special health care needs (Kogan et al., 2008). Additionally, ASD intervention was found to be less family centered than intervention for children with other special health care need (Kogan et al., 2008). Further, many socio-contextual factors are completely ignored by current ASD interventions (Brown

& Rogers, 2003; Cuccaro et al., 1996; Gray, 2002). It is argued that for ASD interventions to be effective they need to look further than the biopsychosocial model and adopt a bio-ecological approach to development and ASD intervention, which places greater emphasis on various levels of context.

3.5 BIO-ECOLOGICAL PERSPECTIVE ON AUTISM AND AUTISM INTERVENTION

From an ecological and eco-systemic perspective, ASD outcomes will be most effective if interventions are aimed towards all ecological levels. To look only at the child with ASD, or even the child and their home, would be insufficient. Eco-systemic concepts of equifinality and multifinality also infer that generalisations from one context to another are insufficient, and understandings of each specific context are warranted (Greif & Lynch, 1983). Political dynamics can also not be ignored in the conceptualization of contextual experiences (Greif & Lynch, 1983). Various arguments are made in support of the move towards a more ecological approach to mental health intervention in general, interventions for children with disabilities more generally, and even for interventions specifically for children with ASD (Cuvo & Vallelunga, 2007; Harry et al., 1995; McLeroy et al., 2003; Moes & Frea, 2000, 2002; Sallis et al., 2008; Trickett, 2009). The relevance of these arguments when using internationally formulated interventions in a South African context is clear.

As can be seen in the literature above, ASD intervention and treatment is largely aimed at what can be considered as Bronfenbrenner's microsystem, with some minimal attention to the mesosystem. The focus thus far is mainly on the child, with some attention given to family relationships and the relationship between home and school. While a progression from child to family focus in intervention appears to be a move in the right direction, it still fails to intervene at all ecological levels. The interaction between other microsystems, and the exo- and macrosystems are largely ignored. Despite ASD being thought to equally affect all races and ethnic groups, little consideration has been given to various socio-contextual factors and research on cultural and contextual issues is few and far between (Brown & Rogers, 2003; Cuccaro et al., 1996). Considerations of these factors need to be made.

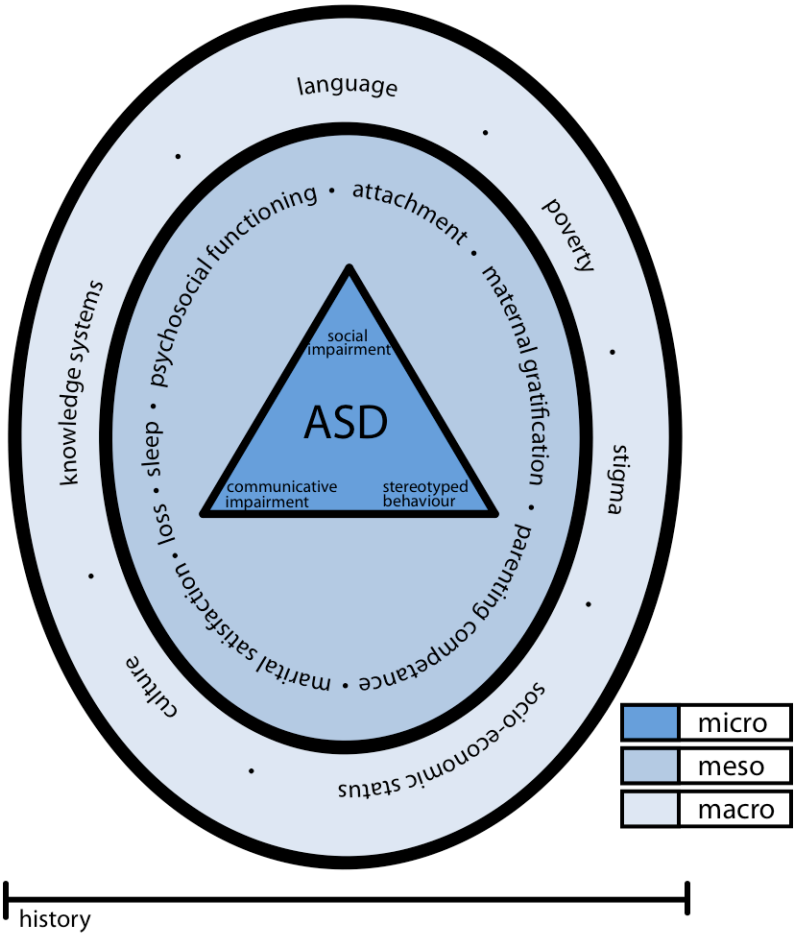


Figure 3.3: Ecological Representation of Target Areas of Bioecological Intervention

3.5.1. POVERTY, SOCIO-ECONOMIC STATUS AND ASD

The first macrolevel ecological factor that this study accounts for is poverty and low socio-economic status. It has been acknowledged internationally that poverty and low socio-economic status (SES) can impact negatively on ASD outcomes (Cuccaro et al., 1996; Mandell, Novak & Zubritsky, 2005; Marcus et al., 2001; Schopler, 2005). With estimates of around 50% of South Africans living in poverty (Martin & Rosa, 2002; Oosthuizen, 2008), and unemployment rates of 22.9% (The World Bank, 2011), the effects of poverty and low SES on ASD outcomes are a crucial aspect for South African ASD interventions to consider.

SES firstly affects ASD outcomes due to lack of access to early and accurate diagnosis and necessary resources and services for intervention (Cuccaro et al., 1996; Mandell et al., 2005; Marcus et al., 2001; Schopler, 2005). Disadvantaged communities in South Africa are most likely to lack the support to take care of the mentally ill (Pretorius-Heuchert & Ahmed, 2001). This has huge implications for the effectiveness of ASD interventions in South Africa, where there is a ratio

of 1 child psychiatrist to every 1 million children (Pillay & Lockhat, 2001). In South Africa, only 0.001% of children with ASD are being serviced in ASD-specific schools, with another 10% being serviced in schools for children with special needs (Autism South Africa [ASA], 2011; Jacklin & Stacey, 2010). This leaves nearly 90% of children with ASD in South Africa either battling in mainstream schools or lacking access to school completely (Jacklin & Stacey, 2010). Further, only 30% of schools for children with special needs in South Africa admit children with ASD (Jacklin & Stacey, 2010). Lack of access to professional specialists, schools and community health services renders effective interventions from a high SES context useless in a low SES context (Montes et al., 2009; Schopler, 2005). For this reason, Ospina et al. (2008) argue that it is crucial to account for access to resources when planning ASD interventions.

Poverty also generally means less access to quality health care services (Brown & Rogers, 2003; Castro-Leal et al., 2000; Randall, 2001). While "quantity" or availability of services to individuals from low socioeconomic brackets appears to have increased internationally, the quality of such services is frequently far below that of the services available to those in the higher socio-economic brackets, with implications for the quality of health outcomes (Fiscella, Franks, Gold & Clancy, 2000). Fiscella and colleagues (2000) note that internationally, research often fails to enquire about the quality of health care services, enquiring only about access. Consequently, little attention is paid to improving the quality of services provided (Fiscella et al., 2000). Locally, Jacklin and Stacey (2010) report that teachers responsible for ASD children in special needs schools report very little training as well as inadequate use of ASD assessment tools and ASD-specific intervention techniques. Additionally, parents with access to ASD or special needs schools may lack the transport, time off work or education to attend and benefit from meetings and home-based interventions, may feel intimidated to do so (Brown & Rogers, 2003) or may be dissatisfied with the services provided (Montes et al., 2009).

Ecological theory and eco-systems theory is considered with the reciprocal impact of individual and environment on one another. Therefore, in addition to

the impact of SES and poverty on the development of the individual noted above, it is crucial to acknowledge the impact of the child's ASD on the family's SES. Montes and Halterman (2008) found that child care problems affected employment in families with children with ASD. Similarly, Kogan and colleagues (2008) found that parents of children with ASD were more likely to report financial problems, and to have reduced or stopped working due to their child's condition. They also reported that their child's health care needs placed great financial stress on their family (Kogan et al., 2008).

3.5.2 CULTURE AND ASD INTERVENTION

Bronfenbrenner (1979, p.258) views culture and subcultures as "patterns of organization and behaviour" that create "internal homogeneity" in relation to settings, roles, and activities. These patterns are upheld by the values held by the members of the culture or subculture (Bronfenbrenner, 1979). Knowledge systems and ways of making meaning can be viewed as contributing to maintenance of cultural and subcultural patterns, and might be viewed as a product of the values of each cultural group.

Two distinct knowledge systems are of particular importance to this study. The first is the Western or Scientific knowledge system, which is highly prominent in the United States of America and Europe, where the majority of knowledge and research on ASD and ASD intervention has developed. The second pertinent knowledge system is the African Indigenous and Traditional knowledge system, which is drawn on by many South African citizens to make meaning and uphold cultural patterns. Western and Indigenous knowledge systems are considered to be largely diametrically opposed (Agrawal, 1995; Smylie et al., 2003). These two knowledge systems contrast in numerous ways, including having differing epistemological and methodological frameworks (Agrawal, 1995; Smylie et al., 2003). This poses a problem for the South African context, where ASD understandings and interventions are largely taken from contexts where Western knowledge systems are prominent and imported, without adaption, into a context where Indigenous knowledge systems are prominent.

As would be expected, a parent's understanding of a disorder as disabling as autism, and their choice of intervention, is affected by the parent's culture, history and, therefore, prominent knowledge system (Brown & Rogers, 2003; Harkness et. al, 2007). Some of the formulated interventions may, in fact, be culturally inappropriate in some settings (Brown & Rogers, 2003). For example, not all of the philosophies of the TEACCH program have been found useful in settings other than the United States of America, where it was developed (Schopler, 2005). Of particular relevance to the South African context is the fact that most ASD intervention strategies focus on increasing autonomy, independence and self-assertion (Brown & Rogers, 2003), which may actually be in contrast to African collectivist culture and indigenous knowledge systems where collectivism, co-dependency and group advancement is considered important.

Different cultural backgrounds of clinician and family, and the history between them, can also impact the intervention outcome (Brown & Rogers, 2003). Here, the issue of culture relates more to unequal access to cultural capital - "embodied", "objectified" and "institutionalised" forms of cultural resources, such as positive disposition of the mind, books, instruction in home language, and favourable policies – due to past discrimination (Bourdieu, 1986). Again, this is a pertinent point for South Africa, with its history of Apartheid. People making use of public services are still largely black, while psychological and educational professionals are largely white (Randall, 2001). Additionally, as noted above, the use of information and knowledge from Western origin is far more prominent than Indigenous knowledge and information with regards to ASD intervention. Further, numerous health and income disparities still exist along racial lines, throughout the world – a result of past and current racism (Jenkins & Thomas, 2000; Randall, 2001). Randall (2001) suggests that greater attention needs to be paid to public policy to rectify racial discriminations in health care.

3.5.3. SOCIETAL STIGMA AND ASD

Stigma is a crucial socio-contextual aspect to consider with regard to any disease or disability. While some of the means for ASD intervention have been feared to cause stigmatization (Sheehy & Duffy, 2009), stigma in relation to ASD is a more

complex issue. Gray (1993; 2002) found that parents, siblings and grandparents, and not the children, felt stigmatized. This was largely attributed to the extremely disruptive symptoms of children with ASD, coupled with their normal physical appearance (Gray, 1993). Stigmatized reactions have been attributed to emotional motivations or reactions (Ling, Mak & Cheng, 2010), yet medical knowledge of the child's diagnosis was found to help families resist felt stigma (Farrugia, 2009). In relation to mental illness more generally, a South African study found that stigma influences preferred treatment modality amongst the general population (Hugo, Boshoff, Traunt, Zungu-Dirwayi & Stein, 2003). The study proposed lack of information as a key contributor to stigma, and proposed the provision of information as a critical intervention against stigma surrounding mental disorders (Hugo et al., 2003). Fighting stigma has been a huge problem in the battle against HIV/AIDS in South Africa (Campbell et al., 2005; Kalichman & Simbayi, 2003; Skinner & Mfecane, 2004). In order to intervene in ASD outcomes in South Africa, an understanding of experiences of stigmatization is critical.

In line with Bronfenbrenner's theories, the same ideological values and norms that lead to stigmatization on the individual level also lead to discrimination at the exolevel. This is shown through policies with regards to mentally disabled in general (Corrigan, Markowitz & Watson, 2004). The law restricts many of the rights and opportunities of the mentally ill, while the news media paints the mentally ill as dangerous and dependent (Corrigan et al., 2004). People with disabilities are also commonly viewed in relation to their cost to society. Societal cost for the USA per individual with autism for their lifetime is estimated at $3.2 million, mostly due to loss of productivity and need for adult care (Ganz, 2007). In South Africa, in 2009, nearly 110 000 children received a child care dependency grant (CDG) valued at R1010 per month, totaling a cost to South African tax payers of over R1 billion per annum (Hall, 2010). Many children with ASD from poorer households are eligible for the CDG due to the chronic and severe nature of the disability (Hall, 2010).

3.5.4. LANGUAGE AND ASD

Yet another huge problem relating to socio-contextual factors is that intervention is frequently offered in different languages from the families' home languages in more diverse settings (Brown & Rogers, 2003). This is a crucial point for South Africa where most educational services are provided in English, despite 75% of South Africans speaking an African language as a first language (Alexander, 1999). Various arguments have focused on the complexities of learning in two languages (Alexander, 1999; Heugh, 2000; Setati, 2005; Setati & Adler, 2000). Toppelberg, Snow and Tager-Flusberg (1999) argue that optimizing the language acquisition environment is crucial for maximizing outcomes for children with ASD, and non-first language schooling should be a carefully considered decision. The fact that most healthcare services will also be largely in English adds to this dilemma (Randall, 2001).

3.6 CONCLUSION

From the literature discussed above it is evident that in order to gain an understanding of parents' experiences of having a child with ASD in the South African context, an ecological approach is necessary. An understanding of the impact of various ecological factors, and specifically, of current interventions and services, is warranted. From the literature discussed above, it is expected that various socio-contextual factors within the South African context, which do not commonly fall within the scope of ASD-intervention, will impact on parents' experiences of having a child with ASD. Possible relevant ecological factors to ASD and ASD intervention in the South African context include poverty, socio-economic status, culture, stigma and language. However, the relevance of these factors is merely assumed without proper empirical investigation. Further, additional ecological factors of relevance may be ignored. Understanding how the ecological factors outlined above, as well as additional unnoted factors, affect the experiences of parents of children with ASD is crucial to intervening effectively and optimizing their experiences and psychological well being.

CHAPTER FOUR: METHODS AND RESEARCH DESIGN

4.1. SAMPLE

The sample utilized in this study consisted of eight biological parents to children with ASD. A doctor, psychiatrist, educational psychologist or ASD specialist had, in each instance, diagnosed the child with ASD. All children of parents in the sample were older than 3 years of age to ensure that they fall within the diagnostic criteria for autism spectrum disorder, and not Aspergers syndrome (American Psychiatric Association, 2000). The parents' children were all children enrolled at a public school for children with ASD, located in central Johannesburg. Parents were all reasonably fluent in English, despite only two parents being first language English speakers.

