

**PRIMARY CAREGIVERS' EXPERIENCES OF RAISING CHILDREN WITH  
AUTISM: A PHENOMENOLOGICAL PERSPECTIVE**

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## ABSTRACT

Autism occupies an extreme position among childhood pathologies due to its severity, duration and impact on the family. In this qualitative study, four primary caregivers of autistic children were interviewed regarding their experiences of the diagnostic process, their post-diagnostic adjustment, and how helping professionals can improve their service rendering to these families. This study utilised a phenomenological approach to look at primary caregivers as the best-informed authority to explore and describe their lived realities and experiences of raising their autistic children in South Africa. The rationale for a phenomenological approach in this study is that such an interpretative inquiry enables material to be collected and analysed within the specific context of the subjective realities of primary caregivers of autistic children in South Africa. The researcher utilised semi-structured, in-depth, face-to-face interviews as method of data collection. Each participant was interviewed over the course of three separate interviews. The themes and categories that resulted from a content analysis of the material were grouped into two broad fields of experience, namely: (1) experiences surrounding the diagnostic process; and (2) the pervasive influence of autism on different areas of family life. In terms of experiences surrounding children's diagnosis, four themes were identified: (1) Being a new parent and making sense out of chaos; (2) Responsibility and blame; (3) Confusion and disillusionment during early experiences with helping professionals; and (4) Feelings about the diagnosis. The pervasive influence of autism on different areas of family life includes: (5) Strained family relationships; (6) Challenges of behaviour management and disciplining the autistic child; (7) Challenges of finding suitable resources for education and day-care; and (8) Maintaining the family unit and doing things as a family.

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## **CHAPTER 1**

### **INTRODUCTION**

Autism is a childhood developmental disorder that is characterised by a combination of qualitative impairments in social interaction, communication, and restricted, repetitive and stereotyped patterns of behaviour, interests and activities. Whilst the majority of children with autism struggle with learning difficulties and behaviour problems, films such as “Rainman” have unfortunately contributed to the common lay perception of autistic children as idiot savants with extraordinary talents in calculation, music or drawing. In reality, autism occupies an extreme position among childhood pathologies in terms of its severity, chronicity, and impact on the family. In this study, the researcher will argue that primary caregivers of autistic children are one of the most stressed parental groups, who are in dire need of effective and efficient professional services to be better able to meet the needs of the family and help them cope with taking care of their autistic children at home and within the community.

The overall goal of this study is to explore and describe how the primary caregivers of children with autism experience the diagnostic process, how they adjust in different areas of family life after the diagnosis has been made, and how helping professionals can improve their service rendering to these families. A phenomenological approach will be used to look at primary caregivers as the best informed authority to explore and describe their lived realities and experiences of the diagnostic process, post-diagnostic coping and adjustment, as well as their primary needs and concerns in relation to the future of their autistic children in South Africa. It is envisaged that data of this nature will lead to information that, in turn, may be used to inform helping professionals to develop effective and efficient intervention models that are sensitive to the unique needs of the identified target population.

The researcher will provide a theoretical underpinning in terms of previous research that sets the context for the present research. The historical view of autism will be traced as professional sentiments changed from caregiver responsibility to caregiver support. Specific challenges and concerns of primary caregivers of autistic children will be discussed, followed by a reflection on grief over the loss of a normal child and specific vulnerabilities and needs of these caregivers. The chapter concludes with a review of typical coping strategies and support networks utilised by primary caregivers of autistic children.

Chapter 3 comprises an explication of the research methodology that was followed in the present study. This includes an overview of the research question and design, participant selection criteria, data collection methods, data processing (analysis and interpretation) and ethical considerations that were adhered to.

Chapter 4 comprises a detailed discussion of the results of the data analysis and interpretation process. The themes and categories that resulted from the data processing will be explored under two broad fields of experience, namely: (1) experiences surrounding the diagnostic process; and (2) the pervasive influence of autism on different areas of family life. In terms of experiences surrounding the diagnostic process, reference will be made to the initial sense of chaos and confusion associated with the birth of an autistic child, the attribution of responsibility and blame for initiating the diagnostic process, primary caregivers' early experiences with helping professionals, and feelings associated with the autism diagnosis. The pervasive influence of autism on different areas of family life will be illustrated by a discussion of the influence of an autistic child on marital relationships, parent-child relationships and sibling relationships. Reference will also be made to the challenges that primary caregivers of autistic children experience with behaviour management and discipline, as well as the search for suitable resources for education and day-care for their children. Finally, the researcher will argue that the presence of an autistic child poses unique challenges to primary caregivers to maintain the family unit and to do things as a family.

The final chapter summarises the major conclusions that can be drawn from the research findings. Recommendations are provided for improved service rendering to families of autistic children, and suggestions are made for further research in the field of autism.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This study aims to explore and describe how the primary caregivers of children with autism experience the diagnostic process, how they adjust in different areas of family life after the diagnosis has been made, and how helping professionals can improve their service rendering to these families.

#### **Definition of Terms**

##### **Primary Caregivers**

For the purposes of this study, the term “primary caregivers” will be used to refer to the mothers/fathers/grandparents/guardians of children with autism who serve as parental figures for these children and are responsible for the day-to-day care and maintenance of these children.

##### **Autism**

Autism will be defined as a developmental disability characterised by a total of six or more items from the following three developmental areas:

1. Qualitative impairment in social interaction, which is characterised by impaired use of multiple nonverbal behaviours to regulate social interaction; failure to develop age appropriate peer relations; disinterest in sharing enjoyment, interests or achievements with others; or lack of social or emotional reciprocity;
2. Qualitative impairments in communication, which is characterised by a delay in or lack of spoken language development; impairment in the ability to initiate or sustain a conversation; stereotyped and repetitive or idiosyncratic language use; or lack of varied, spontaneous make-believe play or socially imitative play; and
3. Restricted repetitive and stereotyped patterns of behaviour, interests and activities, characterised by extreme preoccupation with one or more stereotyped, restricted patterns of interest that is abnormal in intensity and focus; inflexible adherence to specific, non-functional routines or rituals; stereotyped, repetitive motor mannerisms; or persistent preoccupation with parts of objects (American Psychiatric Association, 1994).

## **Historical View of Autism**

Kanner published the first accepted clinical paper that presented a clear picture of the psychological features of autistic children in 1943 (Trevarthen, Aitken, Papoudi, & Robarts, 1998). This significant step challenged the medical profession with the task of understanding how the cognitive and communicative abilities of a child develop so that s/he becomes able to establish emotional contact with other persons.

### **From Caregiver Responsibility to Caregiver Support**

Historically, the primary caregivers of autistic children, especially mothers, were held responsible for the abnormal social and emotional functioning of their children, including poor attachment and lack of reciprocity in social interactions (Burkhardt, 2001). Treatment approaches based on this premise, such as those developed by Bettelheim, were largely ineffective and merely exacerbated primary caregivers' guilt by accusing them of having caused their child's condition (Burkhardt, 2001). Over the course of 60 years, radical interventions were employed; such as the removal of autistic children from their primary caregivers' perceived pathogenic care (Burkhardt, 2001). Behavioural programmes for autistic children, such as those developed by Lovaas, were also extremely taxing on caregivers, since parental homes were often turned into treatment centres for up to 40 hours per week.

Autistic symptoms however continued to display enduring resilience in spite of the implementation of these radical treatments. This finding initiated a gradual shift towards a more supportive understanding of the challenges faced by primary caregivers of autistic children. Only as recently as 2001 did the American Academy of Psychiatric release a report that provides substantial reassurance that caregivers' practices are not the cause of autism and that care should be taken to support, rather than indict, primary caregivers regarding their children's difficulties. This significant paradigm shift has given rise to a myriad of research opportunities to explore primary caregivers' experiences, needs and concerns in relation to their autistic children, so that helping professionals can provide them with accurate information, appropriate diagnoses, effective treatment strategies, and social support whenever possible (Burkhardt, 2001).

### **Challenges and Concerns Experienced by Primary Caregivers of Autistic Children**

The challenges of raising autistic children have mostly been researched in Europe (predominantly England), North America, and Australia (Lainhart, 1999). *Inter alia*, it is maintained

that primary caregivers have to come to terms with having a child with an incapacitating, life-long developmental disability. In addition, they are faced with various concerns, such as the chronicity of care and disappointing prognosis, the effects on the family system, increased financial problems, lack of independence, the attitudes of the public towards them and their children *vis-à-vis* the misunderstood nature of the condition, and the very low levels of social support received by primary caregivers (Boyd, 2002; Gray, 2002; Konstantareas & Homatidis, 1992; Trigonaki, 2002).

Gray (2002) emphasises the importance of the child's developmental stage in determining the specific challenges that face the caregivers of autistic children. During the pre-diagnostic phase, caregivers are often confused, anxious and highly stressed as their children's problems grow more pronounced and they struggle to obtain an accurate diagnosis and treatment for their children. Their distress is often exacerbated by the clinical difficulty and caution amongst professionals to diagnose a young child with autism, as well as failure of these professionals to address caregivers' conflicting feelings of concern, fear, helplessness and guilt that they have somehow caused their children's disabilities (Billington, McNally, & McNally, 2000).

Anecdotes from primary caregivers of autistic children abound with references to professionals who dismissed parental concerns about a toddler's failure to talk and relate socially as excessive anxiety on the part of the primary caregivers (Billington et al., 2000; Boushey, 2001; Davis, 2001; Roth, 2001; Stroud, 2002). Primary caregivers hence believe that their concerns are often dismissed as products of worry (Burkhardt, 2001) rather than astute observation.

Once a diagnosis has been made, the family with an autistic child faces yet another challenge, namely to learn to adjust to and cope with the needs and multiple demands of such a child. According to Gray (2002), caregivers' concerns and anxiety lessen somewhat once the child has been placed in appropriate treatment and educational programmes. This stage of the child's life however remains stressful, since caregivers have to negotiate and interact with a large number of professionals to obtain appropriate educational and financial resources to meet the child's needs. Although problems with schools, treatment providers and other siblings still occur, most families are able to achieve a relative state of homeostasis over the next few years. Family life typically becomes more settled as improvements in the child's sociability, emotional control and attention span culminate in more orderly behaviour. This period of adjustment is however temporary, since the onset of adolescence usually marks an escalation in the severity of autistic symptoms. Adulthood for a person with autism also burdens elderly caregivers with concerns such as supervised living and working arrangements for their adult child (Gray, 2002).

### **Grieving the Loss of a Normal Child**

Boushey (2001) compares caregivers' experiences of adjustment at each of their autistic child's life stages to a grief cycle, since a sense of loss and the eventual acceptance thereof are fundamental components of the psychological life and emotional coping of a person who cares for a child with autism.

Initially, shock may result from the news of the autism diagnosis. Caregivers may become numb and dissociated from the entire process, and it is not uncommon for them to later have very little recollection of how they managed to continue to function through the initial diagnostic stage (Boushey, 2001). Caregivers may further enter into denial about the accuracy of the diagnosis, or experience debilitating guilt and shame that they may have done something wrong during the pregnancy and developmental years of the child's life, that had somehow caused the child's autism (Boushey, 2001; Gray, 2002). Sometimes, the very nature of autism is projected onto the primary caregivers who, in a similar manner to their autistic child, feel themselves isolated from the rest of the world and unable to interact socially with other caregivers with similar concerns (Boushey, 2001). A combination of the aforementioned guilt, shame and isolation may result in debilitating depression if no intervention is sought. Panic often results from a lack of knowledge about their child's condition. Caregivers struggle with the expression of anger at themselves, their spouses, or perhaps even at God. Anger typically gives way to bargaining, during which caregivers convince themselves consciously and/or unconsciously that the child will be "cured" if they follow certain dietary or behavioural programmes and devote themselves entirely to the task of caring for the child with autism (Boushey, 2001). The final stage of eventual acceptance and hope can only surface once primary caregivers relinquish unrealistic bargaining efforts and accept that their child's autistic state is a permanent condition. Eventually, these caregivers are able to maintain some hope in the realisation that the symptoms of autism can diminish with early and persistent intervention, and that they can direct their energy to the realistic goal of teaching the autistic child ways to function in the real world (Boushey, 2001).

### **Vulnerability of Primary Caregivers of Autistic Children**

In light of the above findings, it can be concluded that, among the childhood pathologies, autism occupies an extreme position in terms of its severity, duration and impact on the family. Not only do the primary caregivers of autistic children have to cope with the aforementioned concerns and challenges related to their children's care and well-being, but they also have to manage their own

psychological experiences in a manner that maintains optimal functioning for the sake of the larger family system.

According to Lainhart (1999), caregivers of autistic children have increased rates of developing psychiatric disorders such as major depression and social phobia. The author further concludes that this increased risk of psychiatric difficulties may be directly related to the stress and burden of living with and caring for an autistic child or adult. Boyd (2002) accordingly notes that primary caregivers of autistic children are one of the most stressed parental groups, who are in dire need of effective and efficient professional services to be better able to meet the needs of the family and help them cope with taking care of a child with autism at home and within the community. This is especially relevant in the South African mental health context, which is characterised by limited resources and an increased need for home-based care, as opposed to chronic institutionalisation.

### **Specific Needs of Primary Caregivers of Autistic Children**

Primary caregivers' need for effective and efficient professional services to be better able to meet the needs of the family and help them cope with taking care of a child with autism at home and within the community is widely recognised in literature on this topic (Autism South Africa, 2000; Boushey, 2001; Boyd, 2002).

The provision of practical information on autism and related topics forms the foundation of the majority of intervention programmes aimed at the primary caregivers of autistic children. Information is usually provided regarding the nature and typical features of autistic spectrum disorders, and caregivers are provided with practical guidelines on how to assist their autistic child across a spectrum of problematic behaviours, such as impaired social interaction and communication skills and restricted repetitive and stereotyped patterns of behaviour, interests and activities. Information regarding educational and training programmes for autistic children is also provided, which enables caretakers to initiate practical assistance for their children (Autism South Africa, 2000).

With reference to the needs of primary caregivers of autistic children, Trigonaki (2002) conducted a study that specifically explored the needs of caregivers of autistic children along five basic human needs, as defined by Choice Theory, namely: (1) love/belonging; (2) fun/enjoyment; (3) self-worth/empowerment; (4) freedom; and (5) survival/health. Choice Theory holds that all humans try to fulfil these needs by constructing their unique "quality worlds", which contains people they like or love, their beliefs, and specific wants. When there is a perceived difference between what people want and what they are getting, they try to minimise or eliminate the frustration in order to get closer to

meeting their needs and getting what they want (Trigonaki, 2002). Trigonaki (2002) explored with the caregivers of autistic children their five basic needs and their “quality worlds”, and asked them to evaluate their current situations in order to identify whether what they are getting from the outside world matches what they want in order to fulfil their needs. *Inter alia*, the findings of this study indicated:

1. When caregivers of autistic children first find out about the diagnosis, their “quality worlds” collapse to such an extent that their needs become fused with their children’s needs. This implies that, when their children’s needs are met and fulfilled, theirs are too.
2. The hierarchy of needs in caregivers of autistic children vary from that of caregivers of normal children. Caregivers of autistic children place more value on the need for love and belonging, whereas caregivers of normal children place more importance on their need to have fun and enjoyment in life.
3. During the first years after their child has been diagnosed with autism, caregivers tend to rely on each other within the immediate family environment for support and fulfilment of their needs. However, as time progresses and caregivers learn to accept autism and what comes with it, they begin to explore other ways for helping themselves and their children. As these caregivers’ coping strategies develop, they learn how to enjoy life with a child with autism, and they start to turn to broader social support networks for support and encouragement.