The sample is considered a convenience sample as they were drawn from a school based on convenience (Marshall, 1996; Kelly, 1999b). The sample was relatively homogenous, and the interviews were quite extensive in length, justifying a sample size of eight (Kelly, 1999b). This sample size is further justified by the sensitive nature of the enquiry. Due to the ecological stance of the study, ecological information was obtained through extensive engagement with the various ASD services and interventions. Demographic information was also necessary to map the ecology of the sample. Provided below is a summary of the sample and their relevant demographic information.

The sample ranged in age from 25 to 54 years of age. The children with ASD ranged in age from 5 to 17 years of age. The ratings of the children on the Child Autism Rating Scale (CARS) ranged from mild to severe. Four of the children to parents in the sample were on medication; either Ritalin, Risperdal or both. The home language of participants included various African languages. Six participants identified themselves as either black or African, with two participants, the married couple, identifying themselves as Asian. Seven of the eight participants were South African citizens, and one participant was a Zimbabwean citizen. Four participants were married, and four described themselves as single.

	A	B	C	D	E&F	G	H
Parent's date of birth	02.08.1979	25.03.1976	14.05.1957	15.12.1966	(m) 18.10.1973	02.01.1986	08.12.1980
Parent's Age	31 years	35 years	54yrs	44yrs	37yrs	25yrs	30yrs
Child's date of birth	12.01.2006	25.03.2003	03.03.1994	17.11.2000	22.07.2000	05.10.2003	31.03.2004
Child's Age	5yrs	8yrs	17yrs	10yrs	10yrs	7yrs	7yrs
Home Language	Shona	Tswana	Xhosa	Xhosa	English	Zulu	Tswana
Race	Black	Black	African	Black	Asian	Black	African
Nationality	Zimbabwean	South African	South Africa	South African	South African	South African	South African
Marital Status	Married	Single	Single	Married	Married	Single	Single
Number of children	1	1	3	2	2	2	1
Occupation	Unemployed	Document	Consultant	N/A	Client Liason	Autism practitioner	Trust Officer
Spouse's	Insurance Broker	N/A	N/A	Manager	Unemployed	N/A	N/A
Transport Status	Private	Public	Private	Private	Private	Public	Public
CARS score	31.5	39.5	Unknown	Unknown	26.5	35.5	46.5
Medication	Risperdal, Ritalin	Ritalin	N/A	Risperdal	N/A	N/A	Ritalin, Risperdal
Grant	No	No	Yes	No	No	Yes	Yes
Monthly household income range	R15 001 to R30 000	R5 001-R15 000	Less than R1500	Over R30 000	R5 001 – R15 000	R1501 – R5000	R5001 – R15 000

Table 4.1: Sample Demographics

Three of the participants reported being unemployed. Five participants in the study reported having their own transport, while three reported relying on taxis and other public transport. Only three participants had access to the child disability grant. The monthly household income of participants ranged substantially, from less than R1500 to over R30 000.

4.2. DATA GATHERING TOOLS

This study falls within the interpretivist paradigm, with the aim of understanding and describing the experiences of the relevant parents from within the eco-systems theory framework (Greif & Lynch, 1983; Terre Blanche & Kelly, 1999). Throughout, it aimed to privilege the voices of the participants (Fossey, Harvey, McDermott & Davidson, 2002). A qualitative research method was, therefore, deemed as most appropriate. This study aligns with the assumption that the experiences of the parents could best be understood through interaction (Terre Blanche & Kelly, 1999), and, therefore, made use of a semi-structured interview to gather the necessary data. The semi-structured interview schedule was constructed by the researcher, and can be seen in Appendix A. It attempted to obtain an understanding of parents' experiences of public ASD services and interventions, or lack thereof, on various ecological levels. Some demographic information was also obtained (See Appendix B).

4.3. GENERAL PROCEDURES:

In order to obtain a relevant sample of participants, a particular public school, providing early intervention, support and schooling for children with ASD, was approached. With their permission (see Appendix F), as well as permission from the Gauteng Department of Education (see Appendix H), parents of children with ASD were approached via newsletters handed out by the school. Parents who were willing to participate contacted the researcher via email or telephone, or by leaving their contact details in a sealed box that was placed at the school. Potential participants were then contacted by the researcher and invited to participate. Nine participants contacted the researcher in total. One was excluded from the research as they failed on numerous occasions to provide a date for an interview. Another was excluded as they made contact with the

researcher after data analysis had commenced. All seven other willing participants were interviewed and included in the study. The eighth participant was the husband of another participant, interviewed concurrently with his wife.

At the outset of the interview, the participants were asked to sign an interview and audio-recording consent form. All interviews were conducted by the researcher, and were done face-to-face. Three of the interviews were conducted in the participants' home, at their request. One was conducted at the participant's place of employment, also at their request. Three interviews were conducted at Autism South Africa. All interviews were conducted in a space that allowed for quiet and privacy. All parents were able to attend interviews unseen by school management and employees. A reasonable degree of English language fluency was an inclusion criterion for the study. All eight participants met this criterion. However, only two of the participants (the married couple) were first language English speakers.

On completion of each interview, transcripts were made from audio-recordings of the interviews. To ensure reliability, the transcripts were read through while listening to the recording, as suggested by Terre Blanche & Kelly (1999). The transcripts formed the basis for the analysis. In line with the paradigm and theoretical framework of the study, it is acknowledged that the analysis would have imposed a third person account on the parents' first person experiences (Larkin, Watts & Clifton, 2006). Cognizance was, therefore, made of the researcher's own bias and subjective experiences in the context.

4.4. DATA ANALYSIS

The transcripts of the interviews conducted were analysed using thematic content analysis. First, each transcript was analysed for internal themes, a process known as cumulative coding (Larkin et al., 2006). Next, themes across transcripts were identified, a process called integrative coding (Larkin et al., 2006). Both semantic and latent level meanings were analysed in line with the

recommendations of Braun and Clarke (2006). Both levels of analysis proved significant.

Some theoretical understandings of possible experiences, on each ecological level, had already been outlined in the literature review. These theoretical understandings informed, at least to some degree, the themes which develop (Larkin et al., 2006). Therefore, the thematic content analysis must be considered a deductive-inductive approach (Braun & Clarke, 2006). However, the data drove the themes and not vice versa. The researcher was open to identifying and unpacking themes and concepts not previously outlined in the literature. Various precautions were taken in order to ensure this (Kelly, 1999). These precautions included using a semi-structured rather than a structured interview, consulting extensively with the research supervisor regarding the emerging themes, and keeping a reflective research diary. The study, therefore, acknowledges that the researcher was an active and biased meaning-maker, whose personal understanding and involvement with the participants likely influenced the process of analysis (Larkin et al., 2006). Due to the personal influence of the researcher, the researcher reflected on the interpretive rigour of the study throughout, assessing its authenticity, coherence, reciprocity, typicality and permeability, as outlined by Fossey and colleagues (2002).

4.5. STRATEGIES FOR ENSURING TRUSTWORTHINESS

In order to ensure the trustworthiness of the study, various strategies were undertaken with regards to credibility, dependability, confirmability and transferability. Each will now be discussed in detail. Firstly, credibility refers to the adequate and appropriate representation of reality (Bradley, 1999; Shenton, 2004). Amongst others, strategies for ensuring credibility include a prolonged stay in the field, the researchers experience and background in the field, triangulation, and the search for negative cases (Bradley, 1999; Shenton, 2004; Zhang & Wildemuth, 2009). The researcher's past and ongoing work experience and prolonged engagement in the field of ASD intervention was an important factor for ensuring the credibility of this study. Throughout the analysis, negative

or conflicting cases were sort and presented. It should further be noted that an attempt was made to triangulate the data analysis. It was initially proposed that in addition to the researcher and supervisors' independent coding, ATLAS, a qualitative coding software program would be used, and a comparison of codes across coders would be done. However, it was discovered that formal training was required in order to make use of the software program, and triangulation was therefore not possible. Therefore, only a comparison across research and supervisor codes was made.

Dependability refers to the stability and consistency of the research process and data over time (Bradley, 1999; Zhang & Wildemuth, 2009). In order to ensure dependability in this study, the methodology of the study has been well documented. In addition, dependability was sort through ensuring that all interviews were audio recorded. Verbatim transcripts were written from the audio-recordings, and were checked against the audio-recordings. Further, themes were justified in supervision and in the final written report using a wealth of verbatim quotes from the transcripts.

Confirmability refers to the extent to which the research findings acknowledge and account for the bias and subjectivity of the researcher, as well as the extent to which the findings are confirmed by the findings of another (Bradley, 1999; Shenton, 2004). Here, the role of independent coding by both the supervisor and researcher, as well as extensive discussion regarding the emerging themes, was again important to this study. Additionally, confirmability was sought through extensive documentation and reflection of the researchers' bias and subjectivity throughout the research process as discussed in Chapter Six.

Transferability refers to the ability to generalize the findings of this research to other contexts (Bradley, 1999; Shenton, 2004; Zhang & Wildemuth, 2009). The limited transferability of the research has been clearly noted. The context of the study has been described in detail, and its uniqueness and contrast with other contexts highlighted.

4.6. ETHICAL CONSIDERATIONS

A study of this nature has various pertinent ethical considerations. Firstly, ethical clearance had to be obtained from the University prior to commencement of the study. Secondly, permission was obtained from both the school and the Gauteng Department of Education. Informed consent was of utmost importance, and was operationalised through a participant information sheet, which was handed out to all potential participants. It was clearly indicated to the participants that they will not benefit from the study, nor will their children. Participants were asked to sign an interview consent form as well as an audio-recording consent form. As stipulated on the participant information sheet, participants retained the right to withdraw from the study without personal consequence.

Anonymity could not be guaranteed due to the study's utilization of face-to-face interviews for data collection. Anonymity could also not be promised, despite precautions taken not to disclose the name of the school, because of a lack of similar services provided. Pseudo-names have been used in the transcripts and report in order to provide some third-party anonymity. Confidentiality was yet another difficult issue to address, yet was promised due to various safeguards which were put in place. Three years after examination of the research, all audio-recordings will be destroyed. Until such time, recording will be kept digitally, in a locked office. Participants were asked to consent to the use of verbatim quotes from their interviews and the publishing of transcripts. Participants who request access to the findings will be provided with a one-page summary. The school will be provided with a more detailed report.

It has been noted above that being a parent to a child with ASD can be quite overwhelming and emotionally taxing (Bagenholm & Gillberg, 1991; Bouma & Schweitzer, 1990; Holroyd & McArthur, 1976; Randall & Parker, 1999; Roudrigue et al., 1990). It was, therefore, acknowledged that an interview such as the one outlined above could cause emotional distress for the participants. The researcher made use of the initial interview in order to gauge the appropriateness of the interview questions and structure. The participant did

not appear emotionally overwhelmed, and the interview structure was left unchanged. On some occasions, subsequent to the initial interview, participants became teary. The researcher made use of basic counselling skills to empathetically explore the parents' experiences. Throughout the duration of the interview, the researcher attempted to assess the participant's level of comfort. On one occasion, when the participant became teary, the researcher offered to stop the interview and turn off the recorder. The participant opted to continue. Adequate referral was ensured through providing the participants with contact information for free counseling at the Emthonjeni Centre and the Johannesburg Parent and Child Counselling Centre (JPCCC).

4.7. SUMMARY

This study adopted a qualitative research design, and falls within the interpretivist paradigm. Eight participants, all biological parents to children diagnosed with ASD, were interviewed face-to-face using a semi-structured interview schedule. Verbatim transcripts were written up from audio-recordings of each interview. The transcripts were then analysed using a thematic content analysis. Various steps and measures were taken to ensure that the stud was both trustworthy and ethically sound.

CHAPTER FIVE: RESULTS

5.1. INTRODUCTION

The results of this study were obtained through the thematic content analysis of seven interview transcripts. Before outlining the results, a brief description of the sample is warranted. Seven interviews were conducted during the course of the study. A total of eight participants took part in the research, with one interview consisting of a husband and wife couple. Aside from the married couple, all other participants were female and were interviewed alone. Participants ranged from 25 to 54 years of age, with children with ASD ranging from 5 to 17 years of age. All participants classified themselves as either "Black" or "African" in race, with the exception of the married couple, who classified themselves as "Asian". Only the married couple classified themselves as first language English speakers, but all participants were sufficiently fluent in English to conduct the interview in English without the use of translators. In addition to the married couple who took part in the study, only two other participants were married. The income bracket of the participants showed a great range, from less than R1500 to over R30 000 as a monthly household income. The children of the participants with ASD ranged across the Autism Spectrum, from low to high.

The thematic content analysis of the seven interview transcripts led to the emergence of four main themes, namely: the ***Systemic Impact of ASD (Impact on the Child*** & ***Impact on the Family)***, the ***Inadequacies of ASD Intervention***, ***Two Types of Stigma***, and the ***Importance of Information***. Various subthemes were embedded in each main theme. For the ***Systemic Impact of ASD (Impact on the Family)***, subthemes included ***Emotional, Social, Work*** and ***Marital Relationship***. For the ***Inadequacies of ASD Intervention***, subthemes included ***Dissatisfaction with the Biomedical Model***, ***Lack of ASD Services*** and the ***Impact of Socio-economic Status on Quality of Services***. For the ***Importance of Information***, subthemes included ***Lack of Information*** and ***Positive and Negative Impact of Information***. A super-ordinate theme running across three of these four main themes was also found, namely: ***Contrasting Knowledge Systems***. Clear relationships across themes emerged. Additionally, the ecological nature of the themes was also evident. To justify the central themes, each theme

will be briefly presented, and quotes will be provided. A graphic depiction of the findings can first be seen below in Figure 5.1.