### **Coping Strategies and Support Networks Utilised by Primary Caregivers of Autistic Children**

Prior reference has been made to the grief cycle that results as the primary caregivers of children with autism grieve the loss of a “normal” child. The final stage of hope and acceptance gradually results as these caregivers learn how to adjust to and cope with the multiple demands of an autistic family member. These coping strategies develop and are adjusted throughout the family’s life span, and change as the challenges and needs of the autistic child change.

According to Gray (2003), the experience of coping with a stressful disability such as autism has largely been ignored in the literature. He further reasons that this disability may have very different meanings for mothers and fathers, and necessitate different strategies as they seek to cope with its effects on their families. In order to address this shortcoming in the literature, Gray (2003) conducted a qualitative analysis of the role of gender and coping among parents of children with autism. In terms of practical or problem-solving coping strategies, Gray (2003) noted that there was a significant degree of similarity between both male and female caregivers of autistic children, in that they both used

anticipation and planning as well as dealing with problems as they happened as their most popular practical coping strategies. However, they differed in that the remaining practical coping strategies varied by gender and reflected traditional gender roles. For example, men were more likely to use their work as a coping strategy and to keep their children busy around the house, whereas women were more likely to work with their children to improve their behaviour and to maintain domestic order by keeping their children separated.

In terms of emotional coping, Gray (2003) found that mothers and fathers both reported the control and expression of emotion as the main means by which they coped with the emotional distress brought about by their child's autism. Significant gender differences were also noted in terms of emotional coping. For example, the suppression of feelings by the fathers of autistic children in Gray's study was consistent with previous results reported in the coping literature. When the fathers did express their feelings, they were more likely to report the gender appropriate expression of anger, rather than the sadness and crying that the mothers described in addition to their own feelings of anger and frustration. The mothers were also more likely to rely on their friends and other parents of autistic children to help them cope with emotional distress (Gray, 2003).

As far as general coping is concerned, Gray (2003) found that mothers cited considerably more coping strategies than fathers did, and they also relied heavily on support from other people, including family members and friends. Religious faith also surfaced as an important coping strategy for a number of mothers of autistic children. Fathers of autistic children, on the other hand, described fewer general coping strategies, and there was no specific general coping strategy that proved popular among the fathers. Fathers did, however, appear to take more of a philosophical stance toward their child's disability, which is consistent with a more emotionally reserved coping style for men (Gray, 2003).

In terms of social support networks utilised by the primary caregivers of autistic children, Boyd (2002) conducted a detailed study to examine the relationship between stress and the utilisation of social support networks in the caregivers of children with autism. The literature reviewed in this study revealed a positive association between challenging child characteristics and a caregiver's inclination to seek social support, with caregivers under greater stress being more prone to pursue social support. The best predictors of parent and family problems in the studies reviewed by Boyd (2002) were the autistic children's difficult management problems, their degree of dependency on caregivers, and their need for assistance with self-help skills. These characteristics led parents to seek out social support to relieve some of the stress associated with rearing an autistic child. The use of respite care services in families who have children with autism appeared to be particularly effective (Boyd, 2002). In this

regard, it is significant to note that, in light of the limited resources available within the mental health context in South Africa, the option of respite care is very rarely available to the primary caregivers of autistic children in this country. Boyd (2002) specifically warns against the hazardous effect that limited resources may have on caregivers of autistic children. Caregivers may become caught up in a vicious cycle where a lack of social support can lead caregivers to withdraw from the larger community because of the negative characteristics they associate with their child's disability, which in turn exacerbates their stress levels.

Another interesting finding in Boyd's review of coping literature is that informal support appeared to be a more effective stress-buffer than formal support for female caregivers of autistic children (Boyd, 2002). Specifically, informal support provided by the immediate and extended family, friends, neighbours, and other caregivers of children with disabilities proved to be extremely helpful. Both formally and informally led parent support groups proved highly effective in the reduction of caregiver stress and anxiety. The cumulative results of several studies reviewed by Boyd (2002) further illustrated that caregivers of autistic children who received support related better emotionally to their children and have more positive interactions with them. Furthermore, low levels of social support were the most powerful predictors of depression and anxiety in primary caretakers of autistic children.

In light of the overwhelming evidence in support of the utility of effective social support networks for caregivers of autistic children, Boyd (2002) emphasises the need for continued research that examines how the use of social support by caregivers translates into positive parenting behaviour, increased knowledge of the autistic child's condition, and improved family functioning. Through this knowledge, helping professionals will be better able to meet the needs of the family and help them cope with, accept, and adapt to caring for a child with autism.

### **Relevance of the Present Study**

In this study, the primary caregivers of children who have had a positive diagnosis of autism for at least one year were invited to share their life experiences. Rather than discounting their experiences, this study utilised a phenomenological approach to look at primary caregivers as the best informed authority to explore and describe their lived realities and experiences of the diagnostic process, post-diagnostic coping and adjustment, as well as their primary needs and concerns in relation to the future of their autistic children in South Africa. It is envisaged that data of this nature will lead to knowledge and insight regarding the meanings and interpretations attributed to these primary caregivers' worldviews. This knowledge and understanding may, in turn, be used to inform helping professionals

to develop effective and efficient intervention models and counselling programmes that are sensitive to the unique needs of the identified target population.

### **CHAPTER 3**

#### **RESEARCH METHODOLOGY**

##### **Research Question**

According to Locke, Spirduso and Silverman (1987), research questions are appropriate to qualitative, exploratory studies or incidents about which there is minimal knowledge, which renders it impossible for the researcher to formulate a hypothesis. For the purpose of this study, the following research question has been formulated: “How do the primary caregivers of autistic children experience the diagnostic process and the post-diagnostic adjustment of the family with an autistic child?”

The following secondary questions were asked to explicate the primary research question:

1. How do the primary caregivers of autistic children experience the multi-disciplinary diagnostic process, with specific reference to their affective, behavioural and cognitive responses?
2. What specific problem areas do primary caregivers encounter during the post-diagnostic adjustment phase in relation to the establishment of a daily routine, disciplining the autistic child and obtaining education and day-care?
3. How do primary caregivers experience family relationships as affected by the presence of an autistic child?
4. How can helping professionals improve service rendering to families of autistic children?

##### **Research Design**

This study is qualitative and phenomenological in orientation. According to Manning (1996), qualitative research is regarded as research that produces descriptive material based on spoken or written words and observable behaviour. The elements of experience, judgement, choice and interpretation in context-specific situations are characteristic of qualitative research (Neuman, 1994; Reid & Sherman, 1994).

The aim of a phenomenological approach is to uncover and describe the meaning of lived experience (Kruger, 1988; Lloyd, 1997; McLeod, 2001). The attitude of the phenomenological researcher towards the world of human experience should hence be one of openness to whatever emerges as significant for the adequate understanding of a phenomenon. Kruger (1988) emphasises that the most important concept in phenomenological research is to “describe”. The task of the researcher is

to describe, as accurately as possible, the phenomenon as it appears, rather than to attempt to explain it within a given framework (McLeod, 2001). Essentially, phenomenological praxis in psychology is hence concerned with the “rigorous description of phenomena contextualised in the *Lebenswelt*” (Kruger, 1988, p.149). The researcher’s primary mandate in phenomenological research is to listen to what the incidents/phenomena tell him/her and to remain faithful to the concrete dimensions of the phenomenon as it appears (Kruger, 1988).

In summary, the above information points toward the following criteria that phenomenologically inspired research should aim to fulfil (Kruger, 1988):

1. The research interview situation should involve a description of experience or meaning structure in that it should focus on the phenomenon in its lived-world context;
2. Explication of the protocols should be concerned with the meaning of the data from the participant’s perspective;
3. Essential themes should be extracted in their varying manifestations; and
4. The dialectic between approach, method and content should be maintained.

In light of the aforementioned criteria, the rationale for a phenomenological approach in this study is that such an interpretative inquiry enables material to be collected and analysed within the specific context of the subjective realities of primary caregivers of autistic children in South Africa. In light of the limited financial and human resources available to the public health sector in South Africa, it was further intended that an exploratory study would highlight salient aspects pertaining to primary caregivers’ experiences and that the knowledge gained in this manner could assist helping professionals to plan patient-tailored intervention strategies that maximise the utility of such limited resources.

### **Participants**

The researcher interviewed four research participants between the ages of 31 and 39 years. These participants are all female and they are the biological mothers and primary caregivers of children with autism. Participants came from varied socio-economic strata and races. Three participants are Caucasian, and one is from Xhosa descent. The biographical data of these participants are cited in Table 1.

The study used a purposive recruitment strategy, which is based on the assumption that, in order to gain insight into an experience, one has to select participants from whom one can gain the most relevant information (Grinnell, 1988). Due to the qualitative nature of the study, the participants were

not representative of all the primary caregivers of autistic children in South Africa, and the findings can hence not be generalised to a broader population.

According to Kruger (1988), participants who are suitable for participation in phenomenologically based research in psychology are those who:

1. have had experiences relating to the phenomenon being researched;
2. are verbally fluent and are able to communicate their feelings, thoughts and perceptions in relation to the phenomenon being researched;
3. have the same home-language as the researcher; and
4. express a willingness to be open to the researcher.

With due consideration of the aforementioned criteria, research participants in this study were selected according to the following inclusion criteria:

1. S/he is the primary caregiver of an autistic child between the ages of five and 13 years;
2. His/her child was formally assessed by a multidisciplinary team and was given a diagnosis of autism;
3. His/her child has been a learner at the Quest School for Learners with Autism in Port Elizabeth for at least one year following the diagnosis;
4. S/he is willing to give consent to being interviewed and to the interviews being audio-taped; and
5. S/he is able to confidently converse in either English and/or Afrikaans.

**Table 1**

**Biographical data of research participants**

Participant	Sex	Age (years)	Home Language	Highest level of education	Occupation	Marital status	Children	
							Autistic child	Siblings
A	Female	38	English	Tertiary	Home Executive (Teacher)	Married	Female (7)	Male (10) Male (3)
B	Female	38	English	Tertiary	Game Farm Manager	Married	Male (9)	Male (8) Male (5)
D	Female	31	Xhosa	Grade 12	Fire-fighter	Married	Male (6)	Female (1)
F	Female	39	Afrikaans	Tertiary	Occupational Therapist	Married	Male (9)	Male (7)

### **Data Collection Methods**

For the purpose of this study, the researcher utilised semi-structured, in-depth, face-to-face interviews as method of data collection. According to De Vos (1998), the face-to-face interview assists researchers to understand the closed worlds of individuals, families, organisations, institutions and communities. The purpose of the in-depth, face-to-face interview is hence to understand the interviewee's life experience or situation as expressed in his/her own words (De Vos, 1998). Kruger (1988) further contends that the spoken interview allows participants to be as near as possible to their lived experience, does not preclude the possibility of dialogue during this early phase of research and does not involve the inhibiting effect of the process of writing on spontaneity of expression. The above purpose and advantages of in-depth interviews as method of data collection directly compliment the envisaged aim of this study, which is to explore and describe primary caregivers' phenomenological experiences of raising their autistic children in South Africa.

Audio-recordings of the interviews were made with the informed consent of participants. Data collection was based on a variation of the three-interview series for in-depth, phenomenological interviewing, as described by Seidman (1991). According to Seidman (1991), this method of interviewing involves conducting a series of three separate interviews with each participant. The method is based on the premise that people's behaviour becomes meaningful and understandable when placed in the context of their lives and the lives of those around them. Seidman (1991) contends that, without context, there is little possibility of exploring the meaning of an experience. The three-interview series was hence developed to allow the interviewer and participant to explore an experience and to place it in context. The first interview establishes the context of the participants' experience in the form of a focused life history. During the second interview, the participants are given the opportunity to reconstruct the details of their experience within the context in which it occurs. During the third and final interview, the participants are encouraged to reflect on the meaning their experience holds for them (Seidman, 1991).

In this study, each participant was interviewed over the course of three separate interviews of approximately 60 minutes each. A semi-structured interview guide was drawn up for each interview (Appendix A), with a list of the important areas of inquiry and any standard questions that were deemed necessary (Barker, Pistrang, & Elliot, 1994). A great advantage of the semi-structured interview, according to Kruger (1988), is its flexibility, which allows the researcher to grasp more fully

the participant's experience than would be possible through the implementation of a more rigid methodological technique.

The first interview focused on succinct life histories and the psychological experiences of the primary caregivers of autistic children, up to and including the point when autism was first diagnosed in their children. The second interview focused on adjustment and learning how to cope with the child's special needs after the diagnosis was made. Specifically, the second interview focused on what was helpful, and what hindered adjustment across various areas of functioning, such as the establishment of a daily routine, finding appropriate education, and dealing with the impact of an autistic child on other family members and family relationships. During the third interview, the efficacy and shortcomings of available resources to alleviate the stressors of raising autistic children were explored, as well as the specific needs that are not attended to by these resources, and the concerns that remain for primary caregivers of autistic children regarding their children's futures. Contact with participants over the course of three interviews further allowed for the clarification and/or expansion of material obtained from previous interviews (Seidman, 1991). The researcher also kept a fieldwork journal to reflect on personal experiences during the data collection process that may have affected the validity of the data obtained.

### **Data Processing (Analysis and Interpretation)**

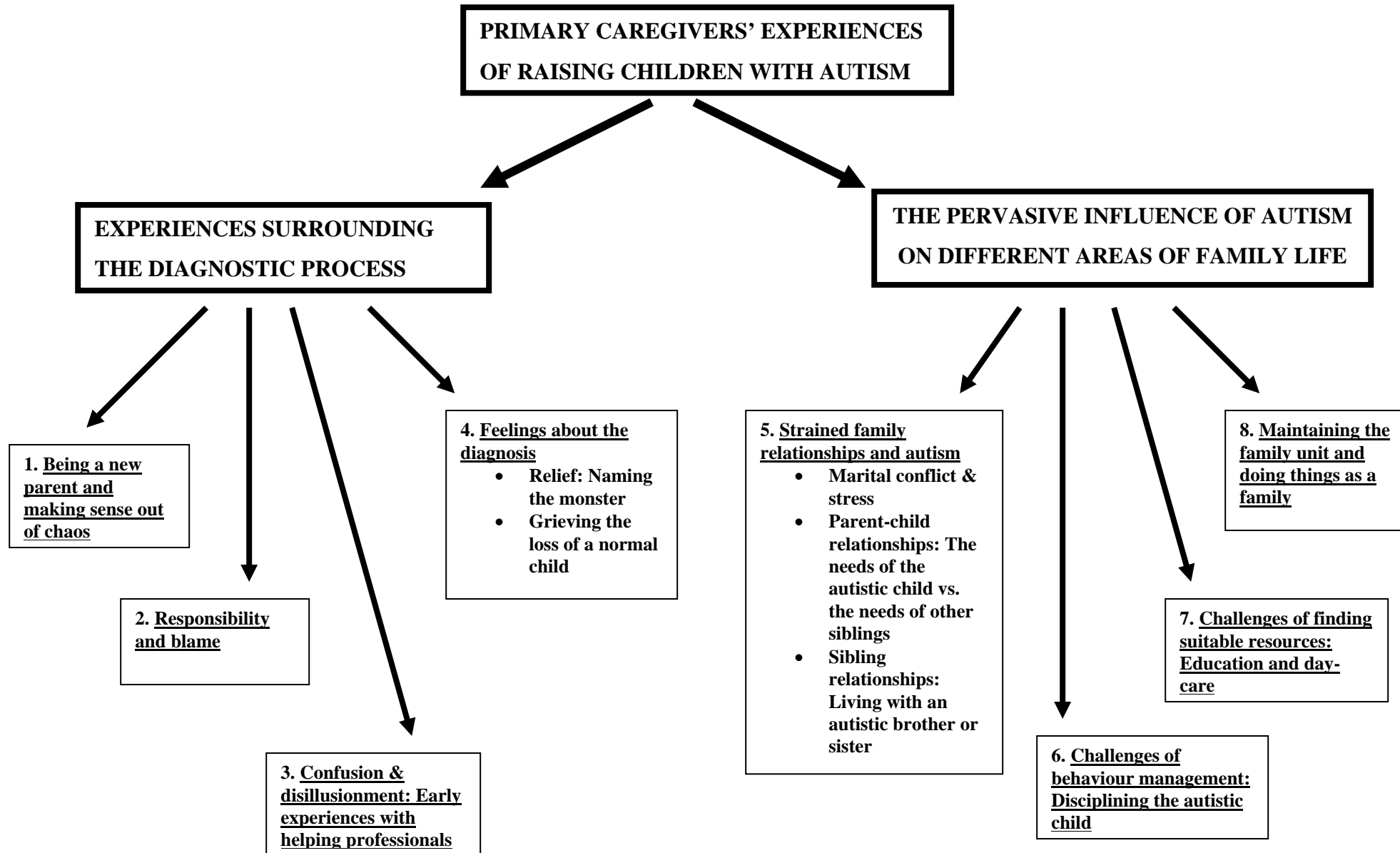
All the recorded material obtained from the research interviews were transcribed. In order to protect participants' anonymity, these transcripts were coded so that the respondents' names did not appear, and the tapes were destroyed at the completion of the study. The transcribing followed the broad categories and order of questions used in the semi-structured interview schedules. The original transcripts of these interviews are included in Appendix B.

The primary form of data analysis was content analysis. The researcher reduced the text by marking individual interesting passages, which were then coded/labelled and grouped into categories (Seidman, 1991). The categories were systematically selected, related to other categories, and connections were made between categories. These categories were then studied for thematic connections within and among them, in order to produce a set of interview excerpts that were thematically organised. The themes and categories that resulted from the data analysis and interpretation process were grouped into two broad fields of experience, namely: (1) experiences surrounding the diagnostic process and (2) the pervasive influence of autism on different areas of family life. These themes and categories are diagrammatically depicted in Figure 1.

The trustworthiness and internal validity of the method of analysis were enhanced by using an independent coder and by appropriating reflexivity to the researcher's role and subjective experiences during the research process (Gergen & Gergen, 1991). Kruger (1988) supports the notion that, in phenomenological research, the researcher cannot be viewed as an independent observer, but must be seen as a participant observer. As such, phenomenological methods of research must thus be "reflexive in nature and intent" in order to remain faithful to their purpose (Kruger, 1988, p.150).

The researcher further considered her reflective learnings and the thematically organised summary of responses against the research question in order to:

1. determine the nature of primary caregivers' psychological experiences of the diagnostic process;
2. produce an understanding of the particular problem areas encountered by these primary caregivers during the post-diagnostic phase; and
3. enable recommendations to be made regarding the extension or development of support structures and counselling models that are sensitive to the unique needs and concerns faced by the primary caregivers of autistic children.



**Figure 1**  
**Results of data analysis & interpretation**

### **Ethical Considerations**

For the purpose of this study, the following ethical considerations were strictly adhered to:

1. ***Information and consent forms:*** Research participants were provided with and asked to sign a printed consent form (Appendix C), which provided an honest and accurate description of the aims and nature of the study. The consent form clearly stated that participation in the study was voluntary, and further included information about how participants' concerns about privacy, anonymity and confidentiality would be addressed.
2. ***Privacy, anonymity and confidentiality of data:*** Although participants' names were known, these did not appear on any data records or analysis sheets or results records. When the study was completed, record sheets were retained. Research participants were asked to sign a standard departmental permission form for all interviews to be audio taped. All audiotapes of research interviews were transcribed, and the audiotapes were destroyed at the completion of the research. Interview transcripts were coded so that participants' names do not appear. No identifying information was included in any subsequent publications of research results. Coded transcripts were submitted as appendices to the researcher's Master's thesis, with the informed consent of research participants.
3. ***Feedback to participants:*** A written summary of the main findings of the study was offered to participants and sent to those who provided their names and addresses. A copy of this abbreviated report was also sent to the principal and governing body of Quest School for Learners with Autism in Port Elizabeth.
4. ***Potential risks:*** This study posed no risk of harm, embarrassment or offence to participants, to third parties, or to the community at large. As a precautionary measure, all participants were provided with referral information for psychological counselling and containment services in the event that they might require such assistance after completion of the research interviews.

## CHAPTER 4

### RESULTS AND DISCUSSION

This chapter comprises a detailed discussion of the results of the data analysis and interpretation process. The themes and categories that resulted from the data processing were grouped into two broad fields of experience, namely: (1) experiences surrounding the diagnostic process; and (2) the pervasive influence of autism on different areas of family life. In terms of participants' experiences surrounding the diagnosis of children with autism, the following four themes were identified:

- ***Theme 1: Being a new parent and making sense out of chaos.*** This theme includes a discussion of caregivers' early recollections of their pregnancies and significant events surrounding the births of the children who were later diagnosed with autism. Brief reference is made to developmental delays and early warning signs that alerted these caregivers to potential abnormalities in their children's development, as well as the psychological defences employed by these caregivers to understand and integrate their children's atypical development.
- ***Theme 2: Responsibility and blame.*** This theme explores the attribution of blame for the child's difficulties and responsibility for initiating and overseeing the diagnostic process, which were typically bestowed on one member of the parental unit.
- ***Theme 3: Confusion and disillusionment during early experiences with helping professionals.*** Caregivers' early experiences with helping professionals during the diagnostic process are explored. Not only were caregivers' concerns negated, but they also found helping professionals to be generally unsupportive and insensitive to their vulnerabilities, fears and confusion regarding their children's condition, prognosis, and feasible treatment options. Suggestions are provided for improved service provision.
- ***Theme 4: Feelings about the diagnosis.*** Caregivers' reactions to receiving the diagnosis of autism are explored. Reactions ranged from initial relief that they finally know what is wrong with the child, to a complex and continuous process of grief over the loss of a "normal" child.

The second broad field of experience that emerged from the data processing relates to the pervasive influence of autism on different areas of family life. The following four themes were grouped under this heading:

- ***Theme 5: Strained family relationships.*** It is argued that the presence of an autistic family member influences the dynamics of all family subsystems. Primary caregivers share their

perceptions of how the presence of an autistic child has influenced the spousal subsystem and the marriage relationship, as well as parent-child relationships with normal developing siblings. Caregivers' accounts of sibling relationships, as influenced by the presence of an autistic brother or sister, are also discussed.

- ***Theme 6: Challenges of behaviour management and disciplining the autistic child.*** Caregivers share their distress regarding autistic children's behaviour problems, as well as the demands of extreme dedication and consistency that are needed in order to address problem behaviours. Caregivers find it difficult to discipline autistic children, since physical punishment or verbal reprimands do not necessarily work with these special children.
- ***Theme 7: Challenges of finding suitable resources for education and day-care.*** This theme explores the difficulties that primary caregivers encounter as they search for suitable day-care and education for autistic children. Mainstream preschools and schools are unable to meet the special education needs of these children, and are often unwilling to accommodate them because of their behaviour problems. Caregivers are faced with limited resources for learners with special education needs in South Africa, and the financial burden associated with such education further exacerbates the stress on these families that are already severely taxed.
- ***Theme 8: Maintaining the family unit and doing things as a family.*** Primary caregivers report that the presence of an autistic child often results in the loss of family friends. The family may further isolate themselves because of public scrutiny and unacceptable behaviour of the autistic child in public places. Specific difficulties with everyday family activities such as shopping, eating out at restaurants, family holidays and leisure activities are discussed. Brief reference is also made to how caregivers of autistic children manage to cope and maintain the family unit. *Inter alia*, they have learnt to plan ahead, live in the moment, and to take time-out in order to replenish their own energy.

Each of the above themes will subsequently be discussed and highlighted by direct quotations from participants' interview transcripts and by an accompanying reflection on relevant literature.

### **Being a New Parent and Making Sense Out of Chaos**

All four participants reported problem free pregnancies, but two experienced complications during the birth process. Both of these participants went into labour one month prematurely, and the infants sustained oxygen deprivation during the long and difficult births. One participant allegedly suffered from undiagnosed hypertension throughout her pregnancy, since she did not receive prenatal care. Her

child was born via an emergency Caesarean section and he was blue at birth. Both participants acknowledged that their children might have sustained mental retardation as a result of anoxia, but they were unclear regarding the possibility of causal relationships between birth trauma and the eventual diagnosis of autism in their children. The remaining two participants gave birth via normal vertex deliveries.

Throughout the accounts of their pregnancies and deliveries, all four participants repeatedly emphasised the normal appearance of the infant, and the complete absence of any visible indication that the child suffered from a developmental disorder. For example:

A: I was healthy, it was a drug free delivery, one and a half hours, no birth trauma... nothing!

Huge baby, four kilos. There was nothing there to indicate that this was going to be a problem.

Some women suffer and the babies are blue... there was nothing like that.

F: *J* (autistic child) was normal in all respects. His scans were all normal. What bothered me on his last scan, was that the one half of his brain seemed to be noticeably smaller than the other half. The doctor reassured me and said that it was very common and normal. She told me that everything was normal. I was also completely normal. I gave birth normally. He had jaundice, but his Apgar scores were 8, 9 and 10. He was in the incubator only for a short while because of the jaundice.

The aetiology and pathogenesis of autism have by no means been conclusively established. Certain broad indications of neurological, biological, immunological and perinatal factors have however been reported in this regard (Kaplan & Sadock, 1998). Since autistic children have significantly more minor congenital physical anomalies than their siblings and normal controls, complications of pregnancy in the first trimester have been implicated (Kaplan & Sadock, 1998). A high incidence of perinatal complications has been found to occur in children with autistic disorder, although no complication has been directly implicated as causative. For example, maternal bleeding after the first trimester and meconium in the amniotic fluid are more often reported in the histories of autistic children than in the general population (Kaplan & Sadock, 1998). Autistic children also have a high incidence of respiratory distress syndrome and anaemia during the neonatal period. A high incidence of medication usage during pregnancy in mothers of autistic children has also been documented (Kaplan & Sadock, 1998). None of the above factors were however identified or even suspected during the pregnancies of the participants in this study.

According to Gerdes, Moore, Ochse and Van Ede (1988), parenthood poses a developmental crisis and a challenging transitional stage for caregivers. New parents may feel overwhelmed by the demands

of caring for a helpless infant. Caregivers' sense of confusion and doubt is even more pronounced as they struggle to understand and integrate debilitating health problems or developmental abnormalities in children who outwardly appear to be perfectly normal. Participants in the present study experienced internal conflict and vacillation between denial and acceptance as they first started to notice developmental delays and early warning signs that alerted them to potential abnormalities in their children's development. These warning signs and developmental delays conform to the conventional descriptions or definitions of autistic behaviour, which list failure to acquire communication skills (or regression of these skills), withdrawal from social and environmental stimuli, and restricted repetitive and stereotyped patterns of behaviour, interests and activities as the three major components of the "triad of impairments" in autistic disorder (Autism South Africa, 2000). For example:

- A: And she just lied there, she wouldn't do anything or roll over, and she didn't try to talk. You know that noise you hear when you phone a fax machine... that noise... she used to make that noise. I used to call her my fax machine... it was a terrible noise. No pre-speech, no boo's and goo's like other babies... It took us a full year to potty train her. She used to take her pooh and smear it all over the cot. It took the whole year from three to four.
- B: I can remember thinking, in those first two weeks, 'He sleeps a lot!' ... He slept more than normal. He was very good... too good... He didn't do this (*gestures wringing movement of hands in front of her face*)... babies do that. He kept his hands still... he really found it difficult to hold his neck up. He only sat at about a year. Then he could properly hold his head up... He was late, like three months later than what I thought was normal for babies of his age... And then, we could just not understand that he wouldn't smile. He had not smiled before. I would call him and call him and call him and call him... and he would not answer.
- F: I noticed that, when he listens, it seems as if he cannot hear his name... We thought he was deaf; I think everybody starts there... He did not respond to his environment; he did not try to make friends. He did not even notice his brother when we brought the baby home from hospital. He would walk over the baby and did not notice him. I know that, with some of my friends, the older children helped with the new baby, like to fetch a bottle. My child was in a world of his own. He used to disappear in the garden. When we went out to eat somewhere, he just disappeared. He never looked back to see if I was coming. He did not seem to worry whether I was following him or not. He never reached out for me to pick him up. He never played normally with toys. He was fascinated with fans and he tried to spin everything; he spun the wheels of a toy car and tried to turn everything. He sometimes rocked a bit, and then he also

used to swing a twig in front of his eyes, or a straw, or even his toothbrush. He was very apathetic. He did not try to dress himself. He did not try to bath himself. He never tried to eat by himself.

All four participants in this study mentioned the period between first noticing the warning signs of autism and eventually obtaining a diagnosis as the most difficult time in their lives with their autistic children. They often felt paralysed with anxiety and fear at the prospect that something terrible might be wrong with the child, and they were also exhausted by their apparent inability to understand the child or to curtail his/her problem behaviours. Participants reported the following experiences of emotional hardship prior to turning to their family doctors or paediatricians for an understanding of their children's behaviours:

- A: I said to my dad on the phone from South Africa, 'I hope it is epilepsy'. But even then I must have hoped against hope, I must have known somewhere here deep inside that it wasn't... you can't put it into words, it's just this sick feeling... I was at my wits' end with *J-A* (autistic child). Her behaviour was bad, the seizures weren't going away... and she was just unhealthy. It was driving us mad, because we didn't know what was going on... I just felt that I was going crazy myself...
- F: The first crisis starts when you realise that your child is not the same as your friends' children. We all had babies at the same time. My child, specifically, was very attractive... he was a very, very pretty baby... It was very traumatic for me, because people stopped me in the shops and said, 'You've got the most beautiful child!' And I knew that something was wrong with him... I think when *J* (autistic child) was about three years old, it became very difficult for me. He was not yet diagnosed at that time. I got very little support. At that stage, even my family still thought that there was nothing wrong with him. He did not fit in anywhere. He didn't make friends. It was always a crisis when we were invited to birthday parties. I was always running around and fussing with this child. Socially, I took a very bad knock. You know, everybody else's children were getting bigger and cute and started to talk and your child... you know that something is seriously wrong with your child... No, it was awful. To try to find out what is wrong with him... and all the weird things that he did. And he can't play properly, and he doesn't learn to do things for himself. He is so completely dependent on you, and also so independent. It was awful.