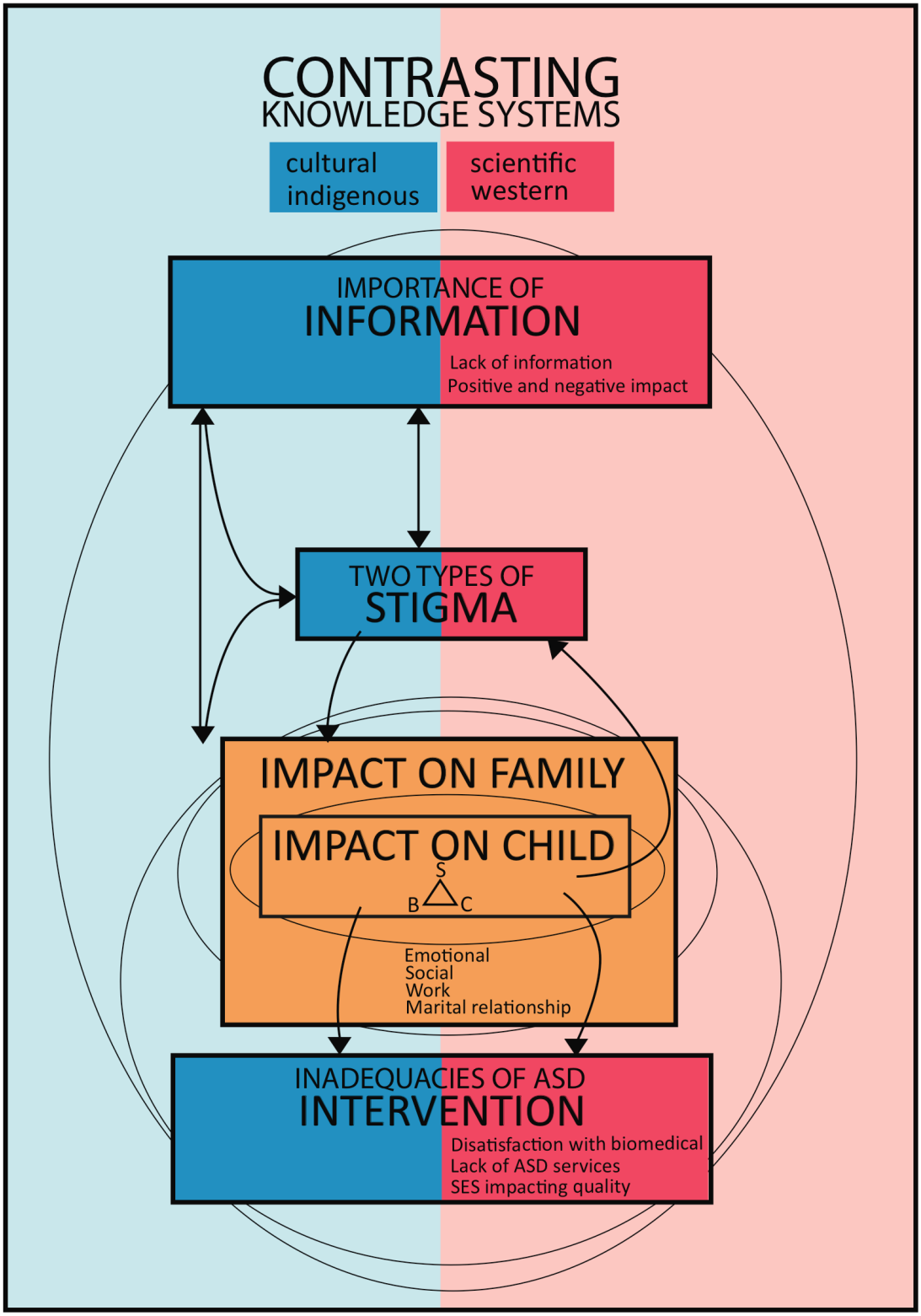


Figure 5.1: Graphic Overview of Thematic Analysis

5.2. CONTRASTING KNOWLEDGE SYSTEMS: THE SUPER-ORDINATE THEME

Across all seven transcripts it was evident that participants were presented with two contrasting knowledge systems, and consequently two different ways of making meaning of ASD. Participants mentioned both Western, scientific knowledge systems and ways to make meaning, as well as cultural, indigenous and religious knowledge systems and ways of making meaning. Many participants aligned themselves to a particular stance. However, all participants alluded to the two contrasting stances in relation to making meaning of ASD and ASD intervention. Quotes that display this theme will be discussed as they appear in three of the four main themes.

5.3. THE SYSTEMIC IMPACT OF AUTISM SPECTRUM DISORDER

The impact of ASD was clearly noted as systemic across all interview transcripts. The systemic impact of ASD was most commonly referred to with regards to two levels, namely the individual level and the family level. Broader systemic impacts were also referred to, but fit better into themes noted later on. For now, a description of the results regarding the impact on the child and the family will be discussed.

5.3.1. THE IMPACT OF ASD ON THE CHILD

All parents described marked impairment with regards to their children in the three areas of impairment associated with ASD, as highlighted in the literature review. These include communicative impairments, social impairments, and odd and stereotyped behaviours. With regard to communicative impairments, the parents found that the child utilized them as an object, and failed to communicate with them. Participants made the following comments:

> **Participant A:** *He would take your hand and push it towards whatever it was.*
>
> **Participant B:** *Communication was always – he always acted out what he wanted.*
>
> **Participant C:** *He just pulls me when he wants something in the fridge.*
>
> **Participant D:** *He cannot make a sentence. He just says one word.*

Participant F: *When he was around two and a half years, normally kids would usually say a few words like the normal mamma or dada, but he never did.*

Participant H: *Whenever he wants something he points.*

Participants further described their children as displaying marked social impairment. This related to both interpersonal interaction as well as the inability to play creatively, within a pretend world. They also described a lack of adherence to social rules and expectations.

Participant A: *If he got impatient with something, he would just scratch you.*

Participant B: *You would give him a car. The first thing he does, he flips it over and then he is playing with the wheels.*

Participant C: *He knows how to play and entertain himself and only on his own. He doesn't want anybody next to him.*

Participant E: *She can't wait. She will scream or she will start crying.*

Participant F: *He would not ummm sort of associate with the people individually. He would be very to himself.*

Participant H: *He didn't want to play with other kids. He would just hit them if he would play with them. He would get very aggressive.*

Lastly, participants described odd stereotyped behaviours displayed by their children. At times this involved obsessive behaviours, such as an extreme preoccupation with cars. At other times, participants reported odd behaviour related to sensory hypo or hyper-reactivity, such as blocking of ears.

Participant A: *He likes cars a lot – he would want all the cars, to keep on getting cars. The house is flooded with cars.*

Participant B: *If you put on the radio, he will close his ears.*

Participant D: *He would close the ears at the back.*

Participant F: *And they always notice him, he's always holding his chin and is jumping about.*

5.3.2. THE IMPACT OF ASD ON THE FAMILY

It was strongly evident across all seven transcripts that ASD is a disorder that not only severely impacts on the child, but also impacts on the entire family system. Participant A best communicated this:

Participant A: *I think it stops being a case of having a child with autism. In the end, we all have it.*

All participants commented regularly on the impact of the child's ASD on themselves, their partners and other siblings. Most often they commented on the impact on themselves. Firstly, the ASD was found to impact the participant, and their family, emotionally and psychologically. Reference was made to the emotional toll that raising a child with ASD had on them.

Participant A: *Having a child with autism puts you in a very fragile mental state.*

Participant C: *I was crying everyday… …It was a real devastating process.*

Participant D: *My husband is not actually [coping], but he is getting better now. I think he realizes that he doesn't have an option. And the brother gets very angry and irritated and frustrated… …And it is draining…*

Participant E: *It was difficult. I used to cry everyday.*

Participant F: *You want to pull your hair out… because the frustration is immense.*

One mother in particular displayed tremendous guilt over her son's ASD.

Participant H: *I feel bad you see, because maybe if I wasn't epileptic, then maybe my son would be normal.*

Often times words indicating psychological disorders and psychopathology were used to describe the psychological and emotional toll of having a child with ASD

on the parent. This depicts the intensity of the experience of the emotional impact.

> **Participant A:** *…so I could actually feel depression setting in…*
>
> **Participant E:** *I was traumatized the way she was behaving.*
>
> **Participant F:** *It was ummmm traumatic, especially for me as a mother.*

Secondly, it was evident that having a child with ASD impacted significantly on the family's social interactions and recreational interpersonal functioning.

> **Participant A:** *So in the end, you just don't want to socialize.*
>
> **Participant B:** *My friends, they know that [my son] is autistic. But it's like, OK, if I can't come I can't come. My friends understand if it's a birthday party, you can't bring [my son].*
>
> **Participant D:** *And you end up not having a social life.*

It was found that having a child with ASD impacted significantly on their work environment and ability to participate in this environment. On two occasions, the child's ASD was reported to lead to dismissal at work. Two other participants reported that they had to quit their job due to the demands of having a child with ASD.

> **Participant A:** *That's why I had to quit… …It's a very pressurized environment and I think my life is pressurized enough without the work load… …I question myself, that if I didn't have a child with autism (if he were normal), would my life be different in terms of profession. And it would be different because before the diagnosis, I never backed down from a challenge, but now I do not want anything that is exhausting.*
>
> **Participant C:** *They did not renew my contract because of the problem I had with the child at the time.*

Participant D: *No, I was working before. Professionally I am a nurse. I'm a theatre nurse. So, I had to leave work. Because he needed speech therapy by then. And OT.*

Participant F: *I used to take off a lot of time before he got enrolled into the school, you know, days of him being sick I was at the beck and call. Jumped in the car, took him to wherever he had to be, pediatrician, doctor, whatever it is. Half a day, a days loss. You don't get paid for it, company guns you down for the time off, and yeah, eventually I was retrenched.*

Participant H: *My work place here, they're complaining at times, because the meetings, we have meetings during the week… and you find that they also want me here at work.*

Lastly, having a child with ASD was found to impact on the marital relationship. This was evident with all participants who were married to or living with the child's other parent. They described the child's ASD as the cause of tension, either presently or previously.

Participant A: *He said I was lying [about the severity of my son's problem], I was just trying to restrain him, and we went through such a difficult time. I was all for leaving him.*

Participant D: *Their husband just left because they can't cope with the strange children. So you find the mother is alone.*

Participant E: *We used to fight a lot, eh, fight a lot, because of [our daughter]. Because I have to take care of her, and I have to take care of everything. I have to take care of him, so it was very hard for him and for me. And he didn't even understand wha wha what was going on… He didn't even ask what was going on, are you okay, or is there something or how are you feeling, so none of like… So it put me down a lot of times.*

Participant F: *That's where him and I fight. My husband and I. Because of that. Because I keep saying, don't tell them that [our son has ASD].*

5.4. THE INADEQUACIES OF ASD INTERVENTION IN SOUTH AFRICA

The second main theme which arose from the thematic analysis was that the current state of ASD intervention in South Africa was inadequate, at the time of writing. The super-ordinate theme, regarding two contrasting knowledge systems and ways of making meaning were evident within the theme of inadequacies of intervention. Participants reported both cultural and religious methods of intervention, as well as scientific and Western forms of intervention. Parents found inadequacies with both.

5.4.1. INADEQUACIES OF CULTURAL, RELIGIOUS AND SPIRITUAL INTERVENTION

Many participants reported adopting or being told to adopt cultural, religious or spiritual interventions, which were rooted in indigenous and cultural knowledge systems. No participants found cultural interventions helpful or useful. Only one participant felt that religious intervention was helpful.

> **Participant A:** *I told them he had been diagnosed with autism. They would say, "Just pray, it will go away".*
>
> **Participant B:** *They say do this and drink that. You will scrub your child with chicken sh#t (laughs), excuse my language… …You will go to that priest and he'll pray for a hundred and fifty days and you'll come out of there and your child will still be autistic.*
>
> **Participant D:** *I relied on God. Because I don't have time to go and see a psychologist for myself, and therapists.*
>
> **Participant E:** *They like, take your child to the sangoma and find out what what…*
>
> **Participant H:** *Well the father thought that maybe it could be that we need to perform some rituals. Ya. But he did that, but still. Ya, but I know deep down that there's nothing that needs to be done.*

5.4.2. INADEQUACIES OF SCIENTIFIC AND WESTERN INTERVENTION

Participants showed higher regard for Western and scientific-based intervention than for more cultural and religious approaches to intervention. However, despite showing a preference for Western and scientific approaches, participants

reported various inadequacies with this approach and its current implementation in South Africa. The inadequacies of Western and scientific approaches included a lack of services, the impact of Socio-Economic Status (SES) on the quality of services, and the inadequacies of a highly biomedical approach to intervention.

5.4.2.1 Lack of ASD Services

Overall, participants described having access to Western and scientific-based services, but felt that the quantity of services was insufficient. All participants expressed a need for more schools, especially schools that were closer by. It was noted that, in part, money impacted on access to services.

> **Participant A:** *There needs to be more schools.*
>
> **Participant B:** *I think that with autism, for starters schools… there isn't.*
>
> **Participant C:** *And we don't have schools at all.*
>
> **Participant E:** *In the rural area there are a lot of kids who needs this school, who needs support, but they aren't able to get it.*
>
> **Participant F:** *It would be wonderful if there were schools closer to us.*
>
> **Participant G:** *There is few schools actually. As you can see, we traveling all the way from [our area]. I wish there could be a school in [our area].*

5.4.2.2. Socio-Economic Status Impacting the Quality of Intervention

Despite all participants in the study having access to basic services such as schools and doctors, participants were largely unhappy or ambivalent about the quality of services they received. They felt that access to quality services was impacted by money and financial status, and prevented them from accessing the best quality services for their child.

> **Participant A:** *They can't afford such services, but you want what is best for your child… …You'll be forced to bring your child here because it's about a thousand rand here, but you are not getting the best service available. And if you want the best you have to pay almost ten thousand, which is too much.*

Participant B: *For people who don't really have money, there is no facilities as such… …If you don't have money, you're really not going to benefit at all.*

Participant D: *People who have a little bit can manage to maneuver through the system. But for the person who… …is not working and is not earning much… …parents are experiencing a lot of problems.*

Participant E: *I've stopped taking her to the doctor since… … so the problem it was, you know… money.*

Participant F: *If you look at [this other school]. They are very fortunate. I mean I've been there, I've seen the facilities. I'd love for my child to go there, but our pockets are not that deep.*

5.4.2.3. Dissatisfaction with the Preference for Biomedical Approaches to Intervention

Participants expressed dissatisfaction with the preference for biomedical approaches, over more bio-psychosocial or bio-ecological approaches to autism intervention. Four participants specifically commented on their dissatisfaction with pharmacological intervention.

Participant A: *The Ritalin works, but only for so long. And I am very anti-medication.*

Participant C: *I gave him Ritalin for about three years. After that I thought, no, it's not working for him… …so I've left doctors and all these concoctions. It really doesn't help.*

Participant D: *We tried Ritalin for concentration, but obviously it didn't work. He just needs more motivation.*

Participant E: *The doctor used to give her the medication, Risperdal, but I stopped her 'cause she was making her like… she was lame, you know, she was not happy, she was not playing.*

One mother commented on how the doctor's interventions lacked helpfulness with regards to her everyday struggles, and failed to acknowledge the impact of ASD on herself.

Participant B: *Can we talk about your emotions or the challenges in general, you know, that kind of thing. So at times its like, okay fine, I'm here for the script so that he can be on medication. That's all there is to it.*

Participants also felt that mental disabilities were given far less attention than physical disabilities, especially with regards to intervention.

Participant B: *I think in general, when we talk about disabilities, we talk about the physical things.*

Participant D: *There are no special policy that will give you special provision for your child. But with someone with a wheelchair they will make a special policy in the workplace… …Most people still don't know what autism is. It's not like other disabilities, where most people are aware of blind people, deaf people. And there are schools for that and what. We are struggling.*

5.5. THE DOUBLE IMPACT OF STIGMA IN THE SOUTH AFRICAN CONTEXT

Parents described experiencing stigma towards themselves and their children due to their disorder. Many people acted rudely, stared at the child or commented that they were mad.

Participant B: *Stigma is also another thing. "Ooooo, that child is mad."*

Participant C: *People are very cruel.*

Participant D: *And you get people who will just have funny remarks when you take him to the shop… …The society and community don't have compassion for children with disability or children with autism.*

Participant F: *You think that this child is mad.*

As with the theme of intervention, the stigma experienced by participants and their children appeared to arise from two contrasting knowledge systems or ways of making meaning. Firstly, it was evident that much stigma arose from cultural and religious knowledge systems and ways of making meaning of the child's behaviour and presentation. Five participants reported being told that

their child was cursed or bewitched. Below are three quotes where this was alluded to:

> **Participant B:** *With black people also, you know we've got cultural issues. We've got witchcraft issues, so acceptance also takes a long time maybe.*

> **Participant D:** *Most of the people are not that nice, because then they, most of the blacks are associated with witchcraft and all these things. It's a bit difficult.*

> **Participant E***: …because she's been bewitched or whatever….*

Secondly, participants experienced stigma which revealed a more Western way of making sense of the child's presentation. Firstly, participants pointed out that their children are frequently assumed to be naughty.

> **Participant A:** *Most people actually think that he's spoilt.*

> **Participant B:** *It's always just that when you're with the child, having to explain, "No, he's not naughty, he's got this condition."*

> **Participant E:** *People used to be like, "ey, ey, you must teach your child some manners".*

> **Participant F:** *….and you think, "Yassis this child is naughty…"*

> **Participant H:** *Even when I meet them they ask, "Where's that naughty boy of yours?"*

Related to society's belief that the child is naughty is the experience of being perceived as a bad parent. This form of stigma also falls within a more Western way of making meaning of the child's ASD.

> **Participant F:** *and you think… "his mother and father don't know how to bring him up".*

> **Participant G:** *My dad says I spoil him. I don't know. They don't understand this condition.*

Some members of society even accused a participant of hitting her child, concluding this only through hearing the child's constant crying, which formed part of his ASD presentation.

> **Participant A:** *And she said, "I have a feeling that you hit your child all the time. I hear him crying all the time." And I don't hit him. She just concluded that I was hitting him all the time.*

Parents also felt that government and work policy failed to make sufficient allowance for their child's condition. They also felt that the community at large did not consider their child to be a valuable member of society. Lastly, it is important to note that stigma was also found to impact on the parent and their psychological functioning. This finding is in line with the finding outlined above in the first major theme, the *Systemic Impact of ASD*, that the child's ASD impacts on the parents more generally.

> **Participant D:** *So its actually a double blow. To have to deal with this and to deal with the community also. You get it from both sides.*

> **Participant F:** *You get really frustrated you want to knock people's teeth out.*

> **Participant H:** *And such comments, they don't go down well with me.*

5.6. THE IMPORTANCE OF INFORMATION IN THE SOUTH AFRICAN CONTEXT

The importance of information marks the final main theme that arose from the thematic content analysis. Although acknowledged in the literature in terms of its positive impact on guarding against stigma, the significance and importance of information to parents of children with ASD is considered an inductive theme in the context of this study. A description of the subthemes of this main theme is needed to accurately depict the significance of information to the participants.

5.6.1. INFORMATION STEMMING FROM TWO KNOWLEDGE SYSTEMS

The super-ordinate theme of contrasting knowledge systems was inherent in this theme. Two types of information, rooted in contrasting knowledge systems, were alluded to across the transcripts. Firstly, cultural, indigenous and religious information was spoken about. Such forms of meaning making were drawn on from family and community members as a source of information for

understanding and explaining the child's behaviour and presentation. No participants appeared to prefer such cultural explanations. One participant preferred religious explanations, and was the same participant who found religious approaches to intervention helpful.

> **Participant A:** *In my culture, there are always other explanations.*
>
> **Participant B:** *There's no awareness. You find the best alternative to say, you know, my child has been bewitched.*
>
> **Participant E:** *They like take your child to the sangoma and find out what what… …But it's not because she's been bewitched or whatever, she has autism.*
>
> **Participant F:** *We did listen to the elders saying that there was sometime or other that the child would speak.*

The second type of information used to make sense and meaning of the child's behaviour and presentation was scientific and Western information. Seven out of the eight participants appeared to preference Western and scientific forms of information.

5.6.2. A LACK OF SCIENTIFIC AND WESTERN INFORMATION ACROSS ECOLOGICAL LEVELS

Information significantly impacted on parent's experiences of having a child with ASD in various respects. Firstly, participants felt there was a general lack of awareness regarding ASD. They felt that this lack of awareness was pervasive over time as well as across ecological levels, from the child's crèche environment and extended family members to the mother's work place and the community at large.

> **Participant A:** *And I don't think, at my workplace, they really understand the gravity of the problem… I don't think people quite understand what autism is, because if I say my child has autism they say "what is that?".*
>
> **Participant B:** *There definitely needs to be a lot of awareness.*

Participant C: *When you go out of the… go to an office and talk about autism, people do not understand.*

Participant D: *Most people still don't know what autism is.*

Participant E: *They never had heard about autism.*

Participant F: *Companies [are] not understanding what autism is all about.*

Participant G: *The only time you know about autism is when it happens to you.*

Participant H: *They don't understand this condition… ….Not a lot of people know about autism.*

Secondly, all participants expressed having no or very little awareness or understanding of ASD before their child was diagnosed. This impacted both on their approach towards others who did not understand their child's condition, as well as on their ability to access services and get an initial diagnosis.

Participant B: *Before they said my son was autistic, I didn't even know the word.*

Participant C: *I did not understand before it affected me.*

Participant F: *I didn't know what autism was. Today I sit here knowing what autism is.*

Participant H: *I didn't know anything about autism before.*

Initially, information that parents did have often came from unlikely and unexpected sources. Information rarely initially came from mental healthcare workers. Many parents had to source their own information to make sense of their child's symptoms or presentation. This information often came from media or the Internet. Four parents reported self-diagnosing their children using information from the media or the Internet.

Participant B: *I was actually at Dischem and then they've got these small books, I think I've got it here, and one of them was saying autistic or ADD or something. I got that and I read it and you know it was like "This is my son!".*

Participant C: *I went onto the Internet and I Googled a lot of things and I was reading and reading and reading and the signs were exactly what was on the net. So I thought, okay, I have an autistic child. So I called here, I made an appointment and I was told to come.*

Participant F: *How we found out about this whole autism thing, it was from Noleen, SABC 3.*

Participant H: *Well, I diagnosed him actually. By the time I went to the doctor I already knew what he…, 'cause I had read about the characteristics of kids with autism.*

5.6.3 THE POSITIVE AND NEGATIVE IMPACT OF GIVING OUT SCIENTIFIC AND WESTERN INFORMATION

Giving out information regarding their child's diagnosis was noted to have a significant impact on their experience of having a child with ASD. This impact was two-fold, and in many ways contrast strongly. Firstly, having and being able to give out information about their child's diagnosis helped to prevent and combat stigmatization. Implied here is that a lack of information in society leads to or caused the stigma they experienced.

Participant A: *It read, "I'm not naughty, I have got autism". It's good that people know.*

Participant C: *But as long as you understand, you don't get irritated…*

Researcher: *Do you think it is changing at all over time, people's reactions to autism?*

Participant D: *No I don't think so. Maybe for people who get information.*

Participant E: *They never had heard about autism. So I think that's the problem with… I think that's the problem. If they did, they would be more understanding.*

> **Participant F:** *Go home and Google autism, see what it is all about and tomorrow if we meet at the same place you will have a different perception of what this child is all about… …If you enlighten the person… "Listen, hey, sorry for him being the way he is, he's autistic"… it just changes that person.*

Despite the usefulness of having and giving out information, with regards to combating and preventing stigma, parents also expressed reservations about giving out information, reporting negative effects of doing so. Two participants found it tiring to constantly have to give out information.

> **Participant B:** *Ya, it's so exhausting just talking about it.*

> **Participant D:** *And you don't always have the energy to explain that the child has autism… …You get tired of explaining all the time.*

One participant was also concerned that the information would lead to further stigmatization.

> **Participant A:** *It's good that people know. But I think it's also bad because people already prejudice your child before, and it depends on their level of understanding. Maybe for them autism means crazy, and whatever he's going to do, even if he laughs like a normal child laughs… … it would be magnified because there is a tag.*

Another participant felt strongly that it was not her responsibility to give out information, and that society should be better informed and not rely on her to give out information.

> **Participant F:** *Why must you tell them that? That is a normal woman. Is she not right in her head that she can't see [my son] is greeting her 10 times. Shouldn't that ring a bell and say something is not right with this child.*

Yet another expressed annoyance at having to repeatedly explain her child's disorder.

> **Participant H:** *Ya, and is just annoys me. Because you explain the same thing time and again.*

5.7. SUMMATION OF RESULTS

This section has outlined the super-ordinate theme and main theme emerging from the thematic content analysis of the interview transcripts, providing quotes from the transcripts as evidence of the themes found. Themes were largely deductive in nature, in line with the method and design of this study, however, additional inductive themes and subthemes were found. A discussion of the outlined themes, drawing on theoretical and empirical understandings, is necessary.

CHAPTER SIX: DISCUSSION

6.1 DISCUSSION OF THEMES

As outlined in the previous chapter, the thematic content analysis resulted in the development of one super-ordinate theme (***Contrasting Knowledge Systems)***, and four main themes (***Systemic Impact of ASD, Inadequacies of ASD Intervention, Two Types of Stigma,*** and ***Importance of Information)*** with various subthemes. The discussion below will highlight areas of convergence and divergence between these findings, the chosen theoretical framework and empirical research reviewed in previous chapters. It will pay particular attention to the distinction between the experiences of South African participants and participants from more researched contexts, such as the United States of America and Europe. This discussion commences with the super-ordinate theme, ***Contrasting Knowledge Systems***.

6.1.1 SUPER-ORDINATE THEME: CONTRASTING KNOWLEDGE SYSTEMS

This study identified one super-ordinate theme. Running across three of the four main themes identified, it was found that participants and society at large made use of two contrasting knowledge systems to make meaning of ASD and ASD interventions, namely Indigenous Knowledge Systems (IKS) and Western Knowledge Systems (WKS). The contrast between IKS and WKS has been well documented in literature (Agrawal, 1995; Ntuli, 2002; Smylie et al., 2003). The super-ordinate theme is congruent with the theoretical framework of this study. Bronfenbrenner (1977; 1979) notes that the macrosystem - which is made up of ideology, culture and subculture - shapes the individual's context. In this study, knowledge systems are conceptualized as forming part of cultural macro-level influences on development.

Additionally, the super-ordinate theme can be explained using eco-systems theory. The child with ASD and his parents can be conceptualized as systems or subsystems embedded within the super-system of the environment. Both IKS and WKS form part of the super-system in South Africa, and can be understood to pass through the permeable boundaries of the parental subsystem, which then becomes used in the functioning of this subsystem. However, due to the

embedded and enduring nature of knowledge systems, the impact of knowledge systems on the individual appear to be greater than the impact of the individual on the knowledge systems. This is consistent with eco-systems theory which states that the influence of the individual and the environment on each other may be unequal (Greif & Lynch, 1983).

Literature recognizes the impact of culture and knowledge systems on how parents understand their child's disability and their choice of intervention (Brown & Rodgers, 2003; Harkness et. al, 2007), as well as the contrasts between Indigenous and Western knowledge systems (Agrawal, 1995; Smylie et al., 2003). Theory also notes that macrolevel factors will lead to heterogeneous contexts (Bronfenbrenner, 1979), and that culture has a relatively enduring influence on systems (Visser, 2007). However, no published literature on the mutual use of Indigenous African knowledge and Western knowledge in understanding ASD and ASD intervention was found. Further, no studies were found to suggest that despite the presence of indigenous knowledge, parents would prefer to draw on WKS. This study found, across the main themes of ***Inadequacies of Intervention*** and ***Importance of Information***, that, despite drawing on both knowledge systems, participants preferred intervention and information based on WKS. This is possibly explained by South Africa's extensive history of colonization, which promoted the acceptance of Western values and knowledge, and the suppression of African values and knowledge (Ntuli, 2002). From an eco-systemic perspective, one can argue that while both IKS and WKS form super-systems, influencing development, WKS have enjoyed greater power than IKS due to colonization. Therefore, WKS had greater influence on parents' experiences despite the mutual existence of IKS, and its distal influence on experiences. This leads to a point of equifinality[1], where the impact of ASD on parents in South Africa is largely similar to the impact experienced internationally, yet occurs via different mechanisms.

[1] Equifinality: Two or more systems can reach the same end state through various, differing paths.

6.1.2. THE SYSTEMIC IMPACT OF ASD

Consistent with clinical understandings of ASD, this study found that parents experienced their child's ASD as impairment in three broad areas of the child's functioning. The three areas of impairment aligned with clinical understandings of ASD as a triad of impairment (Sadock & Sadock, 2007; Wing, 1997). These include social and communicative impairment, and odd and stereotyped behaviour (Sadock & Sadock, 2007; Wing, 1997). This finding is congruent with the bioecological model, which acknowledges that biological and individual factors influence development (Bronfenbrenner & Ceci, 1994).

This study also found that the child's ASD not only impacted on the children themselves, but also impacted significantly on the family. One participant described this most succinctly, stating that "*In the end, we all have it".* This was consistent with Bronfenbrenner's (1977, 1979; Bronfenbrenner & Ceci, 1994) bioecological theory, which argues that there is a reciprocal impact between the child and their context. This finding is further consistent with eco-systems theory, which notes that system boundaries are permeable, allowing systems to influence one another (Greif & Lynch, 1983; Visser, 2007). Additionally, this finding is consistent with empirical research, which has found that children with ASD can impact the family in a variety of ways (Bagenholm & Gillberg, 1991; Bouma & Schweitzer, 1990; Holroyd & McArthur, 1976; Howlin, 1988; Marcus et al., 2005; Randall & Parker, 1999; Roudrigue et al., 1990). The ways in which the child's ASD impacted the family will now be discussed more specifically.

This study found that the child's ASD impacted on four areas of the family's life. Firstly, having a child with ASD was found to impact on the family's emotional and psychological well-being. Participants described it as "*traumatic"* and noted "*crying everyday".* The psychological and emotional impact of having a child or sibling with ASD is noted extensively in empirical research on the impact of ASD on families (Bagenholm & Gillberg, 1991; Ellis, 1989; Gold, 1993; Howlin, 1988; Randall & Parker, 1999).