Gray (2002) confirms these experiences of emotional hardship in his discussion of specific challenges that face the caregivers of autistic children during various stages of the child's development.

He specifically agrees that, during the pre-diagnostic phase, caregivers are often confused, anxious and highly stressed as their children's problems grow more pronounced and they struggle to make sense of their children's peculiar behaviours.

Another phenomenon that occurs during the pre-diagnostic phase is a tendency for caregivers to vacillate between admitting that something is wrong with the child, and denial or rationalisation of growing evidence of autistic warning signs and developmental delays in their children. Denial of reality is perhaps the simplest of self-defence mechanisms and it is a way of distorting what the individual thinks, feels or perceives in a traumatic situation. It consists of defending against anxiety by "closing one's eyes" to the existence of threatening reality (Corey, 1996). Rationalisation, which is often employed together with denial, is used to explain away certain anxiety provoking experiences or losses (Corey, 1996). According to Collins and Collins (2001), caregivers of autistic children have to experience a "journey out of denial" before they can begin to contemplate that their children may suffer from a developmental disorder. In her discussion of the experiences of a professional behavioural therapist who has a child with autism, Palazzo (2001) also mentions caregivers' vacillation between denial and acceptance as they are caught up in a whirlwind of emotion, half knowing that something is terribly wrong with their children and half not wanting to know. All participants in this study voiced initial denial and/or rationalisation of autistic signs and symptoms in their children. For example:

A: So, at seven months, my little warning bells went off... but you don't want to say anything to anybody else... you don't want to... you think that if nobody else can see it, it will just go away... perhaps I was drinking too much coffee... I was breastfeeding... you know, just looking for other reasons.

B: I knew that there was something wrong with *D* (autistic child) and I expected the fact that he was autistic, but 90% of the parents that I know thought that there was something wrong, but then they refused to accept it. And a lot of them still think that they can make it right. A lot of it is just about accepting; it is about how you accept people generally, or yourself, or whatever.

D: It takes time to acknowledge what is wrong as a parent, to acknowledge what is wrong with your child. Although you might have signs, picking up some signs, but no, to accept it and then to go... to get help, it takes time. Sometimes you just want to go, 'Uh-um, there is nothing wrong', although you know that something is wrong and there is a problem.

F: Yes, it's quite difficult when your handicapped child is your oldest child. You don't really know what to expect. [In spite of the warning signs] you remain positive, because you don't

really know how things should have been. If I had had *J* (autistic child) after *I* (normal developing younger sibling), I would have had a reality shock, perhaps a lot sooner than I did.

From the above discussion, it seems evident that parenthood poses a particularly challenging transitional stage for caregivers of autistic children. Their sense of confusion and doubt escalate as they struggle to understand and integrate debilitating health problems or developmental abnormalities in children who outwardly appear to be perfectly normal. Participants in the present study experienced internal conflict as they vacillated between denial or rationalisation and acceptance as they first started to notice developmental delays and early warning signs that alerted them to potential abnormalities in their children's development. They often felt paralysed with anxiety and fear at the prospect that something terrible might be wrong with their children, and they were also exhausted by their apparent inability to understand their children or to curtail their problem behaviours.

### **Responsibility and Blame**

Participants in the present study expressed a tendency for one caregiver to assume a more dominant role in initiating the diagnostic process with their children. This sense of responsibility was also associated with increased pressure and strain on the particular caregiver. For example:

- A: I'm the one who does all the reading and research; he (husband) looks at me. So I'm the authority... Even disciplining and controlling, when he's not sure what to do, I say, 'No, you should do that now.' It's obviously stressful, because he can't deal with things... Yes, I went through the whole guilt thing... I was... I am personally responsible... *(Pause)*... It was so hard... and in this family I have to bear the responsibility, I am the medical person. Every family has one, like the nurse type. And he'll listen to everything I say, so I'm the expert. It was all resting on me, I had to make the decisions... It's been a lonely road, because I've always been like the authority. And being the one with the most knowledge... stumbling around in the dark, yes... but being the expert, and always being the strong one... Nobody can know how the mother feels. You can think, but you can't actually feel that feeling. It's a 24-hour job, and the constant responsibility!
- B: And then I also started thinking that maybe he (autistic child) would resent me later on... when he is a teenager he may decide that he hates me, because I put him through that. So that was a big stress in my head. Am I doing the right thing? The whole time, with each assessment. Shouldn't I just leave it? Bungle on in the darkness or should I put him through this? I also know that I took it upon myself. I took the responsibility on myself; I wouldn't let anybody else

have it. Not even my husband, it was my responsibility and I handled it and dealt with it how I saw fit.

Two research participants were of the opinion that their partners, who assumed less responsibility, often adopted a critical stance by blaming them for the difficulties that are associated with raising children with autism. These experiences are reflected in the following participant statements:

A: I've had her (autistic child) the whole holidays... I had her during all the meals, and her behaviour is worse at the mealtimes, and I have her during all that free time that is not structured. And when I do teach her, I've got this (*turns her head in direction where her youngest child is playing*) to interact with as well, and the household to run, and the mess and the dogs and the horses... all going on at the same time. And I admit, I made a stuff-up and I did the wrong thing, and I can't correct that. He (husband) was very angry with me... it's easy to criticise... you can admit to a mistake and not feel that you have now failed as a parent... But now he (husband) has got a difficult time with that, and he's also got to learn. Look, I made a mistake, and I admitted it. It is an ongoing learning process, and it never stops.

D: You can sometimes see that the father, sometimes he is blaming you. You are not strict, you are too soft, you are not disciplining the child enough, or I don't know.

Participants' experience of more responsibility on one caregiver is confirmed in literature on the psychological adjustment of primary caregivers of autistic children (Chambliss & Doughty, 1994; Moes, Koegel, Schreibman, & Loos, 1992). Moes et al. (1992) constructed stress profiles for 18 mothers and 12 fathers of children with autism. These profiles indicated that female caregivers experience significantly more stress than male caregivers on all three measures of stress that were used in this study. They also contend that the pattern of these profiles suggests that stress is directly related to the differing responsibility assigned to child rearing for each parent, with female caregivers typically being the ones who bear more responsibility. Chambliss and Doughty (1994) agree that the female caregiver generally experiences greater stress and responsibility in caring for an autistic child. Male caregivers, on the other hand, were found to spend significantly less time with the autistic child and were hence less aware of the stress and demands placed on the female caregiver (Chambliss & Doughty, 1994).

Two participants in the present study indicated that their increased responsibility for the autistic child's care also exposed them to blame and criticism by their partners, which exacerbated their perceived stress, self-blame and guilt regarding the autistic child's condition. Leighton (1969) warns helping professionals to pay careful attention to the social and behavioural implications of guilt and the

allocation of blame in their service rendering to caregivers of autistic children. Whereas male caregivers are more likely to place attributions of blame in external sources, such as their spouses, female caregivers are more likely to place attributions of blame in themselves. This phenomenon has been directly linked to high stress levels, poor adjustment and vulnerability of female caregivers of autistic children (Akkok, 1996; Mickelson, Wroble, & Helgeson, 1999).

Results of the present study support previous findings that female caregivers generally experience greater stress and responsibility in caring for autistic children. Their position of increased responsibility also exposes female caregivers to blame and criticism by their partners, which exacerbate their perceived stress, self-blame and guilt regarding the autistic child's condition.

### **Confusion and Disillusionment During Early Experiences With Helping Professionals**

All four participants in the present study first turned to the family doctor or paediatrician for an understanding of their children's behaviours. This typically marked the beginning of a long and difficult road for caregivers as they began to interact with multiple professionals in order to obtain a clinical diagnosis for their child's condition. The relationship between caregivers and helping professionals is one of the most important relationships that mediate caregivers' experience of the diagnostic process. According to Hecimovic, Powell and Christensen (1999), the nature of the family-professional relationship and how families view that relationship are critical determinants of the family system's support. It is this relationship, and the sensitivity, skills, and information with which professionals approach the relationship that defines how much support families receive from the professionals with whom they will interact, because they happen to have a family member with autism. The participants in the present study reported predominantly negative experiences as they interacted with a myriad of helping professionals in the specialities of psychology, neurology, psychiatry, speech and language, occupational therapy and physiotherapy, located in mental health centres, evaluation centres, speech and hearing clinics, state hospitals, private institutions and treatment centres for children.

Participants felt strongly that helping professionals initially negated their concerns and did not take their reports of delayed development in their children seriously. For example:

A: I really wish that someone had just taken me by the shoulders and said to me, 'There is something wrong, sort it out now! Have it investigated.' Not that that would have helped much, because with all the medical help, that just doesn't go anywhere... But nobody had the courage to say, 'Look, there's a developmental problem here. Go, and do some research on this.' What

they don't want to do, certainly the medical people, is that they don't want to empower the parents, because it's almost like they are threatened... The parent's opinion is obviously negated, in this country certainly. It has certainly been my experience.

B: Well, initially I needed someone to say, 'Yes, well, you should be concerned. If you are not happy about it, check it out.' Don't just say, 'Don't worry about it!' ... I think there are lots of over anxious mothers. I'm sure there are, and it must be jolly irritating. But I think someone should be given a chance to state his or her situation.

The above experiences of research participants are strongly supported by anecdotes from primary caregivers of autistic children that abound with references to professionals who dismissed parental concerns about a toddler's failure to talk and relate socially as excessive anxiety on the part of the primary caregivers (Billington et al., 2000; Boushey, 2001; Davis, 2001; Roth, 2001; Stroud, 2002). Primary caregivers hence believe that their concerns are often dismissed as products of worry (Burkhardt, 2001) rather than astute observation. The tendency of helping professionals to negate caregivers' concerns has been found to exacerbate their sense of helplessness and hopelessness, and further contributed to caregivers' feelings of anger and disempowerment (Billington et al., 2000).

Smith (1994) examined the quality of medical care, as experienced by 128 British families of children with autism, and found that progress has been made over the last decade in the shorter time for referral to specialists, younger age at diagnosis and younger age at receipt of special education services. In spite of these improvements, he concludes that difficulties still remain in obtaining initial professional advice and support, a correct diagnosis, and appropriate help in the early years. Participants in the present study experienced similar difficulties during their early encounters with helping professionals. Caregivers indicated that professional opinions were often vague, confusing, contradictory and non-definitive. They also indicated that, either by referral or on their own, they had many professional contacts because the diagnoses of the children were so varied. The most pronounced consequence of these diagnostic difficulties was that caregivers were disillusioned and lost their trust in medical professionals. Participants' experiences with helping professionals were described in the following ways:

A: I took her (autistic child) off to the GP one day and he said (*imitates an angry, shouting voice*), 'Your child has got irreversible brain damage. She's got a tumour. You must rush her off to hospital right now!' ... It is, it was terrible. It was so traumatic... so I took her to see the paediatrician, and he said, 'Man, there's nothing wrong with her... just give her some more protein' ... He took all the blood tests and X-rays and TB and muscular dystrophy and all the

rest... but everything came back normal. So he said we should just wait. It was chaos, 'cause this one here said she had irreversible brain damage... he was actually right, but you want to believe the good guy, you want to believe the one with the good news... so we did. You know, when you are on that level of coping with what is happening around you, you don't think. You can't think, 'Is this right, what he said?' Your emotions just tend to take over. And your hope lies in the people who are meant to know. Now, no hope lies in the people who are meant to know. Everything they say now, I question.

- B: See, we couldn't afford anything private... it took about four or five months, because we had meetings, and then we had to go and have a CAT scan, or an ear check, all at the Johannesburg General Hospital... genetics, blood, urine... all of that kind of stuff. And then we'd wait for the results and they all got together or the psychologist would watch him play or climb up steps... Terrible... absolutely terrible! I could not do it. I could not do the hospital part... I also found that going to assessments and occupational therapy and speech therapy... that was extremely stressful for me, and extremely stressful for *D* (autistic child). Because what I felt, he felt... What made it stressful is that I know what my child is like at home. But when he is in front of strangers and in a new environment, he is not like that at all... And I found the scepticism of people very upsetting, like they would say, 'Now you said that your son could do it, and now he is not doing it.' I found that extremely stressful.
- D: I went everywhere, to sangomas, to everywhere; I was looking for help – to traditional healers and to the doctors... You cannot be sure, like, you feel alone because there's no certain diagnosis, like say, this is what is wrong with the child with autism. Some of them say, no, you must watch the diet, although even the doctors and the dietician, they are contradicting... And it's very confusing for you now as a parent, because they don't say like the same thing...
- F: He (autistic child) went to doctors and speech therapists... It was very difficult for us. His eyes were tested. "Sluggish pupils", that's all they could tell us. The neurologists did all the scans; brain scans. The neurologist... I almost had a fistfight with her! I almost hit her, because she told me that the only sure thing was that my child is not autistic, because he is too warm in his way with people and he makes good eye contact... She totally put us on the wrong track!
- F: The first doctor said I shouldn't bring such a healthy child into his surgery, because the healthy child would only get ill (*Laughs*). The second doctor said that my child is mentally retarded, which is partially true. He is mentally retarded, but only to a certain extent. Most autistic children are, but that is not his primary diagnosis... He went for brain scans. He was 100% fine.

His EEG's showed no epilepsy, nothing. So I sat with this child who looked so healthy and normal and the doctors did not know what was going on. I became very emotional during that time. I tried to read books on autism, but that would just upset me even more... Later on, I hated doctors. They meant nothing to me... Doctors show no empathy. Dr. W (paediatrician) and I have a kind of understanding, but not always. I know there's lots of research going on, but I don't see any results. There is no pill that helps my child. There is no diet that helps him or causes any improvement. There is just not enough support...

Palazzo (2001) confirms the above finding that caregivers of autistic children can become disillusioned and disheartened as they receive inconsistent diagnoses from varying professionals. Their experiences may further be compounded by the clinical difficulty and caution amongst professionals to diagnose a young child with autism, as well as failure of these professionals to address caregivers' lack of knowledge regarding autism and their conflicting feelings of concern, fear, helplessness and guilt that they have somehow caused their children's disabilities (Billington et al., 2000). In recognition of the shortcomings of professional services to caregivers of autistic children, Moore, McConkey, Sines and Cassidy (1999) examined the experiences of both parents and professionals concerning diagnostic and assessment services for children with autistic spectrum disorders in Northern Ireland. The results of this study correspond to some of the experiences that were shared by participants in the present study. For example, many subjects reported that the lack of information about the diagnosis and responsive therapeutic intervention programmes for these children was a key problem (Moore et al., 1999). All subjects further emphasised the need for training to enhance competency in the assessment and diagnosis process for both parents and professionals.