Secondly, this study found that the child's ASD impacted on the family's social and interpersonal functioning. Participants explained that they didn't "*want to*

socialize" and ended up "*not having a social life".* The finding that one child's ASD impacts on the psychosocial functioning of other siblings is noted in literature (Bagenholm & Gillberg, 1991; Howlin, 1988). The impact on the social functioning of the parents has received less empirical attention, but is consistent with ecological and eco-systems theory (Bronfenbrenner, 1977; Greif & Lynch, 1983; Visser, 2007). The lack of attention to the social impact on parents of having a child with ASD, in both understanding ASD as well as implementing intervention is of concern from within an ecological framework. Bronfenbrenner's (1977; 1979) meso-level, where social interaction is represented, is thought to play a critical role in promoting or hindering optimal development. Therefore, this study argues that the negative impact of a child's ASD on the family's social interactions should form an important point of ASD intervention.

The third area of family impact noted in this study was the impact on the parents' work. Two parents reported losing their jobs due to their child's ASD. A second two participants reported quitting their job due to the child's ASD. This ecological finding aligns with Bronfenbrenner's (1977; 1979) ecological theory, which states that the microsystem (the child diagnosed with ASD) will impact and be impacted on by the exosystem (the parent's work place). This is further consistent with empirical findings that having a child with ASD impacts on parent employment (Kogan et al., 2008; Montes & Halterman, 2008). The impact was found to occur in both directions – a finding consistent with ecological theory and ecosystems theory, which both claim a reciprocal impact of systems on each other (Bronfenbrenner, 1977; Greif & Lynch, 1983; Visser, 2007). Having a child with ASD was found to impact on productivity and time spent at work. On some occasions, the child's ASD was attributed as the cause of dismissal or the reason for quitting. However, work obligations were found to limit parent's access to services. Work was noted as preventing parents from attending support groups and attending workshops and meetings.

Lastly, this study found that the child's ASD impacted on the marital relationship. The child's ASD was reported as leading to fights and suspicion. This is

consistent with research on ASD and marital satisfaction noted in the literature review (Roudrigue et al., 1990). This is further consistent with theoretical understandings that note the intricate relationship between the development of each member of a dyad, as well as between dyads within a system (Bronfenbrenner, 1979; Greif & Lynch, 1983).

6.1.3. THE INADEQUACIES OF ASD INTERVENTION IN SOUTH AFRICA

The second main theme identified by this study related to the inadequacies of ASD services and intervention in South Africa. Parents participating in the study expressed great ambivalence towards the current services and interventions offered in South Africa. ASD intervention in South Africa was understood by participants as rooted in two contrasting knowledge systems, as identified in the super-ordinate theme. The finding that the prevalence of two contrasting knowledge systems in the South African context resulted in two contrasting approaches to ASD intervention is consistent with Bronfenbrenner's (1977; 1979) ecological theory. Ecological theory acknowledges that the exosystem (the social structures that determine the context of ASD intervention in South Africa) is a concrete manifestation of the macrosystem (knowledge systems and culture) (Bronfenbrenner, 1977; 1979). According to the findings of this study, one can theorise that the prevalence of both WKS and IKS within the South African context has resulted in both traditionally and scientifically-based understandings of ASD intervention. This is distinctly different from contexts where ASD intervention is most commonly researched, namely in the United States of America and Europe. Parents' experiences of interventions arising from both knowledge systems will now be discussed.

Firstly, this study found that parents spoke about ASD interventions that arise from indigenous knowledge systems. These included visiting "*sangomas*" and "*nyangas*", and "*performing rituals*". Approaches to ASD intervention that arise from indigenous knowledge systems are largely not acknowledged in ASD research more generally. Again this is best explained by the heterogeneity found across contexts due to macrolevel factors (Bronfenbrenner, 1977; 1979), combined with the prominence of Western and Scientific knowledge systems over Indigenous knowledge systems (Agrawal, 1995; Ntuli, 2002). Participants

found interventions that arose from indigenous knowledge systems to be completely inadequate, revealing the prominence and greater power of Western knowledge systems even within the South African context, despite noting the inadequacies of interventions located in the Western knowledge framework.

As noted above, participants appeared to align themselves with a more Western and science-based approach to intervention. However, despite showing preference for science-based interventions over indigenous-based interventions, participants also found interventions based on Western knowledge inadequate. These inadequacies were attributed to the prominence of biomedical approaches, the inadequate quantity of services, and the impact of socio-economic status on quality of services. These findings are again consistent with Bronfenbrenner's (1977; 1979) understanding that macrosystemic factors, such as ideology and economic systems impact on exolevel factors, and determine how public and government services manifest. This in turn impacts on the development and psychological wellbeing of the child and their family, according to both the findings of this study and ecological theory.

To further highlight the interplay between the macrosystem and the exosystem, we will draw on the finding of this study that biomedical interventions are preferred over indigenous interventions, yet are considered inadequate. This study found that parents of children with ASD were dissatisfied by the prevalence of a biomedical focus in disability intervention. Many parents felt that although interventions targeting disabilities exist, they largely focus on physical disabilities (eg. deaf, blind, paraplegic) and not mental disabilities (eg. ASD, intellectually disabled). This finding contrasts with literature, which suggests that a shift to biopsychosocial interventions has taken place in mental healthcare more broadly and within the realm of ASD intervention (Engel, 1977; 1980; Kiesler, 1999; Sadock & Sadock, 2007). Many parents further stated their dissatisfaction with services that focused mainly on pharmacological intervention with regards to ASD. This again contrasts with literature that argues that a shift has taken place within the field on ASD intervention from biomedical

to biopsychosocial interventions (Marcus et al., 2005; Sadock & Sadock, 2007; Schopler, 2005).

This contrast between literature and the findings of this study possibly suggests that while a shift has occurred in Western and European settings, biomedical forms of intervention are still prevalent within the South African context. The low presence of healthcare workers may possibly contribute to the persistence of a biomedical approach in this context (Pillay & Lockhart, 2001), as a biomedical approach to intervention is largely cheaper than a more holistic and ecological approach. Social inequality and poverty may also explain the presumed discrepancies in quality of care internationally and locally (Brown & Rodgers, 2003; Castro-Leal et al., 2000; Randall, 2001). The persistence of a biomedical approach in South Africa allows the impact of ASD to be constructed as an individual problem, and not a result of exolevel structures, such as lack of access, and macrolevel factors, such as inequality and poverty. Biomedical approaches, therefore, allow for unequal structures to remain (Ryan, 1971).

In addition to finding that Western, science-based interventions were inadequate due to the prevalence of biomedical intervention, participants felt that the quantity of services and intervention was insufficient. This finding is consistent with reports in local literature that there is a lack of services for children with ASD in South Africa (ASA, 2011; Jacklin & Stacey, 2010). No direct link between the lack of services noted on the exolevel, and the macrosystemic factors that may have led to such an exolevel manifestation were noted in the analysis. However, literature can be used to provide possible explanations. Literature notes that economic systems and socio-economic status impact on access to ASD intervention (Cuccaro et al., 1996; Mandell et al., 2005; Marcus et al., 2001; Schopler, 2005). It is, therefore, hypothesized here that the historical, economic and political context of South Africa has contributed significantly to the limited access to intervention in South Africa for children with ASD and their families.

Lastly, this study found that ASD interventions were inadequate due to the impact of socio-economic status on the quality of accessible ASD intervention. This finding is, again, consistent with ecological theory, which argues that there

is a reciprocal interplay between the macrosystem (economic systems), the exosystem (the parents' own financial context) and the mesosystem (the interplay between the parents' financial circumstance and the child's school) (Bronfenbrenner, 1977; 1979). This finding is also consistent with literature discussed above that notes the impact of socio-economic status on access to quality mental healthcare generally (Brown & Rogers, 2003; Castro-Leal et al., 2000; Randall, 2001), and in South Africa specifically (Jacklin & Stacey, 2010).

6.1.4 TWO TYPES OF STIGMA

The third theme identified by this study involved parents' experiences of stigma. Participants relayed that their children were often thought to be naughty. Again, the significant impact of a macrolevel construct such as stigma on the experiences and development of children with ASD and their families is consistent with ecological and eco-systems theory. The findings are further consistent with experiences of stigma noted empirically by parents of children with ASD internationally (Gray, 1993; 2002). In addition, parents explained that they were frequently assumed to be inadequate parents. This finding is further consistent with Gray's (1993; 2002) research, which found that parents and family members felt stigmatized themselves. However, this study found the emotional and psychological impact of the stigmatization experienced by the family to be of particular concern. Similarly, the inadequacies of work and government policy and the lack of value attributed to individuals with ASD can be understood as a form of stigmatization, rooted in Western knowledge. This is congruent with international perceptions and understandings of disability (Corrigan et al., 2004). The consistency regarding the nature of stigma experienced internationally and in the South African context is understood as a manifestation of the high influence of Western knowledge systems in the South African, American and European context, as is noted above in the super-ordinate theme of this study to influence parents' experience.

Consistent with the influence found of two contrasting knowledge systems on ASD intervention, this study found that parents experienced two forms of stigma. This second form of stigma experienced by participants was understood to arise from indigenous knowledge systems. Parents reported being told that their

children were "*bewitched*" or "*cursed*". Such experiences have not been noted in Western and European studies on stigma experienced by parents of children with ASD. This finding can be understood using ecological theory, which notes that macrosystemic factors determine the homogeneity or heterogeneity of experiences in two contexts (Bronfenbrenner, 1979). The prevalence of a second, unique knowledge system within the South African context can, therefore, be understood to cause the heterogeneous experiences of South African parents with regards to stigma.

6.1.5. THE IMPORTANCE OF INFORMATION

A fourth theme was identified during the analysis. This study found that information had a significant impact on parents' experiences of having a child with ASD. As with the inadequacies of intervention and the experiences of stigma, both Western and Indigenous knowledge systems were found to contribute to the information available to parents of children with ASD in the South African context. Parents explained that they received explanations regarding their child's symptoms, based on Indigenous and Western knowledge systems. Parents showed a preference for Western-based information.

This study found that the lack of information on ASD, based specifically on Western knowledge systems, across ecological levels, impacted negatively on their experiences of having a child with ASD. Parents noted that prior to the diagnosis, they lacked information regarding ASD. They further felt that there was an insufficient understanding of ASD in their work environment and in the broader community. This lack of information initially prevented access to a correct diagnosis, and was understood as the cause of stigma based on both Western and Indigenous knowledge systems.

Consistent with Farrugia's (2009) research, this study found that providing others with information was thought by participants to guard against stigma. A second international study also found that descriptive (pointing out of similarities between the child with ASD and the participants) and explanatory (clinical information on ASD) information guarded against stigma and reduced

negative responses of primary school children towards peers with ASD (Campbell, Ferguson, Herzinger, Jackson & Marino, 2003). Here, information about ASD distributed by the parents can be understood theoretically as acting as positive feedback to the community, encouraging a new homeostasis or state of balance. Parents experience stigma from community members and respond by providing information, causing more favorable community responses and, in turn, more favourable parent experiences.

This study found that, in addition to information guarding against stigma, providing information had negative implications for the family and their child with ASD. Some felt that it increased stigma. This is consistent with international empirical findings (Sheehy & Duffy, 2009). Others found it "*exhausting*" and "*tiring*". The inconsistency between the findings of this study and international findings can be understood using Bronfenbrenner's ecological theory. As noted above, the interplay of various ecological levels is thought to lead to heterogeneous experiences in heterogeneous contexts (Bronfenbrenner, 1979).

6.1.6. THE ECOLOGY OF THE THEMES

As depicted in the graphic overview in Figure 5.1, the themes that arose from the thematic content analysis can be conceptualized as pertaining to various nested levels of the child's environment, consistent with both ecological and eco-systems theory. Using Bronfenbrenner's (1977: 1979) ecological theory, the four main themes can be understood to fall on various ecological levels. The impact of ASD on the child and their family make up the microsystem, on the individual and family levels. The inadequacies of ASD intervention fall on the exo-level, and speak to the availability and quality of concrete services (Bronfenbrenner, 1977; 1979). The types and impact of information, as well as the types of stigma experienced by parents of children with ASD speak to macrosystemic factors. The super-ordinate theme of knowledge systems is considered a macro-level factor, but its manifestation on the exo-level with regards to available services is also evident. Similarly, using eco-systems theory, the various themes are understood as forming nested layers of sub-systems, systems and supersystems (Greif & Lynch, 1983; Visser, 2007). The family, specifically, is a clearly defined

system, of which the parents form a subsystem. Information, intervention, stigma and knowledge systems form part of the supersystem.

6.1.7 THE RECIPROCAL INTERACTION OF THE THEMES

Consistent with ecological theory, which theorizes that each level of the ecology impacts on one another (Bronfenbrenner, 1977; 1979), this study found distinct relationships between the four main themes identified. Firstly, the child's disorder was found to impact on the family. Further, the child's disorder led to the need for intervention, for both the child and the family. The child's ASD, and the behaviours and impairments that result from the disorder, were found to cause stigma reactions from society. In turn, the stigma that resulted from the child's behaviour was found to impact significantly on the family. Stigma and information were found to impact one another, with a lack of information found to cause stigma, and the provision of information found to combat stigma. The relationship between stigma and information also impacted on the family. The absence of information caused stigma, which negatively impacted directly on the family. Providing information helped guard against the impact of stigma on the family, but also impacted them negatively, causing exhaustion.

Eco-systems theory is useful for understanding the flow of information from one permeable system to another. Firstly, the family systems and communities noted in this study must be conceptualized as open, permeable systems due to their noted influence on each other. The child's triad of impairments serve as an output to the environment as seen through the impact on the family's functioning, the need for intervention, and stigmatized reaction from the public. The community's stigmatized reactions serve as an input for the family, whose functioning is negatively impacted by the stigma. Information may form an output from the family system into the community system. It is this flow of information across open systems that result in the circular and reciprocal impact of family and community systems on one another. Further, parents consistently noted that their experiences of having a child with ASD had not changed over time. This suggests a state of homeostasis between the community and families of children with ASD.

6.2. RECOMMENDATIONS

Various recommendations will now be made on the basis of the findings of this study as outlined above. Firstly, this study recommends that a move towards a bioecological approach to ASD intervention is required within the South African context. This study has revealed a systemic impact of ASD, and, therefore, should be matched with a systemic approach to intervention. Currently, ASD intervention in South Africa is largely biomedical in nature, revealing a mismatch between the impact of ASD and the points of intervention. This recommendation has various implications. Firstly, a greater focus needs to be placed on intervention focused at families of children with ASD. This includes interventions that focus on family emotional wellbeing, increasing positive social interaction, creating supportive work environments, and increasing marital satisfaction. Secondly, greater focus needs to be placed on intervening at the community level. Such interventions should include a focus on increasing community knowledge and information regarding ASD and implementing policy change, which ensures equal attention to mental and physical disabilities.

Secondly, it is recommended that ASD intervention should take greater cognizance of the two contrasting knowledge systems utilized within the South African context. These findings suggest that, most importantly, ASD intervention needs to tackle stigma rooted in both knowledge systems. Currently, stigma prevention interventions are centered around Western knowledge systems, and fail to address Indigenous understandings and ways of making meaning. The provision of information should, therefore, also be cognizant of Indigenous knowledge systems and their influence on parents' experiences.

Secondly, this study highlights the need to lobby for a greater number of high quality ASD schools, specifically for those in lower socio-economic brackets. Further research from within a policy research framework is recommended in order to assist with obtaining this goal. Particular attention should be paid to ensuring a high quality of intervention, and access alone. Attention to the principles provided by Fiscella and colleagues (2000) for promoting equal access to equal quality healthcare services across socioeconomic status in the US is recommended in the pursuit of this goal. The first principle outlined here is to

acknowledge quality, not only quantity, as a disparity problem (Fiscella et al., 2000). Secondly, research on the quality of services provided across economic levels should be obtained, with measures of healthcare quality being stratified by socioeconomic status (Fiscella et al., 2000). Lastly, the interplay between race and socio-economic status must be acknowledged (Fiscella et al., 2000). Whilst developed internationally, these principles may prove beneficial for improving equality of healthcare services in South Africa. It is recommended that national research in South Africa account for the quality of services provided, and the relationship between quality and SES in planning for services provision.

6.3 PERSONAL REFLEXIVITY

Personal reflexivity and acknowledging one's subjectivity, and its possible contribution to and impact on the research process, is a crucial element of qualitative research. It is particularly important to acknowledge that from the outset of this study, researcher bias and experiences played a role. At the time of writing, the researcher had worked as an ASD educator for nearly a year. During the course of the researcher's employment in ASD intervention, the researcher was exposed to the parents' experiences within the context. This experience played a large role in the conceptualization of the research project, as well as the literature that was explored and the interview schedule that was developed. The researcher has also been involved in ASD diagnostics[2] for over a year. Researcher bias in the development of the key themes must be considered, and forms the primary reason for the deductive nature of this research. However, cognizance of the researcher's subjectivity allowed for intentional exploration of inductive findings.

It is also of importance to note that the researcher felt deeply empathic towards the research participants. Due to the researcher's training in psychotherapy, the clear communication of the emotional and psychological impact of the child's ASD on the parents' functioning and the communicated lack of supportive services, the researcher commonly felt a desire to act supportively and respond in a therapeutic manner. This desire to respond therapeutically was taken to

[2] The researcher volunteers on an on-going basis as the Autism South Africa ASD screening clinic.

supervision and reflected on. The researcher ensured that the role of researcher was maintained prior to and during the course of the interview. Following the interview, the researcher was able to act more supportively without impacting on the data obtained.

6.4 STRENGTHS AND LIMITATIONS

It is important to acknowledge the various limitations of this study. Firstly, this study made use of a single set of semi-structured interviews. It did not provide an opportunity for participants to elaborate or validate previous statements, or confirm the researcher's findings. This limits the truth-value of the findings presented above. A further limitation of this study is researcher bias and influence. As noted above, the researcher had spent over a year working in the context of ASD diagnosis and intervention, and went into the research with pre-existing perceptions regarding parents' experiences. As a measure to counter the impact on the researcher's experiences, a reflective diary was kept over the course of the research. Further, the researcher's supervisor did an independent analysis of the transcripts. The independent findings of both the supervisor and researcher were then discussed and made sense of congruently.

Obtaining information across ecological levels is logistically complex (Sallis et al., 2008), and was beyond the scope of this study. However, the study's failure to obtain data across various ecological levels, due to logistical complexity and limitations in scope, is a noted limitation of this study. Due to the qualitative nature of the study, a further limitation is the inability to generalize the findings more broadly, due to the small sample size and homogeneity of the group. Additionally, the sample was taken solely from a Johannesburg school, and therefore, the findings are limited to Johannesburg, and are not necessarily representative of the whole of South Africa. The sample was based on convenience, marking a further limitation of the study. Lastly, the deductive nature of this research marks a further limitation. This likely limited the themes identified in the analysis.

Despite its limitations, this study had various strengths. Firstly, the data from the interviews was very rich. Secondly, the researcher bias, noted above as a

limitation of this study, can also be viewed as a strength of this study. The researcher's prolonged exposure to the context of ASD intervention allowed the researcher to become immersed in and familiar with the context of ASD intervention in South Africa. This increases the credibility of the researcher's findings. A third strength of this study is that the findings largely agreed with theoretical and empirical findings more broadly. Additionally, this research marks an important contribution to the body of South African literature on ASD and ASD intervention, as some of the findings of the study differed from previous research. Lastly, this study may prove useful in assisting in lobbying for greater funding and services for children with ASD and their families in South Africa.

6.5 IMPLICATIONS FOR FUTURE RESEARCH

This study, as with qualitative studies more generally, has provided an in-depth overview of a small, homogenous sample's experience of having a child with ASD in the South African context. Although the sample utilized provided important and valid information regarding this experience, further research is needed to understand the experiences of a broader range of South African citizens. This study acknowledges particularly the need to understand the experiences of those without any access to basic ASD-specific services, such as schooling, unlike those utilized in this study. Additionally, the experiences of those parents who are located rurally are necessary in order to better understand the impact of Indigenous knowledge systems on parents' experiences. A similar study using a larger, heterogenous sample and a mixed methods approach is recommended in order to enable greater generalization of the findings.

As recommended above, this study indicates the need for further research into policy change to promote the wellbeing and optimal development of children with ASD and their families. Specific areas of policy research implied as necessary by the findings of this study include implementation of protective work policy for parents with mentally disabled children, policy ensuring access to ASD-specific services for all children with ASD and their families, and policy ensuring quality ASD-specific services for all children with ASD and their families. Following policy change recommendations, implementation of policy

changes must be ensured using further research.

Lastly, limitations in scope prevented this study from sufficiently investigating the experiences of parents of children with ASD from the framework of socio-cultural theory. Future research should investigate the impact of socio-cultural factors such as lack of education, low access to resources and information, and poverty on parents' ability to provide their children with ASD with appropriate mediated learning experiences and cultural tools. Therefore, a Vygotskian framework is recommended for future research in this area.

6.6 CONCLUSION

In conclusion, this study found both points of convergence and divergence between the experiences of parents in the South African context and parents internationally, in more researched contexts. Experiences converge with regards to the systemic impact of ASD on the family, specifically with regards to the emotional, work-related and marital impact. The impact on parental social relationships is not acknowledged internationally. Experiences further converge with regards to the inadequacies of intervention, experiences of stigma and importance of information, particularly in combating stigma. However, the experiences diverge with regards to the presence of two types of information, stigma and intervention, which are found in the South African context and are not acknowledged elsewhere. Further, biomedical approaches to intervention seem to be more prominent in the South African context, as opposed to biopsychosocial approaches prominent internationally. The impact of socio-economic status and quality of services are also more prominent themes in the South African context. This research has highlighted the need to move towards bioecological approaches to understanding ASD and ASD intervention in the South African context.

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APPENDICES

Appendix A: Interview Schedule

Parents' Experiences of a Having a Child With ASD

Semi-Structured Interview Schedule

1. **Tell me what it was like for you when you realized your child was different?**
   a. What were his social skills, communication and behavioural symptoms like?
2. **Can you tell me how your child is doing at the moment, in terms of his ASD?**
   a. What are his social skills, communication and behavioural symptoms like now?
   b. What else has improved?
   c. What other problems do you still experience with him?
3. **How are the people at home dealing with his ASD?**
   a. How did you and your family react to his diagnosis?
   b. How is his ASD affecting things at home currently?
   c. Can you tell me how things have gotten worse or better over time?
4. **Can you tell me about the school and your experience of working with them?**
   a. How is the communication between school, the doctor and home?
   b. Can you tell me how things have gotten worse or better over time?
5. **How does your work place affect your experience of having a child with ASD?**
   a. How does your work react to you needing time off for school meetings or doctor's appointments?
   b. In what ways does your work support you in terms of having a child with autism?
   c. What work policies are in place that either positively or negatively affect your experience of having a child with ASD?
   d. What more could your work place do to make having a child with ASD easier?
   e. Can you tell me how things have gotten worse or better over time?
6. **Can you tell me about your experiences of other services?**
   a. What do you think about the child disability grant system?
   b. Can you tell me about your access to necessary services?
   c. What do you think about how the government helps people with autism?
   d. Can you tell me about your experiences of working with the doctors and other professionals?
   e. Was it difficult to get a diagnosis?
   f. Can you tell me a bit about your transport situation?
   g. What services that are available have you found useful and helpful?
   h. What services do you need that aren't available?
   i. Can you tell me about your experience of being part of an English language school and health care service?
   j. Can you tell me about how things have improved or gotten worse over time?
7. **What kinds of support do you have?**
   a. Can you tell me how things have gotten worse or better over time?
9. **How do you make sense of his ASD?**
   a. How valuable do you think people think your child is as a member of society?
   b. Can you tell me how things have changed or not changed over time?
10. **What are your experiences like of people's perceptions of and reactions to ASD?**
    a. How do your neighbours and family friends react to your child?
    b. How do society and the community react to people with ASD?
    c. How do they make sense of and understand his autism?
    d. Have you experienced any stigma (negative reactions from people) because of your child?
    e. Can you tell me how things have changed or not changed over time?

Appendix B: Demographic Questionnaire



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development
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Tel: (+27) 072 224 3988
Email: nicki.dawson@gmail.com

Date of Interview:	dd	mm	yyyy
Participant's Date of Birth:	dd	mm	yyyy
Child's Date of Birth:	dd	mm	yyyy
Date of School Entry:	dd	mm	yyyy

Participant's Pseudoname:	
Child's Pseudoname:	

Home Language:	
Race:	
Nationality:	
Marital Status:	
Number of Children:	
Mother's Occupation:	
Father's Occupation:	
Transport Status:	

CARS Score:	
No. of Children in Child's Class:	
Therapies Received:	
Medication:	
Grants Received:	
Hospital Your Child Uses:	
Additional Services Used:	

Monthly Household Income Range:	(Please tick)
Less than R1500	
R1501 to R5000	
R5001 to R15 000	
R15 001 to R30 000	
Over R30 000	

Appendix C: Participant Information Sheet

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

School of Human and Community Development
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Email: nicki.dawson@gmail.com

Hello,

My name is Nicola Dawson, and I am conducting research for the purposes of obtaining a Masters degree at the University of the Witwatersrand. My research supervisor is Prof. Daleen Alexander, a lecturer at the Department of Psychology at the University of the Witwatersrand. Her contact telephone number is (011) 717-4526 and her e-mail address is dinah.alexander@wits.ac.za.

My area of focus is parents' experiences of having a child with ASD in the South African context. I would like to invite you to participate in this study.

Participation in this research will entail being interviewed by me, at Autism South Africa's offices, or another place of convenience. The interview will be conducted at a time that is convenient for you. It will be conducted in English, so a degree of fluency in the English language is required. The interview will last approximately one hour. With your permission, this interview will be audio-recorded in order to ensure accuracy and reliability of information. Participation is voluntary, and no person will be advantaged or disadvantaged in any way for choosing to participate or not participate in the study. You may refuse to answer any questions you would prefer not to, and you may choose to withdraw from the study at any point, without personal consequence. There are no direct benefits or risks to participating in this research. The line of questioning may make you feel emotional. If so, you will be provided with access to free counseling at the Emthonjeni Centre or JPCCC.

All of your responses will be kept confidential. Although direct quotes might be used, no information that could identify you would be included in the research report. The names of you and your child will be changed. I am unable, however, to provide full anonymity, as you will meet me face to face. Also, while I will not disclose the name of the school, a lack of similar services may allow people reading my research to infer which school was used. Access to the audio-recordings will be restricted to me and my supervisor. They will be processed and transcribed only by me. For the duration of the study, the audio-tapes will be stored safely in a location with restricted access. Three years after the research has been examined, all audio-tape recordings will be destroyed. The results of the research and the interview transcripts will be reported in my research report, and may also be published in a journal article. You will be provided with a one page summary of my findings on request.

If you choose to participate in the study please contact me telephonically (+27) 072 224 3988 or via e-mail at nicki.dawson@gmail.com. Alternately, please leave your contact information for me in the box marked "ASD research" in the school entrance.

Yours faithfully,
Nicola Dawson

For free counselling, contact the Emthonjeni Community Clinic on 011 717 4513 or JPCCC on 011 484 1734.

Appendix D: Interview Consent Form



I, _____, consent to be interviewed by Nicola Dawson for her study of parents' experiences of having a child with ASD in the South African context.

I understand:

- the nature and purpose of this study;
- that participation in this interview is voluntary;
- that I may refuse to answer any questions I would prefer not to;
- that I may withdraw from the study at any time;
- that no negative consequences will arise if I decide to withdraw, decline participation or refuse to answer a question;
- that no identifying information will be included in the research report, and my responses will remain confidential;
- that direct quotes may be used in the published work based on this research; however, no identifying information will be used and my name and the name of my child will be changed so as to protect my identity;
- that transcripts of the interview will be published in the research report;
- that there are no ensured, direct benefits to participating in this study;
- that there are no known risks associated with this study, however, the line of questioning may make me feel emotional, in which case I will be provided with access to free counseling.

Signed: _____

Date: _____

Appendix E: Audio-recording Consent Form



I, _____, consent to the audio-recording of my interview with Nicola Dawson for her study of parents' experiences of having a child with ASD in the South African context.

I understand that:

- access to the audio-tapes will be restricted to the researcher, Nicola Dawson, and her supervisor;
- the audio-tapes will only be processed and transcribed by the researcher, Nicola Dawson;
- no identifying information will be included in the transcripts or the research report;
- direct quotes may be used in the published work based on this research; however, no identifying information will be used and my name as well as the name of the my child will be changed so as to protect my identity;
- the audio-tapes will be stored safely in a location with restricted access
- all audio-tape recordings will be destroyed three years after the research has been examined.

Signed: _____

Date: _____

Appendix F: School Permission Letter

Appendix F: School Permission



[redacted]

Nurture our Youth with Knowledge

[redacted]

e-mail ronel@gam.co.za

[redacted]

[redacted]

e-mail ronel@gam.co.za
aqua@iburst.co.za

[redacted]

18 January 2011

TO WHOM IT MAY CONCERN

This letter serves to confirm that we give Nicola Dawson permission to use our school to recruit participants for her studies on " An ecological perspective of parents' experiences of a public ASD intervention". We are willing to help her by distributing participant invitation letters to the parents of our children.
We also provide permission for her to spend time in the context to gain an understanding of the school environment and all the services it provides. We will be happy to answer any questions in this regard. Further, we are happy for her to use our boardroom and office facilities for her to interview the parents as part of her study.
Lastly, we would like to confirm that we are in full support of her study and are interested in the outcome of the study.