Autism South Africa (2000) advocates that the provision of practical information on autism and related topics should form the foundation of intervention programmes aimed at the primary caregivers of autistic children. Caregivers need to be empowered with information regarding the nature and typical features of autistic spectrum disorders, practical guidelines on how to assist their autistic children across a spectrum of problematic behaviours, and information regarding educational resources and training programmes for autistic children that will enable caregivers to initiate practical assistance for their children (Autism South Africa, 2000; Nissenbaum, Tollefson, & Reese, 2002). Helping professionals should hence strive to empower caregivers and employ a collaborative parent-professional model, whereby primary caregivers are recognised as experts on their children's behaviours and become active participants in their children's treatment (Elder, 2001). Based on their

own experiences with helping professionals, research participants in the present study provided the following suggestions for improved service provision:

- A: There should be a psychiatrist or psychologist or medical person on board with the educators. They need like a case manager, someone who can integrate the whole lot... They need to open up their minds to other people's opinions: parents, educators, OT's, speech therapists, and look at the whole case. Having a case manager will be excellent. We need an autism centre. So, if you suspect the child is autistic, this is where you can go and this is what you can do.
- B: And I also think that parents and children with problems should not be assessed away from their home environment. I don't think you get a true reflection at all. I think there should be a team of people who, if a problem is picked up, they go and see the family at the family's home... I wish it could have happened to me. That my reports to the clinic sister had been taken seriously and that someone could have come to my home and seen my child. That would have cost a quarter of what it cost the state, because I did not pay for my assessment. It was done through the state. It would have been much less traumatic, and we would have had an answer quickly. Instead of waiting almost a year, which is how long it took.
- F: Although they are professionals, I want them to treat me as an equal. They should be able to cry with me. I don't want you to think that you are so cute and grand and you are now going to help me from your one-up position. It's about being human and knowing how traumatic it is for parents. Then I can really talk to you, because you can understand my pain, how I feel like an outcast, and how I may be ashamed when I have to go somewhere with my child. We need a place where we don't get send from pillar to post, but where you can go, get all the tests and assessments done, and walk out with a diagnosis and a plan.

From the above discussion, it is concluded that the relationship between caregivers and helping professionals is one of the most important relationships that mediate caregivers' experience of the diagnostic process. All participants reported an initial tendency among helping professionals to negate their concerns and reports of delayed development in their children. Consequently, participants' sense of helplessness and hopelessness escalated, together with feelings of anger and disempowerment. Professional opinions were often vague, confusing, contradictory and non-definitive. Participants often had many professional contacts because the diagnoses of the children were so varied. As a result of these diagnostic difficulties, caregivers were disillusioned and lost their trust in medical professionals. Helping professionals are encouraged to empower caregivers with information and resources, and to

employ a collaborative parent-professional model, whereby primary caregivers are recognised as experts on their children's behaviours and become active participants in their children's treatment.

### **Feelings About the Diagnosis**

Autism occupies an extreme position among the childhood pathologies in terms of its severity, duration and impact on the family. For this reason, no child and no family go untouched by the diagnosis, and the feelings that caregivers have related to an initial diagnosis change over time (Merzer, 2001). In the present study, participants' reactions to the diagnosis of autism in their children ranged from initial relief that they finally know what is wrong with the child, to a complex and continuous process of grief over the loss of a "normal" child.

#### **Relief: Naming the Monster**

The previous discussion highlighted the difficulties that primary caregivers of autistic children encountered as they embarked on the long and treacherous road to determine what is wrong with their children. Participants in the present study reported that their concerns and anxiety lessened somewhat once the children were diagnosed, since they were now in a position to seek appropriate treatment and educational programmes suitable to their children's unique needs. Participants' sense of relief was reflected in the following statements:

- A: She (friend) had been reading about this other child and came across an autism website, which was actually the ASA (Autism South Africa) site. So we started to tick things off, like 'Look, *J-A* (autistic child) does this and this', so we had a bit of an inkling. I just couldn't believe it, because I was so hoping for a word to give to this thing that my child has got... Since that day, since she was four and a half... we've taken control.
- B: With *D* (autistic child), I can remember feeling relief that at least we know what it is; at least we now knew how to start working with him and doing a home programme or something. At least he wasn't deaf and we weren't barking up the wrong tree or wasting time or whatever.
- F: I like having a diagnosis. I know they say you shouldn't label a child, but it is a sign for us as parents; it gives us a place to start. It is probably one of the most tragic diagnoses that they can give you, but at least I know now that there is a spectrum and that my child is not the worst.

Kessler (1974) confirms that diagnostic labelling is necessary, despite its drawbacks, since it enables both caregivers and professionals to customise treatment programmes to the unique needs of the child. It is also beneficial to identify the primary diagnosis as focus for treatment, since many autistic children may have a double diagnosis, such as mental retardation with symptoms of autism. Hall (2000) warns that caregivers' relief over the arrival at a diagnosis should however not be mistaken for gratefulness. She is of the opinion that their relief may merely result from the fact that, by comparison, they have not received news of a life-threatening situation in their child, such as a brain tumour (Hall, 2000).

### **Grieving the Loss of a Normal Child**

According to Boushey (2001), caregivers' experiences of adjustment at each of their autistic child's life stages can be compared to a grief cycle, since a sense of loss and the eventual acceptance thereof are fundamental components of the psychological life and emotional coping of a person who cares for a child with autism. Due to the chronicity of their children's diagnosis, these caregivers experience a complicated form of non-finite loss and grief (Bruce & Schultz, 2002) that is ongoing and changing as life continually falls short of expectations. According to Bruce and Schultz (2002), caregivers can only arrive at a level of acceptance if they are continuously supported to preserve their identity and to restore a sense of control over their child's condition. Participants in the present study confirmed that they moved through a grief process in response to the loss of a normal child. The non-finite nature of the loss further caused them to re-experience the grief cycle as different losses emerged at different stages of the autistic child's development. Participants expressed varying emotions that are associated with stages in the grief cycle, namely: initial shock and denial; anger and resentment; depression; and eventual acceptance (Tommasone & Tommasone, 2000). Initial *shock and denial* were expressed in the following ways:

A: At the end of the interview, she said, 'Your child is autistic, take her to Quest.' So I thought, 'What? She doesn't sit in the corner and rock!'

B: I accepted it a lot easier than my husband did, I suppose because I had much more contact with *D* (autistic child) on a daily basis than he did. I think that he felt quite isolated... he kind of isolated himself from it. He almost pretended it wasn't happening... He often pretended that it wasn't happening and that it would definitely get better and that it would go away... like it was just an overreaction. He thought he would grow out of it or that something would change.

F: Whenever my husband brought a book on autism home, I used to throw it in the dustbin. I just didn't want to know anything, because my child is not autistic! That's what I told myself. Yes, I also went through that initial denial.

Participants also felt *angry and resented* the difficulties that they experienced in caring for their autistic children. For example:

A: I do sometimes get so cross, especially if I haven't had enough breaks, or we're having a particularly up-hill time, you know. And when you let go, that anger is terrible... terrible anger.

B: And then I started getting cross, because I thought that I should have managed my pregnancy and the birth better and should have been more assertive about it.

*Depression* presented in various forms and combinations of guilt, sorrow and tearfulness. For example:

A: Yes, there's always that guilt and regret, but that doesn't take you anywhere. But you also have to go through it, and then move on. Just don't stay there. And then you go into the whole thing of, 'Ag well, that's it!' We became sort of fatalistic... I mean we have to carry on with our lives... because of *J-A* (autistic child)... The sense of sorrow and loss is with you. The older *J-A* got, the more I realised what I have lost. When I see other moms with their children in Grade 1 and their uniforms and little suitcases and sitting in the restaurant, having something to eat... that's tough to see that and know that I haven't got that... and I'll never have that with my daughter... I used to break into these crying sessions and get depressed... and just felt this blackness, like this is not a good day. I don't have many of them now. *J-A* used to make me feel like that, because I wasn't in control of her.

D: I'm very like feeling that guilt, because with autism you've got that guilt all the time as a parent. Is it something you have done, or what is it? What makes this child like this? *A* (autistic child) looks as if he is someone who is lacking something, you see. I try to give him love. Everything I give him, it's as if he's lacking something. He's crying out for something. There's this special thing that he wants, and you don't understand.

F: Every now and then we were fine for months, but then we would fall apart again. I became so depressed, because it is very traumatic. Especially when your friends start to talk about school uniforms and you're still worried that your child can't do anything!

According to research participants, they were able to attain some level of *acceptance* once they adjusted their expectations regarding their children's abilities and their futures. Caregivers also adjusted their expectations of themselves by accepting the reality of their situations and by allowing

themselves to learn and to make mistakes in the difficult task of raising children with autism. For example:

- A: But I can't be perfect, I can't get it all right for her (autistic child)... so many parents try to live by that fantasy... that they can do everything... Look, I was there... My purpose is to teach her how to be in the real world. Incorporate her in what we do. We can't just ignore her because she stands in the corner... She's just like a normal child, you know, looking for that affection. And to remember that that's my child, she's my child, and the autism is something that we have to deal with and intervene and try to get the child out of it.
- D: This is a problem we are having; A (autistic child) is our problem. We have to deal with it. A is not going to change, you see. We don't get that time for ourselves, but we must just accept him the way he is.
- F: I think that I am too stressed and anxious inside. I am by nature an anxious person. I strive to be perfect, and if I'm going to try that with *J* (autistic child), I am completely going to fall apart. I had to learn to just completely reprogram myself... I know that God gave him to me. I don't know why on earth, but I know that He has a purpose with *J*'s life, and I am just the person that He left him with to try to fulfil that purpose.

The above experiences of shock and denial, anger, depression and eventual acceptance are also referred to by Boushey (2001) in her discussion of the grief cycle, as experienced by the caregivers of children with autism. According to this author, initial shock may result from the news of the autism diagnosis. Caregivers may become numb and dissociated from the entire process, and it is not uncommon for them to later have very little recollection of how they managed to continue to function through the initial diagnostic stage (Boushey, 2001). Caregivers may further enter into denial about the accuracy of the diagnosis, or experience debilitating guilt and shame that they may have done something wrong during the pregnancy and developmental years of the child's life, that had somehow caused the child's autism (Boushey, 2001; Gray, 2002). Sometimes, the very nature of autism is projected onto the primary caregivers who, in a similar manner to their autistic child, feel themselves isolated from the rest of the world and unable to interact socially with other caregivers with similar concerns (Boushey, 2001). A combination of the aforementioned guilt, shame and isolation may result in debilitating depression if no intervention is sought. Panic often results from a lack of knowledge about their child's condition. Caregivers struggle with the expression of anger at themselves, their spouses, or perhaps even at God. The final stage of eventual acceptance and hope can only surface once primary caregivers relinquish unrealistic bargaining efforts and accept that their child's autistic

state is a permanent condition. Eventually, these caregivers are able to maintain some hope in the realisation that the symptoms of autism can diminish with early and persistent intervention, and that they can direct their energy to the realistic goal of teaching the autistic child ways to function in the real world (Boushey, 2001). This eventual sense of purpose as a parent was also directly expressed by participants in the present study.

The above discussion provides supporting evidence that no family goes untouched by the diagnosis of a child with autism. Initial relief needs to be viewed with caution, since it may merely result from the fact that, by comparison, caregivers have not received news of life-threatening conditions in their children. Caregivers of autistic children experience a complicated form of non-finite loss and grief that is ongoing and changing as life continually falls short of expectations. Participants in the present study confirmed that they moved through a grief process in response to the loss of a normal child. Participants expressed varying emotions that are associated with stages in the grief cycle, namely: initial shock and denial; anger and resentment; depression; and eventual acceptance. Helping professionals can aid the caregivers of autistic children in their journey to adjustment by respecting and addressing their emotions of loss and grief, encouraging families to take time to heal, and by providing them with facts about autism and related disabilities.

### **Strained Family Relationships and Autism**

Family systems theory holds that, due to the interrelatedness of family subsystems, any change in the family reverberates through all subsystems and affects the relational dynamics in all of these subsystems (Becvar & Becvar, 2000). It is inevitable that the chronic stress generated by caring for a developmentally handicapped child will trickle down to the various components, including parents and siblings, of the family system (Fishman & Wolf, 1991). Accordingly, it is argued here that the presence of an autistic family member and subsequent reciprocal interaction effects within the family system influence the dynamics in all family subsystems. One research participant accurately reflected this phenomenon by saying, “The whole family shares the autistic person in the family.” Research participants were of the opinion that the presence of an autistic child has influenced the spousal subsystem and the marriage relationship, as well as parent-child relationships with normal developing siblings. Based on caregivers’ observations, sibling relationships also do not remain untouched by the presence of an autistic brother or sister.

### **Marital Conflict and Stress**

All four participants in the present study referred to conflict in the marital relationship that emerged after the birth of the autistic child. The most common cause of conflict related to the extreme demands on time and energy that the autistic child made on caregivers, which gave them little or no time to spend as a couple. Participants also reported that their partners felt neglected and/or unloved as a result of the time that they spent attending to the needs of the autistic child. Participants expressed the perceived impact on the marital relationship as follows:

- B: I think raising *D* (autistic child) had more of an impact on my husband than it did on any of my two children... He really struggled with it, because *D* was with me the whole time. He would actually get cross with me and say that I was obsessed with *D*... I ignored my husband a lot... I mean, he was like number six in line. Get in the queue, you know. Maybe he would get some of my attention then. And that caused friction in the marriage, because he thought I did not love him enough or whatever. And I felt that I was just so busy loving *D* that I could not be bothered to love anyone else... I think what *R* (husband) missed most is just the conversation and just the two of us, because I used to collapse. When the children fell asleep, I fell asleep. When they woke up, I'd wake up, and then it was go, go, go. So we never had time alone, and we could not leave them with anyone else... And, what used to happen is that we used to argue. Mainly at night, when the children were sleeping, when I was tired. He used to just say that I was obsessed with the children and that I ignored him and that I didn't care about him or whatever, and I just used to agree. Yes, it's true, I can't or I don't care or whatever... I am just doing what I have to or whatever and then we'd talk about it and it would be sort of over, but not resolved. And it is only since *D* came to boarding school, the last three years or whatever, that we have had time together as a couple. So, it put a lot of strain on our marriage.
- D: It is so difficult, even at home. Sometimes it's so hard, because you don't have a normal life, you and your husband, when he (autistic child) is around. There is always destruction... it also affects your marriage.
- F: I was up and down, and he (husband) also went up and down with me. I am more professional in that sense (understanding and caring for the autistic child), and he just followed me. It was a crisis, especially in our marriage. I think you either "jell" at a time like this, or you fall apart as a couple.

Conflicting results have been found in studies that examined the influence of having autistic children on marital relationships. According to Koegel, Schreibman and O'Neill (1983), parents of autistic children exhibited the same level of marital happiness on the Dyadic Adjustment Scale as a

normative group of happily married couples, and showed considerably better marital adjustment than a normative group of divorced couples. These authors hence conclude that the presence of an autistic child does not have aversive effects on the marital relationship. A similar study by Blair (1996) indicated that, whilst most respondents felt that having an autistic child had added stress to their marriages, only 31% felt that the increased stress had an aversive impact on their marriage. The majority of respondents in the study felt that their marriages had been strengthened by their experience (Blair, 1996). A larger body of literature however exists that supports the finding of increased marital conflict in the present study. According to Takatomi, Suzuki and Dendo (1974), marital relationships in families of autistic children are characterised by disagreement, dependency of the husband, defensiveness of the wife, and lack of communication. Detrimental effects on marital relations have also been noted by Sharpley and Bitsika (1997), who support the findings of increased parental stress and complaints of neglect by the spouses of participants in the present study. In more severe cases, parental disagreement on subjective aspects, such as the fairness of each parent's share of parenting and how much each parent should do, could result in irreparable breakdown of the marital relationship and eventual divorce (Hall, 2000; Milgram & Atzil, 1987).

### **Parent-child Relationships: The Needs of the Autistic Child Versus the Needs of Other Siblings**

All respondents in the present study agreed that the birth of their autistic children affected the relationships with their other children. Caregivers mentioned a tendency to devote less parental attention to normal developing siblings, due to the extreme demands that their autistic children made on their time and energy. Caregivers were also concerned and felt that they had to make conscious efforts to spend quality time with their normal developing children. Two participants reported guilt and regret that they had missed out on special moments during their younger children's development, due to their preoccupation with the needs of their autistic children. Participants made the following comments regarding the relationships with their normal developing children:

- A: I cannot interact with him (oldest child) without having to communicate with *J-A* (autistic child), because she needs so much calibration... We've got to be careful now, because *J-A* can actually cause him to completely alienate himself from us. We've got to see that he's also parented, because one tends to under-parent the children who can cope... I cannot even speak to them without being interrupted... I cannot even help him with his homework.
- A: That woman in Cape Town (behaviour therapist) said I have to give *J* and *B* (normal developing siblings) half an hour each of uninterrupted parent time without *J-A* (autistic child) every day. It

sounds so little, but you know, to find half an hour for one-on-one is not easy! I often have to rearrange the whole night, and schedules change all the time with sports and stuff (*Throws her hands up in the air and laughs.*)

- B: I can't actually remember. I can't remember *N* (normal developing sibling) learning to walk, talk, anything... he taught himself. I actually can't remember... With *N*, I think he was ignored a lot. He was a copier, and I was barely coping with *D* (autistic child) and with the both of them.
- F: Something that I regret is that I could never really enjoy *I* (normal developing sibling), because I was always so worried about *J* (autistic child). With *I*'s first birthday... a friend of mine had to host his first birthday party. Do you know how traumatised I was because of that? ... I can't remember anything about *I*... I just remember the confusion with doctors and struggling with *J* with his vomiting and not being able to get him off the nappies.

The above experiences of research participants are confirmed by anecdotal reports from parents of autistic children (Billington et al., 2000; Boushey, 2001; Davis, 2001; Roth, 2001; Stroud, 2002). Similar to participants in the present study, these caregivers were often concerned that they did not spend enough quality time with their normal developing children, due to the demands and special needs of their autistic children. It is also not unusual for caregivers to over-estimate the coping abilities of normal developing siblings and hence to under-parent these siblings (Roth, 2001). Caregivers of autistic children appear to find themselves in a situation that requires the constant negotiation of the needs of the autistic child versus the needs of normal developing siblings (Powers, 2000). This sense of internal conflict, together with the guilt that they may be neglecting their other children, often exacerbate parental stress and may spill over into other family subsystems, such as the marital relationship (Sharpley & Bitsika, 1997).

### **Sibling Relationships: Living with an Autistic Brother or Sister**

A growing area of research in Clinical Psychology is the exploration of siblings as a significant subsystem of the family. A focal point has been understanding the impact a disabled child has on the sibling relationship (Schubert, 1995). In the present study, caregivers shared their perceptions of how the presence of an autistic brother or sister has influenced sibling relationships. Research participants reported that their normal developing children demonstrated anger or resentment toward the autistic sibling, and often felt shame or embarrassment as a result of the autistic child's peculiar behaviours. Two participants felt that the presence of an autistic sibling had resulted in greater responsibility of their other children. One participant expressed concern about the aggressive behaviour or bullying that

her autistic child demonstrated toward a much younger sibling. All four participants reported signs of sadness or depression in their children as a result of the impact of the autistic child on family life. An example of **anger or resentment** in normal developing siblings is:

A: He (older brother) really battles with *J-A* (autistic sister). There's a lot of anger that I pick up on a lot of the time. I try to show him that I express my anger too, not at her, but about her... It's hard to know how to address it without being blatant, because he's obviously sick of his sister, but he's also growing up and trying to make sense of his sister.

Siblings' **shame or embarrassment** about the peculiar behaviours of an autistic brother or sister was expressed as follows:

A: She (autistic sister) is the kind of child that, if she wants to wee, she'll just go off and squat on the grass and wee. And he (older brother) is very embarrassed about that. He doesn't want to invite his friends over here, especially those who don't understand her. It's tough; it's very tough for him.

F: That was the first time that I noticed my second child getting embarrassed. Now, we've got this rule: It's okay to get embarrassed. It's okay. It's not nice to have a brother like *J* (autistic brother). It is not easy or nice for any one of us, but unfortunately we live with this situation and we have to make the best of it. So, it's all right to get embarrassed.

An example of a sense of **responsibility** for the autistic sibling is:

B: *N* (younger brother) is very protective over *D* (autistic brother). There was a time when they were little... we'd go somewhere, and he would say, 'This is my brother, *D*, and he is autistic.' That is how he would introduce the family. So he is always trying to excuse himself and he always asks, 'Will *D* ever come right? How does it work?' So it worries him... But *N* takes everything on himself... he's just that kind of person. He takes on responsibility. He has told us that *D* will live with him when he's older. All of that... and I mean, I have never asked him to look after *D* or anything like that.

**Depression or sadness** in normal developing siblings was described as follows:

A: There's no support available for siblings... The affect on the siblings is, I think, the hardest. But he (*points to youngest child playing in the background*) is fine, because he has never known anything else, being the third one. He hasn't known it, the loss. He's actually more attracted to abnormal children than normal children! He just thinks that's how life goes... so for him there's no loss. But *J* (oldest child)... he has seen how she (autistic child) has changed our lives. At times, I think we must take *J* to a psychologist, just to make sure that we've covered all our

bases and he can talk to someone outside the family, you know... because I don't want him to have problems because of *J-A* (autistic child).

F: It's difficult, you know. It is just as difficult for *I* (younger brother) as it is for any other child to form a relationship with *J* (autistic child). And *J* is sometimes rude to him. For example, if he brings *J* an Easter egg or pours some juice for *J*, then *J* doesn't want it or he throws it down. *I*'s little heart used to break when it first happened... Yes, it's very sad for *I* that he doesn't really have an older brother. He desperately wants an older brother and he wants to be part of a family, because we are not a real family in his eyes.

One participant expressed the following concern about ***aggressive behaviour or bullying*** of a much younger sibling by the autistic child:

D: He is jealous. *A* (autistic child) is jealous... He's related to this one (baby sister), but he will smack her or push her... Sometimes she will look at him as if she is trying to understand what is wrong with him. The baby will look at him; she won't cry, but she will be thinking. She's got those questions, 'What is wrong with this one?' She wants to play with him, but *A* only plays by hitting the baby or by doing something wrong. She will be scared... You will see her running with *A* coming, running... (*imitates a high pitched screaming sound*)... she cries all of a sudden like that without *A* even touching her.

According to Kaminsky and Dewey (2001), sibling relationships in families of children with autism are characterised by less intimacy, prosocial behaviour and nurturance than those of normal developing siblings. Siblings of autistic children have also been found to have lower self-esteem than those of normal siblings, and it is argued that they may benefit from an intervention such as group therapy specifically for siblings of brothers and sisters with autism (Prystalski, 1998). Gold (1993) supports the finding of depression or sadness in siblings of autistic children that was reported in the present study. This author compared 22 siblings of autistic boys and 34 other siblings on measures of depression, social adjustment, and the amount of child-care and domestic responsibility the siblings carry within the family. Siblings of autistic boys scored significantly higher on depression than the comparison group (Gold, 1993). Depression amongst siblings of autistic children has also been linked to increased loneliness of these siblings, since they are not able to communicate or interact in a fulfilling, reciprocal manner with an autistic brother or sister (Bagenholm & Gillberg, 1991).

Two participants in the present study were of the opinion that normal developing siblings were worried about and assumed responsibility for an autistic sibling. According to Bagenholm and Gillberg (1991) and Siegel and Silverstein (1994), it is not uncommon for some siblings to adopt the role of

“brother’s keeper”, thereby assuming responsibility for and worrying about the future of an autistic sibling. These siblings’ concerns about the autistic sibling may be exacerbated by a limited understanding of the nature of autistic disorder and of the impact of this disorder on the affected sibling’s future (Glasberg, 2000).

Anger or resentment toward an autistic sibling was reported in the present study. This often results because of the autistic child’s embarrassing and problematic behaviours and extreme demands on caregivers’ time and energy. Under these circumstances, normal developing siblings may be left with feelings of frustration, anger and resentment toward the child with autism (Barry & Singer, 2001). Whilst this anger and resentment could culminate in aggressive behaviour toward the autistic sibling (Siegel & Silverstein, 1994), a reversed dynamic is more often observed. Because of the communication problems and challenging behaviours that individuals with autism often exhibit, siblings with autism may rely on inappropriate behaviour, such as aggression, to achieve functional effects normally produced with speech. It is therefore not unusual for an older sibling with autism or a related developmental disability to exhibit aggressive behaviours toward an infant or toddler sibling (Barry & Singer, 2001). A participant in the present study reported a similar experience of bullying of a toddler sibling by her autistic brother.

The above discussion illustrates how different family subsystems are affected by the presence of an autistic child. In accordance with the principles of systems theory, participants in the present study reported that conflict in the parental subsystem could spill over into the spousal subsystem or the sibling subsystem and vice versa, thereby illustrating the interdependence of subsystems within the family unit. The most common cause of conflict in the marital relationship related to the extreme demands on time and energy that the autistic child made on caregivers, which gave them little or no time to spend as a couple. Parent-child relationships with normal developing children were affected in that caregivers experienced a tendency to under-parent normal developing siblings. Participants expressed guilt and regret that they had missed out on special moments during their younger children’s development, due to their preoccupation with the needs of their autistic children. Participants further shared their perceptions of how the presence of an autistic brother or sister has influenced sibling relationships. Normal developing children demonstrated anger or resentment toward the autistic sibling, and often felt shame or embarrassment as a result of the autistic child’s peculiar behaviours. In some cases, the presence of an autistic sibling had resulted in greater responsibility of normal developing siblings. All participants noted signs of sadness or depression in their children as a result of the impact of the autistic child on family life.

### **Challenges of Behaviour Management and Disciplining the Autistic Child**

There is little doubt that parenting a child with autism is extremely demanding. Because of the socially inappropriate and aggressive nature of much autistic behaviour, caregivers of autistic children often report high levels of anxiety, depression, and everyday stress from parenting (Sharpley & Bitsika, 1997). Sharpley and Bitsika (1997) go as far as to single out autistic children's behaviour problems as the most common source of stress arising from parenting, and they contend that it is not uncommon for caregivers of autistic children to feel that they are sometimes stretched beyond their limits as a result of their children's problematic behaviours. Participants in the present study also voiced distress regarding their autistic children's behaviour problems. One participant accurately reflected this distress with the following comment:

A: Well, before the diagnosis, *J-A* (autistic child) was like her own agent. She did whatever she wanted to do, and we sort of chased her around! I just ran around doing damage control. I was *J-A*'s damage control expert. At that time, we didn't have the psychological know-how or power to say that this is not acceptable behaviour. We tried so hard... we were getting into such a dilemma of *J-A* ruling the home. We weren't in control. She was in control because of her behaviour.

All participants in the present study reported that they experienced difficulty in disciplining their autistic children, irrespective of the method of behaviour management that they employed. For example:

B: I find it difficult to discipline him (autistic child). I speak to him, but I can't shout at him and I can't change the pitch of my voice. Because, when I do, he gets very upset. And then it escalates into a complete breakdown. He'll start wailing if he thinks I'm really cross... [It] is very hard for me, especially because it is traumatic for him. It is not, like I can explain it to a 5-year-old.

D: To discipline him (autistic child), it's difficult for me... It doesn't help to talk to him. Sometimes I just have to smack him... Sometimes he listens, when I have to smack him so

hard, he will stop... You have to be very harsh. You have to use that voice with him. You can't speak like, 'No, A!' (softly). You have to be, 'No, A!' (loudly).

The difficulty that participants experienced with behaviour management often related to the extreme demands of dedication and consistency that are needed in order to address problem behaviours in autistic children. For example:

A: You have to be obsessively consistent. Not just consistent, you have to be obsessive about it. If you once don't allow this, you must never allow this... and nobody in your care team, even my mother and my father, may allow that behaviour, because she (autistic child) will respond to the minimum level of inconsistency... It's tough, but you have to intervene. You dictate to her what she does, but you do it because you love her and you hate the autism... We had to fight very hard to get her where she is. It's been hard work all the time, and you have to stay confident to manage the child.

B: But it is actually just to confront that thing and say, 'Okay, I'm not taking this any more. This is going to happen, it has to happen... And try to explain things to him (autistic child) and carry on and stick it out, even though he is screaming blue murder. But things like that I found extremely stressful, that I couldn't rationalise in my mind, like why should it be so scary for him or painful or whatever?

Participants in the present study utilised a combination of behaviour management techniques, the choice of which depended on various factors, such as the caregivers' parenting style and the autistic child's temperament. Participants reported the following methods of behaviour management:

### ***Physical punishment***

B: I smack them, all of them, when they fight or when they're naughty or when *D* (autistic child) is naughty, he gets a smack. He gets very upset by a smack. It's not a hard smack or a beating or anything like that. He will usually stop doing what he's doing straight away. And then he withdraws and kind of pulls himself together.

### ***Physical restraint or physical manipulation***

A: So I'll sit her on my lap and hold her, until she gives me eye contact... With *J-A* (autistic child), I can't always hold her, because she gets violent... she bangs her head at me or she'll kick me. So I make her stand and cross her arms like this... (*stretches arms in front of her body and crosses them at the wrists*)... and say, 'Now you stand until you can look at me.' ... when she shows submission, I know we are now calibrated.

F: We are strict, but we have never in our lives raised our hands or hit him with a wooden spoon or anything like that... that child doesn't know what a hiding is. Usually, I can get him to eat his food by using small rewards... but when he doesn't want to, I just take his hand and simply work through him. Sometimes I stand behind his body and I walk through his legs with my legs and eventually we get where we are meant to go... So we use physical manipulation. We work through him... work through his hands. Hand over hand, things get done.

***Verbal reprimands and limit setting***

B: I speak to him, but I can't shout at him and I can't change the pitch of my voice. Because, when I do, he gets very upset.

F: He gets the fright of his life when your eyes get cross or if you start to talk louder or just raise the pitch of your voice. That's how we control him. He is very sensitive... When he starts to jump on the furniture, which he sometimes does, I say (*Talks in a firm voice*), 'No, J, no!' And when he stops, 'Thank you, Darling.' Everything is 'no' and 'thank you'. We get by in this way, but I know it doesn't work for everybody.

Parental stress and difficulty experienced with behaviour management and disciplining have been widely documented in theoretical guidelines for caregivers of autistic children (Dunlap, Robbins, & Darrow, 1994; Jones, 1998). Dunlap et al. (1994) support reports from participants in the present study that extreme dedication and consistency are required to curtail the high frequency of challenging, aggressive and other destructive behaviours in autistic children. According to Connor (1998), successful behaviour management in autistic children requires a systematic approach based upon ongoing and consistent assessments, individual planning, and a consistency of management and expectation among all involved in the child's day-to-day care. It is therefore not surprising that caregivers of autistic children need external support and special training in the task of behaviour management. Teachers, family members and published materials were identified as the most helpful of available resources to aid caregivers in this regard (Dunlap et al., 1994). Parent education programmes have also become an effective mode of treatment delivery for teaching families effective behavioural strategies to manage challenging behaviours in young children with autism (Moes & Frea, 2002).