P C van Biljon
Principal

Appendix G	

GAUTENG DEPARTMENT OF EDUCATION

RESEARCH REQUEST FORM

REQUEST TO CONDUCT RESEARCH IN INSTITUTIONS AND/OR OFFICES OF THE GAUTENG DEPARTMENT OF EDUCATION

1. PARTICULARS OF THE RESEARCHER

1.1	Details of the Researcher
Surname and Initials:	Dawson, N.K.
First Name/s:	Nicola Kathleen
Title (Prof / Dr / Mr / Mrs / Ms):	Ms
Student Number (if relevant):	0606689X
ID Number:	8612230066080
Gender (Male/Female):	Female

1.2	Private Contact Details
Home Address	*Postal Address (if different)*
15 King Gardens, Pentrich Road,	
Victory Park, Randburg	
Postal Code: 2195	*Postal Code:*
Tel: (011) 782 4914	
Cell: 072 224 3988	
Fax: ( )	
E-mail: nicki.dawson@gmail.com	

2. PURPOSE & DETAILS OF THE PROPOSED RESEARCH

2.1	Purpose of the Research (Place cross where appropriate)
Undergraduate Study - Self	
Postgraduate Study - Self	x
Post-Doctoral Study	
Private Company/Agency – Commissioned by Provincial and/or National Government Department/s	
Private Research by Independent Researcher	
Non-Governmental Organisation	
National Department of Education Commissioned Study	
Commissions and Committees	
Independent Research Agency	
Statutory Research Agency	
Independent Study by Higher Education Institution	

2.2	If Post-Graduate Study – Please indicate by placing a "X" in the appropriate column	
Honours	*Masters*	*Doctorate*
	X	

2.3	Full title of Thesis / Dissertation / Research Project
An Ecological Perspective on Parents' Experiences of Having a Child With	
Autistic Spectrum Disorder (ASD) in the South African Context.	

2.4	Value of the Research to Education (Attach Research Proposal)
To lobby for greater access to ASD intervention in South Africa.	
To improve parents' perceived experiences of having a child with ASD in a	
public ASD-specific school in South Africa, before replicating such services.	

2.5	Student and Postgraduate Enrolment Particulars (if applicable)
Name of institution where enrolled:	University of Witswatersrand
Degree / Qualification:	Masters in Community Counselling
Faculty:	Humanities
Department:	Human and Community Development
Name of Supervisor / Promoter:	Prof. Daleen Alexander

2.6	Employer (where applicable)
Name of Organisation/School:	N/A
Position in Organisation:	N/A
Head of Organisation:	N/A
Street Address:	N/A
Postal Code:	N/A
Telephone Number (Code + Ext):	N/A
Fax Number:	N/A
E-mail:	N/A

2.7	PERSAL Number (where applicable)						
N/A							

3. PROPOSED RESEARCH METHOD/S

(Please indicate by placing a cross in the appropriate block whether the following modes would be adopted)

3.1 ***Questionnaire/s (If Yes, supply copies of each to be used)***

YES	x	NO	

3.2 ***Interview/s (If Yes, provide copies of each schedule)***

YES	x	NO	

3.3 *Use of official documents*

YES		NO	x
If Yes, please specify the document/s:			

3.4 *Workshop/s / Group Discussions. (If Yes, Supply details)*

YES		NO	x

3.5 *Standardised Tests (e.g. Psychometric Tests)*

YES		NO	x
If Yes, please specify the test/s to be used and provide a copy/ies			

4. RESEARCH PROCESSES

4.1 ***Types of Institutions.*** **(Please indicate by placing a cross alongside all types of institutions to be researched).**

INSTITUTIONS	Mark with "X" here
Primary Schools	
Secondary Schools	
Technical Schools	
ABET Centres	
ECD Sites	
LSEN Schools	x
Further Education & Training Institutions	
Other	

4.2 ***Number of institution/s involved in the study.*** **(Kindly place a sum and the total in the spaces provided).**

Type of Institution	Total
Primary Schools	
Secondary Schools	
Technical Schools	
ABET Centres	
ECD Sites	
LSEN Schools	1
Further Education & Training Institutions	
Other	
GRAND TOTAL	1

4.3 ***Name/s of institutions to be researched.*** **(Please complete on a separate sheet and append if space is deemed insufficient).**

Name/s of Institution/s
Johannesburg Hospital School – Out-patient division

4.4 ***District/s where the study is to be conducted.*** **(Please mark with an "X").**

District	
Johannesburg East	x
Johannesburg South	
Johannesburg West	
Johannesburg North	
Gauteng North	
Gauteng West	
Tshwane North	
Tshwane South	
Ekhuruleni East	

District	
Ekhuruleni West	
Sedibeng East	
Sedibeng West	

If Head Office/s (Please indicate Directorate/s)

NOTE:

If you have not as yet identified your sample/s, a list of the names and addresses of all the institutions and districts under the jurisdiction of the GDE is available from the department at a small fee.

4.5 ***Number of learners to be involved per school.*** **(Please indicate the number by gender).**

Grade	*1*		*2*		*3*		*4*		*5*		*6*	
Gender	B	G	B	G	B	G	B	G	B	G	B	G
Number												

Grade	*7*		*8*		*9*		*10*		*11*		*12*	
Gender	B	G	B	G	B	G	B	G	B	G	B	G
Number												

4.6 ***Number of educators/officials involved in the study.*** **(Please indicate the number in the relevant column).**

Type of staff	Educators	HODs	Deputy Principals	Principal	Lecturers	Office Based Officials
Number	0	0	0	0	0	0

4.7 ***Are the participants to be involved in groups or individually?*** **Please mark with an "X".**

Participation	
Groups	
Individually	x

4.8 ***Average period of time each participant will be involved in the test or any other research activity*** **(Please indicate time in minutes)**

Participant/s	Activity	Time
Parents	Interview	1 to 1.5 hours
Parents	Questionaire	10 minutes

4.9 ***Time of day that you propose to conduct your research.*** **Please mark with an "X".**

School Hours	During Break	After School Hours
		x

4.10 ***School term/s during which the research would be undertaken.*** **Please mark with an "X".**

First Term	Second Term	Third Term
	x	x

DECLARATION BY THE RESEARCHER	
1. *I declare that all statements made by myself in this application are true and accurate.* 2. *I have read and fully understand all the conditions associated with the granting of approval to conduct research within the GDE, as outlined in the GDE Research Briefing Document, and undertake to abide by them.* 3. *Should I fail to adhere to any of the approval conditions set out by the GDE, I would be in breach of the agreement reached with the organisation, and all privileges associated with the granting of approval to conduct research, would fall away.*	
Signature:	ANOUS
Date:	24/11/2011

DECLARATION BY SUPERVISOR / PROMOTER / LECTURER	
I declare that: - ***1. The applicant is enrolled at the institution / employed by the organisation to which the undersigned is attached.*** ***2. The overall research processes meet the criteria of:*** • ***Educational Accountability*** • ***Proper Research Design*** • ***Sensitivity towards Participants*** • ***Correct Content and Terminology*** • ***Acceptable Grammar*** • ***Absence of Non-essential / Superfluous items***	
Surname:	**Alexander**
First Name/s:	**Daleen**
Institution / Organisation:	**University of Witwatersrand**
Faculty:	**Humanities**
Department:	**Psychology**
Telephone:	**(011) 717 4526**
Fax:	
Cell:	
E-mail:	**Dinah.Alexander@wits.ac.za**
Signature:	
Date:	

N.B. This form (and all other relevant documentation where available) may be completed and forwarded electronically to Ebrahim Farista (ebrahimf@gpg.gov.za) or Nomvula Ubisi (nomvulau@gpg.gov.za). The last 2 pages of this document must however contain the original signatures of both the researcher and his/her supervisor or promoter. These pages may therefore be faxed or hand delivered. Please mark fax - For Attention: Ebrahim Farista at 011 355 0512 (fax) or hand deliver (in closed envelope) to Ebrahim Farista (Room 911) or Nomvula Ubisi (Room 910), 111 Commissioner Street, Johannesburg.

Appendix H: GDE Permission

UMnyango WezeMfundo
Department of Education

Lefapha la Thuto
Departement van Onderwys

Enquiries: Nomvula Ubisi (011)3550488

Date:	**03 May 2011**
Name of Researcher:	**Dawson Nicola Kathleen**
Address of Researcher:	**15 King Gardens, Pentrich Road**
	Victory Park
	Randburg 2195
Telephone Number:	**0117824914/0722243988**
Fax Number:	**N/A**
Research Topic:	**An Ecological Perspective on Parents' Experiences of Having a Child with Autistic Spectrum Disorder in the South African Context**
Number and type of schools:	**1 LSEN School**
District/s/HO	**Johannesburg East**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

Permission has been granted to proceed with the above study subject to the conditions listed below being met, and may be withdrawn should any of these conditions be flouted:

1. ***The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.***
2. ***The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.***
3. ***A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.***

Office of the Chief Director: Information and Knowledge Management
Room 501, 111 Commissioner Street, Johannesburg, 2000 P.O.Box 7710, Johannesburg, 2000
Tel: (011) 355-0809 Fax: (011) 355-0734

4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher must supply the Director: Knowledge Management & Research with one Hard Cover bound and one Ring bound copy of the final, approved research report. The researcher would also provide the said manager with an electronic copy of the research abstract/summary and/or annotation.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

Nomvula Ubisi
DEPUTY CHIEF EDUCATION SPECIALIST: RESEARCH

The contents of this letter has been read and understood by the researcher.	
Signature of Researcher:	
Date:	24/11/2011

16. STATEMENT OF PRINCIPLES FOR POSTGRADUATE SUPERVISION

IN A CONTEXT OF ACADEMIC FREEDOM AND WITHIN A FRAMEWORK OF INDIVIDUAL AUTONOMY AND THE PURSUIT OF KNOWLEDGE THIS AGREEMENT IS WRITTEN IN THE BELIEF THAT THERE IS A RECIPROCAL RELATIONSHIP AND MUTUAL ACCOUNTABILITY BETWEEN SUPERVISOR AND STUDENT.

THE SUPERVISOR AND THE STUDENT:

1. Will establish agreed roles and clear processes to be maintained by both parties. In the case of joint supervision everyone's role needs to be clarified.
2. Will meet regularly and as frequently as is reasonable to ensure steady progress towards the completion of the proposal, research report, or dissertation or thesis. This time varies but the normal minimum requirement for face-to- face contact, spread across each year of registration is: 10 contact hours for an Honours project, 15 contact hours for a Masters by research report and 24 contact hours for a Masters by dissertation and a PhD.
3. Will keep appointments, be punctual and respond timeously to messages.
4. Will keep one another informed of any planned vacations or absences as well as changes in his or her personal circumstances that might impact on the work schedule. Unplanned absences or delays should be discussed as soon as possible and arrangements should be made to catch up lost time.
5. Will ensure that research on animal or human subjects is conducted according to the procedures and the requirements of the relevant University Ethics committee.
6. Will together complete progress reports on the research project, as requested by each Faculty Graduate Studies Committee.

THE SUPERVISOR:

1. Undertakes to provide guidance for the student's research project in relation to the design and scope of the project, the relevant literature and information sources, research methods and techniques and methods of data analysis.
2. Has a responsibility to be accessible to the student.
3. Will be prepared for meetings with the student. This includes being up-to-date on the latest work in his/her area of expertise.
4. Will expect written work as jointly agreed, and will return that work with constructive criticism within a timeframe (a suggestion of 2-4 weeks) jointly agreed at the outset of the research.
5. Will provide advice that can help the student to improve his/her writing. This may include referrals for language training and academic writing. The supervisor will provide guidance on technical aspects of writing such as referencing as well as on discipline specific requirements. Detailed correction of drafts and instruction in aspects of language and style are not the responsibility of the supervisor.
6. Will support the student in the production of a research report, dissertation or thesis. Provision should be allowed for adequate, mutually respectful, discussion around recommendations made.
7. Will assist with the construction of a written time schedule which outlines the expected completion dates of successive stages of the work.
8. Will ensure the student has the opportunity to present work at postgraduate/staff seminars/national/international conferences as appropriate.
9. Will assist with the publication of research articles as appropriate.
10. Will discuss the ownership of research conducted by the student in accordance with the University guidelines and rules on intellectual property, co-authorship and copyright.
11. Will ensure that the research is conducted in accordance with the University's policy on plagiarism.
12. Will ensure that the student is made aware in writing of the inadequacy of progress and/or of any work where the standard is below par. Acceptability will be according to criteria previously supplied to the student.
13. Has a duty to refuse to allow the submission of sub-standard work for examination, regardless of the circumstances. If the student chooses to submit without the consent of the supervisor, then this should be clearly recorded and the appropriate procedures followed.

THE STUDENT:

1. Undertakes to work independently under the guidance of the supervisor. This includes reading widely to ensure that the literature pertinent to his/her chosen topic has been identified and consulted.
2. Is obliged to make appointments to see the supervisor and will arrange meeting times well in advance.
3. Will think carefully about how to derive maximum benefit from these contact sessions by planning what he/she wants in these sessions.
4. Should submit written work for discussion with the supervisor well in advance of a scheduled meeting. The kind and frequency of written work should be agreed with the supervisor at the outset of the research.
5. Undertakes to submit written work that is relatively free of basic spelling mistakes, incorrect punctuation and grammatical errors. Responsibility for the accuracy of language, the overall structure and coherence of the final research report, dissertation or thesis rests with the student.
6. Undertakes to heed the advice given by the supervisor and to engage in discussion around suggestions made. Ultimately the student has to take responsibility for the quality and presentation of the work.
7. Should strive, within reasonable bounds, to maintain a focus on his/her research area and to work within the agreed time schedule.
8. Will prepare material for presentations at seminars and conferences.
9. Undertakes to submit papers for publication.
10. Agrees to honour agreements about ownership of the research and in accordance with the University's guidelines and rules in relation to co-authorship, copyright and intellectual property.
11. Will ensure that the work contains no instances of plagiarism and that all citations are properly referenced and that the list of references is accurate, complete and consistent.
12. Agrees to work in accordance with the criteria of acceptability as supplied by the supervisor.
13. Undertakes not to place the supervisor under undue pressure to submit work for examination until the supervisor is satisfied that it has reached an acceptable level of quality.

I confirm that I have read and understood this statement and agree to be guided by its principles

Name of student : Nicola Kathleen Dawson

Student's signature : [signature]

Name of Supervisor : Daleen Alexander

Supervisor's signature : _____

Name of Co-Supervisor : _____

Co-Supervisor's signature : _____

The broad area of study is: Ecological perspective of parents' experiences of having a child with ASD

Provisional submission date is: _____

Degree : MA Community Counselling

School : Human and Community Development

Faculty : Humanities

Date : _____

Specific agreements pertaining to: ownership and joint publication, funding, etc. may be attached and signed.

GRIEVANCE PROCEDURES. It should be acknowledged that during the course of the research, both students and supervisors can feel aggrieved. In this event, matters should be dealt with as swiftly as possible by the parties involved and, if necessary, the appropriate Postgraduate Coordinators and Committees. There is, in addition, a University Grievance Policy to help guide deliberations. It is available on www.wits.ac.za/prospective/postgraduate.