It is helpful for caregivers of autistic children to interpret their children's problematic behaviours not as malevolent, but as efforts at communication (Jones, 1998). By deciphering the communicative intent or function of problematic behaviours, caregivers can then guide their children to more acceptable modes of communication. Helpful procedures for prevention and intervention include ignoring, interrupting, redirecting, and rewarding target behaviours (Jones, 1998). Similar to reports by

participants in the present study, Moes and Frea (2002) found that behaviour management techniques that work for one child might not necessarily work for another. The success of behaviour management techniques does not only depend on the child's unique temperament (Jones, 1998), but it is also contingent on family members' ability to integrate them into the specific contexts in which challenging behaviours occur (Moes & Frea, 2002).

The above discussion illustrates the difficulties that caregivers of autistic children experience with behaviour management and disciplining of their autistic children. Caregivers shared their distress regarding autistic children's behaviour problems, as well as the demands of extreme dedication and consistency that are needed in order to address problem behaviours. Caregivers find it difficult to discipline autistic children, since physical punishment or verbal reprimands do not necessarily work with these special and diverse children.

### **Challenges of Finding Suitable Resources for Education and Day-care**

In his discussion of the developmental stages of autistic children, Gray (2002) contends that caregivers' concerns and anxiety lessen somewhat once the autistic child has been placed in appropriate day-care and/or educational programmes. He however qualifies this statement by saying that this stage in the autistic child's life remains stressful, since caregivers have to negotiate and interact with a large number of professionals in order to obtain appropriate educational and financial resources to meet the child's needs. Participants in the present study reported similar difficulties in their search for appropriate day-care and education for their autistic children.

All participants repeatedly needed to move their children from one preschool or day-care centre to the next, since these facilities were either unable or unwilling to manage the autistic child's problem behaviours or to meet the child's special needs. These changes were not only traumatic for the children concerned, but caregivers also experienced emotional turmoil as the search for appropriate resources began anew. The following excerpts reflect the challenges that research participants experienced with day-care centres and preschools:

D: Even at crèche they could not take care of him. They said no, uh-uh, they cannot take care of A (autistic child). He was coming home dirty... He's very much hyperactive and he's playing alone. They must look for him when sometimes they can't find him. They will find him, maybe playing with the dog or the dog's bowl, and in the dog's kennel. He will play there alone... He was in crèche only for a short time... But then they said that they could not keep him there, and he was still too young to go to Quest (special school for learners with autism).

- A: We were just muddling along. I took her (autistic child) to about four preschools. They all said, ‘Oh no, we can’t handle her, we can’t handle her!’ ... She was unmanageable, and I needed a break! I thought it was okay and that she was old enough, but they all kicked her out. They said that they can’t manage her, she throws out popcorn, takes other children’s food, she bullies them on the playground, or she wants to swing all the time. And eventually I took her to Aurora, because they’ve got a care centre for disabled children.
- B: I met a woman in [home town] who had a Montessori playschool, and I thought that I’d like to send my children there... And Montessori was good for him (autistic child), because it is so behaviourally orientated... I remember that children were horrible to him, older children... And then she closed, so I took the two of them to [mainstream preschool], and I didn’t like them at all. They didn’t like *D* (autistic child), and I felt badly treated by the teachers and the institution and whatever. They had big classes and they didn’t understand the problem... They didn’t want to understand the problem. It’s a normal mainstream preschool. They just treated me badly and they treated my child badly. So I took them out of there, and I sent *D* to [another mainstream preschool], which is an Afrikaans school, a preschool... and I found them great! Much more accepting. They had two other children that they did not know what was the matter, but they were obviously attention deficit or something.

All participants in this study have autistic children of school-going age, who are learners at Quest School for Learners with Autism in Port Elizabeth. Caregivers had to go through extensive evaluation and assessment programmes with their children, who also had to undergo an observation period of one month before they were permanently accepted into the school. Whilst participants were generally satisfied with the education that their children received at this facility, they did not necessarily regard it as a long-term solution, and they were concerned about the extent to which the school equipped their children for life after school. For example:

- D: He (autistic child) just needs education, but is it going to be normal education, or is he going to stay here in Quest? At the end of the day, what is Quest going to do for him? Although they’ve got that structured environment for him, but you wonder up until when. Is he going to be able to fend for himself? I wish he can get like something, or play sport or something. Something that he’s going to build... going to mould him to be someone, you see.
- F: I am concerned that, if he’s no longer in school, he’s not going to have the same goal directedness in his life. I am concerned that he won’t know how to keep himself busy. I am

concerned that we won't have the means or resources to keep him occupied. I would like him to remain included at Quest, even if it's just to do odd little jobs.

Only one participant ran a structured home-based education programme in addition to her child's formal schooling. The biggest deterring factor for the implementation of home-based programmes is the cost of such programmes. Participants were of the opinion that their children's education in general is very costly, which poses additional challenges for caregivers and children from low-income households. Participants made the following comments regarding the high cost of their children's education:

A: If I had enough money, I would keep her (autistic child) in an eight or nine hour programme every day at home. But I just can't afford it... The biggest expense for her now is obviously the tutoring. If I lived in Cape Town, I would pay R50.00 an hour. That's because it's specialised one-on-one tutoring, and that's what they get paid by parents there. If I lived in America, then \$45.00-\$60.00 an hour. I pay a whole lot less than that, and I say, 'This is what I can pay. Can you help me?' And those are the terms that they must agree to... We try to think of it in this way: If *J-A* (autistic child) went to a private school; we would be looking at say R1000.00 a month. Now, *J-A* is costing us about R2000.00 a month, just her education, because we've got tutoring and school. So what we've got to do is just to borrow money and extend our overdraft... I mean, what do you do? You are in trouble; you are seriously in trouble if you've got no money. There is nothing there... no free state services for disabled children.

D: It's good to have Quest, like a school where they can take care of your child... but although it's very much expensive, and it's very expensive to raise an autistic child... Education is expensive. Because here at hostel, you are paying about R950.00 a month. The hostel fees and the school fees also...and the school fees it's R200.00, so it's expensive.

Davis (2001) confirms the above experiences of research participants in his anecdotal account of raising his autistic son. In terms of day-care, he experienced childminders to be ignorant regarding the specific needs and methods for teaching autistic children. Similar to participants in the present study, Davis (2001) noted that mainstream preschools were either unwilling or unable to manage his son's behaviour problems. They were also resistant to acquire the necessary skills to do so. For this reason, he was often asked to seek alternative day-care for his son, which caused great stress for him and his wife. The problem is further exacerbated when both caregivers are employed and when appropriate day-care is thus essential (Haeussler & Kurtz-Costes, 1998). Haeussler and Kurtz-Costes (1998) conducted a study regarding mothers' experiences and requirements of day-care centres. Forty mothers

of preschoolers with autism were interviewed about their children's day-care programmes and the factors that influenced their selection of one day-care centre over another. These mothers of children with autism had many of the same concerns as mothers of normal developing children. They valued safety, warm, loving and competent caregivers, and cleanliness. They were also concerned about the extent to which day-care centres had programme features that might be especially important for their autistic children, such as a focus on skills of adaptation in the outside world (which participants in the present study also mentioned as a primary concern), the availability of special services, and an individualised programme for each child. Davis (2001) is of the opinion that the search for funding for his son's home-based education programme was a major stressor in his family. Similar to participants in the present study, Norton and Drew (1994) agree that the high cost of specialised education is one of the most potent stressors in families of autistic children.

According to Dempsey and Foreman (2001), there is a wide variety of specialised education methods for children with autism. *Inter alia*, these include sensory-motor therapies (sensory integration training, auditory integration therapy and music therapy), applied behaviour analysis, communication therapies, multi-treatment programmes, play therapy and group therapy. A detailed discussion of these education methods falls beyond the scope of the present study. It is suffice to say that the selection of a method, or combination of methods that will best meet the unique needs of their autistic children, poses a troublesome task for caregivers (Dempsey & Foreman, 2001). Hurth, Shaw, Izeman, Whaley and Rogers (1999) suggest that caregivers should regard the following programme practices as critical in their selection of appropriate education programmes for their autistic children: early intervention; individualisation; specialised curriculum; family involvement; systematic instruction; intensity of engagement; structured environment; developmentally appropriate practices; and integration with typical peers. The above criteria are however based on the premise that caregivers have multiple resources to choose from in the first place. In light of the limited resources for learners with special education needs, caregivers of autistic children in South Africa are faced with a completely different situation. Quest School for Learners with Autism in Port Elizabeth is the only facility in the Eastern Cape that caters for children with autism, with other major centres located in Cape Town, Johannesburg, Pretoria and Durban (Autism South Africa, 2000).

This theme explored the difficulties that primary caregivers encounter as they search for suitable day-care and education for their autistic children. Mainstream preschools and schools are unable to meet the special education needs of these children, and are often unwilling to accommodate them because of their behaviour problems. Caregivers are faced with limited resources for learners with

special education needs in South Africa, and the financial burden associated with such education further exacerbates the stress on these families that are already severely taxed.

### **Maintaining the Family Unit and Doing Things as a Family**

From the above discussions, it is evident that autism has a pervasive influence on different areas of family life. Relational dynamics in different family subsystems are adversely affected, and caregivers are faced with unique challenges in areas of behaviour management, discipline, education, and day-care. In conclusion, it is argued that the presence of an autistic family member poses unique challenges to primary caregivers to maintain the family unit.

Two threats to the family unit were identified in this study. Firstly, participants experienced that the presence of an autistic child often resulted in the loss of family friends. For example:

A: It's just impossible. You can't have a normal life... people don't know how to interact with us as a family any more... everybody has moved away. We don't have family friends any more. People stopped inviting us for meals or to go out for coffee or to go out to eat, because it's so unpleasant with *J-A* (autistic child). We just don't have that. I don't know how this is going to play out in the future, or where we are going to find friends.

F: You lose your friends, because everybody goes on outings or goes away for weekends, and you know that your [autistic] child can't join in, because he makes funny noises the whole time and he spins stuff around. People find that irritating.

Families further isolated themselves because of public scrutiny and unacceptable behaviour of the autistic child in public places. For example:

B: I think many parents who stay in the city with a difficult child isolate themselves even more, because there are so many people who can criticise or query or whatever. You just get so sick of explaining to people that your child is autistic.

D: Your life is not the same any more when you've got an autistic child... You don't go visit friends. And you are scared to go to public places with him because he will just... be wild. Go all over the place and people start looking at you. Some of them, they think, 'No, this is a spoilt child.' Because he will take this, he will take this, he will take this, and they won't understand... You hardly go to churches, you can't go with him.

Participants found that everyday family activities (that typically foster family cohesion) became cumbersome chores, rather than opportunities to enjoy socially as a family. Shopping and family meals, either at home or at restaurants, were mentioned as specific challenging activities. According to research participants, it is easy for their autistic children to become over-stimulated in shops, which usually results in temper tantrums and defiant behaviour. For example:

- A: Going to the shops is a mission, because I have to have one hand on her (autistic child's) hand. We've got to a point now, that she's big enough, that she may not go in the trolley... Before, she had to stay in the trolley, because she would run around and unpack and open up chocolates and eat them or grab handfuls of nuts. If you left her in the shops... I would just pretend she isn't mine. Terrible, terrible behaviour in the shops and restaurants and any public place. Taking her to the shops for shopping therapy used to be impossible, now that's improving...
- B: Look, I mean he (autistic child) could scream a place down if he was over-stimulated, like a shopping centre or something... He loves shopping, and the escalators and lifts and whatever. But then, it can get too much for him, and then he just flips out... *D* (autistic child) used to scream the place down... So he used to stand at the checkout, screaming... for the whole 20 minutes or however long it took to ring up.

Due to their children's food fads and difficulties related to eating, participants seldom enjoyed meals together as a family. Their children's inappropriate behaviour also made it difficult for participants to go out to restaurants with their families, or to have meals with friends. Experiences surrounding meals and eating were described as follows:

- A: *J-A* (autistic child) has now got to eat separately from us, because she can't behave at meals. I've now intervened and taken control and decided that we're going to stop this... For now it's eating slowly and normally without screaming or throwing her food around and without throwing a tantrum and without gobbling, by herself, without us telling her to do that all the time... It's really not easy... If she sees the food, if she sees me dishing up the food, she throws a tantrum, because it's not coming fast enough.
- F: He (autistic child) has got very specific food preferences and dislikes... We had it very difficult with him. He was raised on Purity and spaghetti. Spaghetti and tomatoes, that's all that he could keep down. His eating was very limited. The disadvantage of this is that we can't sit around the table and eat together as a family... I often say to *C* (husband), 'Listen, I can't take this any more! Just go get *J* a McDonald's burger or some Kentucky.' So *J* (autistic child) often eats completely different from the rest of the family... Sometimes we fall apart emotionally because

we have to struggle so much with each meal. He just sits here (*dining room table*) and stares out the window. He looks at the water in the pool and forgets to eat. His food gets ice cold.

Sometimes we have to reheat it up to three times. And then there are times when I just throw it all away or give it to the dog and I suppose he has to go hungry then, but I just can't carry on like that any longer.

A: We take her (autistic child) to restaurants for her therapy, not for fun. So when we take her to a restaurant, we have got to take a hundred things for her to do and sit her right up the wall and put your hands around her and say, 'You behave now.' It's absolutely not fun.

In addition to difficulties in shops and restaurants, participants experienced restrictions on family holiday and leisure activities. Participants felt that extra planning and preparation are necessary with an autistic family member, since activities such as outdoor camping, that lack structure or boundaries, are not necessarily suitable for autistic children. All participants felt that the presence of an autistic family member makes it very difficult and challenging to do things as a family, but they nonetheless agreed on the importance of building pleasant family memories. The following comment accurately reflects this sentiment:

A: We didn't know what to do. We felt so strongly that we need good family memories. If all our weekends were spent chasing *J-A* (autistic child), the boys were going to get nothing. One can only swim so often. I mean, the pool is one aspect, but it is not enough to keep a family together. I like riding... the boys don't really like riding so much. *J* (oldest son) can ride and *J-A* (autistic child) loves it. So we had to make a choice together, and consider the financial costs... So it's all very compartmentalised, our roles are very compartmentalised. So we had to find something that we could all do together. So the boat was that, and *J-A* loves the boat.

According to Vaughn, Wilson and Dunlap (2002), the implementation of fundamental daily activities within the community can be a challenge for families with children who have significant disabilities and problematic behaviours. As was the experience of participants in the present study, these authors contend that community outings, such as visits to shops or restaurants, can become the venue for confrontation and sources of embarrassment due to the children's challenging behaviours. They agree on the threat that serious challenging behaviour holds for the family unit, since it exacerbates families' reluctance to pursue family routines, thus placing them at risk for social isolation (Vaughn et al., 2002). Boyd (2002) also warns against the threat of social isolation and withdrawal, since caregivers of autistic children may become caught up in a vicious cycle where a lack of public awareness and tolerance can lead caregivers to withdraw from the larger community because of

negative characteristics they associate with their child's disability. The above experiences of research participants are further confirmed in a study by O'Moore (1978), who interviewed 25 mothers of autistic children regarding the problems that arise in the rearing of autistic children. Similar to findings in the present study, these mothers reported that the families' social contacts decreased after the birth of their autistic children. They also reported challenges to cope with their children's behaviours during shopping, family outings, and holidays (O'Moore, 1978).

The above discussion illustrates the challenges that caregivers of autistic children face with everyday family activities such as shopping, family meals, eating out at restaurants, family holidays, and leisure activities. In spite of all these challenges, primary caregivers still manage to cope and to maintain the family unit. *Inter alia*, they have learnt to plan ahead, live in the moment, and to take time-out in order to replenish their own energy. The following interview excerpts illustrate these ways of coping:

#### ***Living in the moment***

F: You know, you never know what to expect with these children. They are surprise packets. One day, one thing; the next day, another. I don't know, we just seem to deal with things as they happen. That makes it easier for everyone. I don't get stressed any more that he should one day be perfect. I no longer force *J* (autistic child) to go shopping with me. I know he enjoys walking, so we go walking together, old *J* and I! I don't force him to do funny things. We rather get in the car and go buy an ice cream and go sit by the seaside. We enjoy simple moments like that, you see? That's how I cope.

#### ***Planning ahead***

A: You just have to strategically plan all the time... even though you are planning ahead, you also just take every day as it comes... Like, what are my plans for the day? Like, for example, I need to be able to cook supper in the morning, so that when the kids are here in the afternoon, I can be there for them. The real time is now, but you've also got to plan ahead, so that you can have the moment.

#### ***Taking time-out***

F: Once a year, *C* (husband) and I go away together. This year, we went to [holiday destination]. We stayed there for a week in the loveliest Bed and Breakfast. Then we just forget about the stress and the children and everything. Sometimes, we also get away for a weekend... We give ourselves that time. So, we also take good care of ourselves... For example, if I get off early

from work, I won't rush home every time to be with the children; I'll go watch a movie or go visit a friend.

Gray (2003) conducted a qualitative analysis of the role of gender and coping among parents of children with autism. In terms of practical or problem-solving coping strategies, he noted that there was a significant degree of similarity between both male and female caregivers of autistic children, in that they both used anticipation and planning as well as dealing with problems as they happened as their most popular practical coping strategies. Gray (2003) hence agrees with participants in the present study that planning ahead and living in the moment constitute effective ways of coping with everyday demands of raising children with autism. According to Boyd (2002) and Norton and Drew (1994), the use of respite care services in families who have children with autism appears to be particularly effective to alleviate some of the stresses in these families. The provision of respite care services provides over-stressed caregivers with essential time-out to replenish their own energy. In this regard, it is significant to note that, in light of the limited resources available within the mental health context in South Africa, the option of respite care is very rarely available to the primary caregivers of autistic children in this country. Participants in the present study nonetheless made conscious efforts to take time-out for themselves, mainly via the support and assistance of grandparents.

The above discussion supports the notion that the presence of an autistic child poses unique challenges to primary caregivers to maintain the family unit. Two threats to the family unit were identified, namely loss of family friends; and social withdrawal due to public criticism and inappropriate behaviour of the autistic child in public places. Specific difficulties were reported with everyday family activities such as shopping, eating out at restaurants, family holidays and leisure activities. Participants nonetheless managed to cope by planning ahead, living in the moment, and taking time-out in order to replenish their own energy.

## CHAPTER 5

### CONCLUSION

The overall goal of this study is to explore and describe how the primary caregivers of children with autism experience the diagnostic process, how they adjust in different areas of family life after the diagnosis has been made, and how helping professionals can improve their service rendering to these families. This goal was attained by conducting a series of three semi-structured interviews each with four research participants, who are the primary caregivers of autistic children attending Quest School for Learners with Autism in Port Elizabeth. Central themes and categories that resulted from the data analysis and interpretation process were discussed and evaluated as they correlate with and/or contribute to existing literature.

The following conclusions can be drawn from the research findings:

1. The psychological turmoil of primary caregivers of autistic children already starts shortly after the birth of the infant, prior to the initiation of the diagnostic process. Caregivers may be riddled with confusion and doubt as they struggle to understand health problems or developmental abnormalities in children who outwardly appear to be perfectly normal. Some caregivers may vacillate between denial or rationalisation and acceptance when they first start to notice developmental delays and early warning signs in their children. During the pre-diagnostic stage, caregivers of autistic children are often anxious and fearful that something terrible might be wrong with their children, and they can become discouraged by their apparent inability to understand their children or to curtail their problem behaviours.
2. Female caregivers generally experience greater stress and responsibility in caring for autistic children than their male partners. Their position of increased responsibility exposes female caregivers to blame and criticism by their partners, which exacerbate their perceived stress, self-blame and guilt regarding the autistic child's condition.
3. The relationship between caregivers and helping professionals is one of the most important relationships that mediate caregivers' experiences of the diagnostic process. Caregivers of autistic children feel disempowered by a tendency among helping professionals to negate their concerns and to not take reports of delayed development in their children seriously. Professional opinions expressed during the diagnostic process are sometimes vague, confusing, contradictory and non-definitive. Either by referral or on their own, most primary caregivers of autistic children have many professional contacts, because the diagnoses of the children are so

varied. As a result of these diagnostic difficulties, the possibility exists that primary caregivers of autistic children could become disillusioned and lose their trust in medical professionals.

4. No family goes untouched by the diagnosis of a child with autism. Initial relief needs to be viewed with caution, since it may merely result from the fact that, by comparison, caregivers have not received news of life-threatening conditions in their children. Caregivers of autistic children experience a complicated form of non-finite loss and grief that is ongoing and changing as life continually falls short of expectations. The grief process of primary caregivers of autistic children relates to the loss of a normal child. Various emotions are associated with stages in this grief cycle, namely: initial shock and denial; anger and resentment; depression; and eventual acceptance.
5. In accordance with the principles of systems theory, all family subsystems are affected by the presence of an autistic child. It is not uncommon that conflict in the parental subsystem could spill over into the spousal subsystem or the sibling subsystem and vice versa, thereby illustrating the interdependence of subsystems within the family unit. A common cause of conflict in marital relationships relates to extreme demands on time and energy that autistic children make on caregivers, which give them little or no time to spend with their partners. Parent-child relationships with normal developing children are affected in that caregivers tend to under-parent normal developing siblings. Caregivers may be left with guilt and regret that they had missed out on special moments during their younger children's development, due to their preoccupation with the needs of their autistic children. Normal developing siblings may demonstrate anger or resentment toward the autistic sibling, and often feel shame or embarrassment as a result of the autistic child's peculiar behaviours. An increased sense of responsibility and sadness or depression has further been noted in siblings of autistic children.
6. Autism has a pervasive influence on different areas of family life, which poses unique challenges to the family's post-diagnostic adjustment. Primary caregivers are often distressed by their autistic children's behaviour problems, as well as the demands of extreme dedication and consistency that are needed in order to address such problem behaviours. Caregivers find it difficult to discipline autistic children, since physical punishment or verbal reprimands do not necessarily work with these special children. Primary caregivers of autistic children face further challenges as they search for suitable day-care and education for their children. Mainstream preschools and schools are unable to meet the special education needs of these children, and are often unwilling to accommodate them because of their behaviour problems. Caregivers are

faced with limited resources for learners with special education needs in South Africa, and the financial burden associated with such education further exacerbates the stress on these families. Due to the presence and special needs of an autistic child, it may be difficult for primary caregivers to maintain the family unit and to do things as a family. It is not uncommon for families to lose family friends or to isolate themselves because of public criticism and inappropriate behaviour of the autistic child in public places. Everyday family activities such as shopping, eating out at restaurants, family holidays and leisure activities can potentially become stressful experiences rather than opportunities to enjoy socially as a family. In spite of adversity and challenges, caregivers of autistic children still manage to maintain the family unit by planning ahead, living in the moment, and taking time-out in order to replenish their own energy.

The following recommendations are provided for improved service rendering to families of autistic children:

1. Helping professionals are encouraged to empower caregivers with information and resources, and to employ a collaborative parent-professional model, whereby primary caregivers are recognised as experts on their children's behaviours and become active participants in their children's treatment. Helping professionals can aid the caregivers of autistic children in their journey to adjustment by respecting and addressing their emotions of loss and grief, encouraging families to take time to heal, and by providing them with facts about autism and related disabilities. Specific attention needs to be given to the attribution of blame and responsibility within the family, as well as possible spillover effects in the marriage relationship, parent-child relationships, and/or sibling relationships.
2. Primary caregivers of autistic children may benefit from professionally run support groups where they can share challenges, experiences and learnings in the difficult task of raising children with autism.
3. Research participants called for greater collaboration and partnership between multi-disciplinary professionals during the diagnostic process. Holistic assessments are recommended that evaluate autistic children and their families within their micro-, meso-, and macro-environments. Specialist medical centres for children with pervasive developmental disorders may provide suitable resources for such services, and could further increase public awareness of and empathy for the unique challenges that families with autistic children encounter.

In light of the limited scope of the present study, the researcher could not explore the influence of an autistic family member on family dynamics in greater depth. Since all participants in the present study are female, possible gender differences in male caregivers' experiences of raising children with autism remain unexplored. Reports of sibling relationships, as affected by the presence of an autistic brother or sister, were based on caregivers' observations. Future studies that are aimed directly at siblings of autistic children are recommended to compare parental observations with siblings' phenomenological accounts of life with an autistic sibling.

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## **APPENDICES**

Appendix A: Semi-structured Interview Guides

Appendix B: Interview Transcripts

Appendix C: Participant Information Letter and Consent Form

## APPENDIX A: SEMI-STRUCTURED INTERVIEW GUIDES

### INTERVIEW 1: EXPERIENCES UP TO AND INCLUDING THE DIAGNOSTIC PROCESS

- Researcher introduces self and summarises the aim of the study. Go through information letter with participant and answer any questions that s/he may have.
- Ask participant to complete and sign the departmental consent form to audiotape the series of 3 interviews.
- Main areas of inquiry:

[Start questions with: *How have you experienced...; What is your understanding of...; Please tell me more about...; What was it like...; What do you remember most...; What was most helpful...; What made it difficult...; What (if anything) would you have done differently...; What sense did you make of...]*

1. Biographical data (Name, age, employment, highest level of education, home language, marital status).
  2. Family size and focussed family history (Employment of caregivers, birth order of children, basic characteristics/personalities of family members).
  3. How did you experience [name of autistic child] as an infant and baby? What was s/he like as a toddler and before going to school? What do you remember most as you think back to that time?
  4. How did it come about that you decided to seek help for [child's name]? Tell me about this time in your family's life. Who first mentioned the word autism? What sense did you make out of such a diagnosis/ what did that diagnosis mean to you? What was particularly difficult during this time? What was helpful? How did you feel during this stage? What did you do/felt like doing after you were told? What thoughts and concerns ran through your mind as you tried to understand your child's condition?
- Summarise main areas covered in the interview. Ask participants to share anything else about the pre-diagnostic stage and diagnostic process that they regard as important or that the researcher did not ask about.
  - Arrange time for 2<sup>nd</sup> interview.

**INTERVIEW 2:  
POSTDIAGNOSTIC ADJUSTMENT AND COPING**

- Clarify aspects from first interview, if need be.
- Introduce topic of 2<sup>nd</sup> interview: Postdiagnostic adjustment and coping.
- Main areas of inquiry:

[Start questions with: *How have you experienced...; What is your understanding of...; Please tell me more about...; What was it like...; What do you remember most...; What was most helpful...; What made it difficult...; What (if anything) would you have done differently...; What sense did you make of...]*

1. Tell me about the general running of the household after [child's name] was diagnosed with autism. How is this different now than it was when s/he was first diagnosed? How did you manage daily tasks such as meals, bath time, using the toilet, bedtime, and fun activities? What difficulties did you encounter? What helped?
  2. How did you cope with all the demands on your time and energy? What or who was most helpful in coping with the demands of raising a child with autism? Who did you turn to for help?
  3. Tell me about your experiences, struggles and eventual adjustment in terms of:
    - 3.1. your child's education and day care;
    - 3.2. effective methods of behaviour control and discipline; and
    - 3.3. the impact of the autistic child on other siblings and family members.
- Summarise main areas covered in the interview. Ask participants to share anything else about the postdiagnostic adjustment and coping that they regard as important or that the researcher did not ask about.
  - Arrange time for 3<sup>rd</sup> interview.

### **INTERVIEW 3: PRIMARY NEEDS, CONCERNS AND SUPPORT SYSTEMS**

- Clarify aspects from 2<sup>nd</sup> interview, if need be.
- Introduce topic of 3<sup>rd</sup> interview: Primary needs and concerns, and efficacy of available support systems.
- Main areas of inquiry:

[Start questions with: *How have you experienced...; What is your understanding of...; Please tell me more about...; What was it like...; What do you remember most...; What was most helpful...; What made it difficult...; What (if anything) would you have done differently...; What sense did you make of...]*

1. As you think back to everything that you have been through with [child's name], what did you feel most uncertain and alone about? What did you really need help with? What did you need in order to be able to also take care of yourself?
  2. How do you feel about the resources and support systems available to caregivers of autistic children in your region (Port Elizabeth)? What formal support systems and helpful organisations are available to you? What informal support networks have helped you through tough times? How did you experience the efficacy of these resources? What do you still need? How can the services available to caregivers of autistic children be improved?
  3. What are your thoughts about [child's name's] future? What are your main concerns about him/her? What gives you hope?
- Summarise main areas covered in the interview. Ask participants to share anything else about their needs, concerns, or thoughts about available resources and support systems that they regard as important or that the researcher did not ask about.
  - Thank participants for their willingness to share their experiences. Obtain postal address or telephone number to provide summarised details of the major findings and recommendations of the study at the completion of the research to participants who want this information.

## APPENDIX B: INTERVIEW TRANSCRIPTS

### INTERVIEW TRANSCRIPTS PARTICIPANT A

#### BIOGRAPHICAL DATA

<b>Pseudonym:</b>	A
<b>Sex:</b>	Female
<b>Age:</b>	38 years
<b>Occupation:</b>	Home executive
<b>Highest level of education:</b>	Tertiary (Teacher)
<b>Home language:</b>	English
<b>Marital status:</b>	Married
<b>Relation to autistic child:</b>	Mother
<b>Autistic child:</b>	J-A, Female, 7 years old. Has an older brother (10) and younger brother (3).
<b>Date/s of interviews:</b>	9 April 2003

*(Prior to starting the interviews, the researcher went through the information letter that was distributed to participants, with consent forms, prior to the commencement of the research. The researcher further explained the aim of the study, the manner in which confidentiality and anonymity would be ensured, and asked research participants to complete and sign the departmental consent forms to audiotape and transcribe the series of three interviews.)*

#### INTERVIEW 1: EXPERIENCES UP TO AND INCLUDING THE DIAGNOSTIC PROCESS

- R: Firstly, please tell me about your family... you, your husband, and the children. How do you perceive their personalities and the relationships between the various family members