SUPERVISOR – SUPERVISEE AGREEMENT

Supervisor: Daleen Alexander

Supervisee: Nicola Kathleen Dawson

1. The supervisor and supervisee will meet for supervision at least:

2x times a month.

If any of these meetings are cancelled the reason will be documented.

2. The supervisor will undertake to read and comment on any drafts within 3 weeks of receipt. If workload or absence makes this impossible, this will be clearly conveyed to the supervisee and a realistic time frame negotiated.

3. The supervisee will undertake to keep the supervisor regularly informed of her/his progress, and of any absences from university.

Signed on date 18/04/2011

Supervisor: [signature] Supervisee: [signature]

PUBLICATION AGREEMENT

The University's Policy on Intellectual Property (S2002/2150A) specifies that research carried out under supervision of an employee of the university belongs to the university. However, copyright of the thesis or report belongs to the student for 24 months after submission. Thereafter copyright reverts to the University. Thus, it is advisable for students to work on publishing their research as soon as possible. It is also important for student and supervisor to negotiate on how this work will take place, and the order of authorship.

The paper to be submitted for publication will be worked on by:

Nicola Kathleen Dawson and Daleen Alexander

The authors of the paper will be (in specified order):

1. Nicola Kathleen Dawson
2. Daleen Alexander
3.
4.

Signed on date 18/04/2011

Supervisor: [signature] Supervisee: [signature]

Supervisor Report

Supervisor's Name: Daleen Alexander
Student's Name: Nicola Dawson
Course: Masters in Community-based Counselling Psychology
Course Coordinator: Malose Langa
Title of Research: Ecological perspective of parents' experiences of having a child with Autistic Spectrum Disorder in the South African Context.

	Appropriately Reflected	Not Applicable
A. Participant Information Sheet		
➢ Appropriate Greeting	✓	
➢ Uses accessible language	✓	
➢ Researcher introduced	✓	
➢ Nature of research explained and motivated.	✓	
➢ Invitation to participate	✓	
➢ Guarantee of confidentiality	✓	
➢ Guarantee of anonymity		✓
➢ Mechanisms for confidentiality/anonymity explained	✓	
➢ Clear explanation of risks (even if none)	✓	
➢ Clear explanation of benefits (even if none)	✓	
➢ Clear explanation of what participation will involve	✓	
➢ Right to withdraw explained (for interviews)	✓	
➢ Explanation of how results will be disseminated	✓	
➢ Explanation of where participants can access results	✓	
➢ If recording: ➢ Request permission ➢ Explanation of how tapes will be kept ➢ Explanation that tapes will be destroyed	✓	
➢ If research is sensitive: ➢ Arrangement for accessible counseling ➢ Statement of contact details for counseling in letter ➢ Statement that it will be free	✓	
➢ Contact details of researcher stated	✓	
B. Consent forms		
Interviews		
➢ Guarantee of confidentiality	✓	
➢ Explanation of risks and benefits (even if none)	✓	
➢ Right to withdraw	✓	
➢ Right to not answer any questions	✓	
➢ Use of direct quotes	✓	
➢ Signature of participant	✓	
Guardian Consent (14 years or younger)		
➢ Guarantee of confidentiality		
➢ Explanation of risks and benefits (even if none)		
➢ Right to withdraw		
➢ Right to not answer any questions		
➢ Use of direct quotes		

➢ Signature of guardian		
Assent form (14 years or younger)		
➢ Guarantee of confidentiality		
➢ Explanation of risks and benefits (even if none)		
➢ Right to withdraw		
➢ Right to not answer any questions		
➢ Use of direct quotes		
➢ Signature of participant		
Recording Consent		
➢ identity will be protected	✓	
➢ Access to tapes restricted	✓	
➢ Safe keeping of tapes	✓	
➢ Tapes will be destroyed	✓	
➢ Signature of participant	✓	

Recommendation		
Population group is not vulnerable	Yes	No
Research is minimal risk and non-invasive	~~Yes~~	No
The researchers personal safety is not compromised	~~Yes~~	No
The research is appropriate for the students level of expertise	~~Yes~~	No
Comments (Must be completed):		
Proposal has been edited and all recommended corrections were adhered to. [illegible]		

Appendix K: Ethics Form

University of the Witwatersrand, Johannesburg

Application to the Human Research Ethics Committee (HREC Non-Medical)

Use this form in applying for clearance of research involving human participants ('human subjects'[1]).

Instructions

1. Completed applications must be submitted to the Research Office by the last day of the month for consideration at the meeting during the following month.
2. Incomplete applications will NOT be considered.
3. Applications will NOT be processed without signatures from supervisors (where relevant) and the Head of School/Unit.
4. Photocopying should be done 'back to back' to save paper.
5. All submissions and materials must be typed. Handwritten submissions are NOT acceptable. Glossy and fancy binding NOT necessary.
6. All appendixes, if any, must stapled to the ethics form and collated

The following documents must be included with your application as numbered appendices:

☑ **Check list**

For all research:

		No. of copies required
	Completed Ethics Application Form	10
	Copies of the research proposal	4
	Copies of proposed questionnaires/interview schedules	4
	Participant Information sheet	4

Where applicable (Attach to this form):

	Acknowledgement of Informed Consent form (for participant's signature)	4
	Relevant permissions (from, e.g. company's HR department, National authorities such as Education, Correctional Services, etc.) or other legally required consent	4
	Any other required/appropriate release or consent forms (e.g.: Focus group participant consent form, consent to record (audio), model release (for video or photography), etc.	4
	Guardian consent form (for participants under the age of 14)	4
	Minor assent form	4
	Other (Please specify)	4

Declaration:

I recognise that it is my responsibility to conduct my research in an ethical manner according to Guidelines of the University of the Witwatersrand, according to any laws and/or legal frameworks that may apply, and according to the norms and expectations of my discipline.

In preparing this Application for Ethics Clearance from the University of the Witwatersrand, I have consulted the **Guidelines for Human Research Ethics Clearance Application /non-medical** (a separate document available on this web site http://web.wits.ac.za/Academic/Research/Applications.htm and have familiarised myself with the ethical guidelines specific to my discipline.

Signature

Name of Researcher/Applicant Nicola Kathleen Dawson

[1] In place of the term 'human subjects', University of Witwatersrand prefers to use the term '(research) participants' in order to reflect the difference between the bio-medical sciences—where 'research subjects' is more appropriate—and the humanities and social sciences.

Researcher's personal data

Surname	Dawson			Name:	Nicola Kathleen			
Title (circle one):		Prof		Dr		Mr	x	Ms		Other:
Department/discipline	Community Counselling, Department of Psychology							
School	School of Human and Community Development							
University address	1 Jan Smuts Avenue, Johannesburg, 2004							
Staff / Student number	0606689X	x	Full time		Part time		Staff	
Your telephone(s)	072 224 3988; 011 782 4914							
Your Email:	Nicki.Dawson@gmail.com							
Name of Supervisor	Daleen Alexander							
Supervisor's email address	Dinah.Alexander@wits.ac.za							
Supervisor's tel. number(s)	011 717 4526							

TITLE OF RESEARCH PROJECT

An Ecological Perspective on Parents' Experiences of Having a Child With ASD in the South African Context.

Is this research for degree purposes?					X	Yes		No	
If so, for what degree?		Honours	X	MA		PhD		Other (specify):	
Has it been approved by the relevant higher degrees committee or other relevant unit?		Yes	x	No		Submitted & pending			

Where will the research be carried out?

Interviews will be carried out at Autism South Africa, in the same building as the school. The school is located in Johannesburg.

What are the aims & objectives of the research relevant to human research participants (Please list; be brief)

1. To understand parents' experiences of having a child with ASD in the South African context.
2. To understand the impact of current interventions and services on their experiences.
3. To understand the impact of other ecological factors on their experiences.

List the names and affiliations of any *additional* researchers who will be covered by this ethics protocol

N/A

Has appropriate formal permission been obtained, if required (e.g. employer, government department, land owner, etc.)?

	Yes (attached)		Not required	x	Pending (must be supplied before permission is granted)

Do you have any financial or material interest associated with your research participants or with the organisations that you will work with during your research?

	Yes, current	X	No		Potential conflicts of interest may exist

If yes, please explain how you will manage any existing or potential conflicts of interest.

N/A

Protocols submitted to the Committee must have sufficient information to enable the committee to judge the ethical implication of the proposed research. Please be brief and concise but also as specific and informative as possible.

How will data on human research participants be collected (techniques, methods, procedures)? Be brief but specific	
x	Formal interviews using questionnaires, schedule/list of questions, or formal protocol (**Attach all questionnaires, schedules, etc.**)
x	Informal interviews, semi-structured or open ended interviews (**Attach interview protocol, or guidelines**)
	Ethnographic observation, participant observation, other informal descriptive and / or interactive methods
	'Focus group', seminar/discussion group, or other group-orientated research
	Community-based, participant, or 'action research' methods or technique such as drama workshops, community theatre, training workshops, participant rural appraisal (PRA), rapid rural appraisal (RRA), etc.
	Research on/in therapeutic or counselling contexts
	Observation of public performance, and/or public behaviour observation
	Photography, video and/or audio recording (**specific separate consent forms may be required**)
	Mapping or other techniques that involve direct interaction with participants (otherwise exempt)
	Other research methods or techniques—explain below.
Details: See Appendix A for the informal interview struture. See Appendix B for the demographic questionaire	

How will informed consent be obtained?	x	Formal (Signed form)		Informal or Verbal		Other (e.g. public speech)
Explain your strategy for ensuring informed consent						
Participants will be provided with a participant information sheet, informing them of the nature of the study. Participants will then be asked to sign a consent form noting that they understand the nature of the study, as well as to consent to the recording of the interview. Only participants with a reasonable degree of English fluency will be placed into the pool from which to randomly pull participants, and will, therefore, will all be informed in English.						
Attach participant's information sheets, informed consent forms, and/or other related materials						

NB: ***informed consent*** in the social science and humanities research involving human participants
Where informal ethnographic or participant observation methods are used, or where signed Informed Consent forms are not possible, or for research involving group contexts (focus group, Participant Rapid Assessment, Rapid Rural Appraisal, public performance, workshops) **state how the quality of informed consent will be assured**. It is essential that direct participants in research be fully informed and agree on this basis to participate in research.

Who will the research participants be? Parents of children diagnosed with ASD, attending a public school for children with ASD.					
Age range?	21 and older				
Does this research expose either the participant or the researcher to any potential risks or harm that they would not otherwise be exposed to?			Yes	x	No
Will research involve vulnerable categories?		x	Yes		No
If so, state which ones:	The participants are parents of children with a pervasive developmental disorder (ASD), which is known to cause stress and be emotionally taxing.				
How will participants be selected and approached?	Participants will be contacted through letters distributed by the school, inviting them to participate in the study. If they are interested in participating, parents can contact the researcher directly, via email or telephone, or leave their contact details for the researcher in a sealed box at the school. Potential participants will then be contacted by the researcher and invited to participate.				
How will any existing vulnerabilities among research participants be addressed?	During the interview, the researcher will continuously try and assess the participant's level of comfort. If the particpant becomes overwhelmed during the interview, the researcher will stop the interview and attempt to contain the situation. Adequate referral will then be ensured. The participant will be referred to the Emtonjeni Community Clinic or JPCCC for free counselling services.				

NB: The term 'Vulnerable categories' includes, among others, children under 14, orphans, prisoners, persons with cognitive or communication disorders, people who are traumatised or currently in traumatic situations.

Can **confidentiality** be guaranteed?	x	Yes		No
Can **anonymity** be guaranteed in resulting reports, theses and/or publications?		Yes	x	No

Explain how this will be done? What will participants be told in this regard?

Confidentiality is guarenteed due to various safeguards put in place. These include that three years after examination of the research, all audio-recordings will be destroyed. Until such time, recording will be kept digitally, in a locked office. Participants will be asked to consent to the use of verbatim quotes from their interviews and the publishing of transcripts. Participants will retain the right to not answer any questions they are not comfortable with answering, and will be fully informed of this right.
First party anonymity cannot be guarenteed as the participants will be interviewed, face-to-face, by the researcher. However, third party anonymity will be guarenteed through the use of pseudo names and the removing of any identifying information.

NB: While confidentiality may be desirable, it cannot be guaranteed in, for example, focus groups, or ethnographic observation. Similarly anonymity should be preserved in questionnaires, but cannot be offered in workshop methodologies, focus group research, etc. All data however should be kept confidential and safe from unauthorised access once it has been collected. Informants should have the right to remain anonymous in the final report, and this must be respected in handling of all data relating to them.

What is to be **done with the research data** after completion of the project?

Audio-recordings of the interviews will be kept until three years after examination. After three years, all audio-recordings will be destroyed. Transcripts will be published in the final research reports, but pseudo names will be used and all other identifying information will be removed.

NB: 'Raw' or unprocessed data, especially **where the identity or personal data of research participants is included, must be safeguarded** and preserved from unauthorised access. Data may be destroyed after use, but **preservation in an archive or personal collection** may also be appropriate, desirable or even essential. For instance, data sets that contain **historically important information** or information that relates to **national heritage** must be preserved and should be placed in a public archive where possible and appropriate.
All data should be preserved in a way that **respects the nature of the original participants' consent**.

10. How will the results be **reported**, and who will have access to this/these?

Results will be written up in a research report, for degree pusposes. Therefore, various Wits University Students will have access to the results. The results may also be published in a relevant academic journal, and therefore, be available to the general public. Interested participants will be given a one page summary of the results on request. Also, the relevant school will be provided with an extensive summary of the results.

SIGNATURES (REQUIRED)

In signing this form, the researcher and supervisor (if any) of this project undertake to ensure that any amendments to this project that are required by the Human Research Ethics Committee are made before the project commences.

Declaration: We, the signatories, declare that all information on this form is correct and that we will strive to maintain the highest ethical standards in this research, according to disciplinary and university expectations at all time, recognising that ethical practice in research is always a continuing process.

	Date	Name	Signature
Applicant		Nicola Dawson	
Research **Supervisor**'s name & signature (for students)		Daleen Alexander	
Dept/**Unit Head**'s name & signature			

Appendix L: Ethics Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MACC/11/001 IH**
PROJECT TITLE:	An ecological perspective on parents' experiences of having a child with Autistic Spectrum Disorder (ASD) in the South African context.
INVESTIGATORS	Dawson Nicola
DEPARTMENT	Psychology
DATE CONSIDERED	23/03/11
DECISION OF COMMITTEE*	Approved

This ethical clearance is valid for 2 years and may be renewed upon application

DATE: 19 May 2011

CHAIRPERSON _____
(Professor M. Lucas)

cc Supervisor: Dr Daleen Alexander
Psychology

DECLARATION OF INVESTIGATOR (S)

To be completed in duplicate and **one copy** returned to the Secretary, Room 100015, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure, as approved, I/we undertake to submit a revised protocol to the Committee.

This ethical clearance will expire on 31 December 2013

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES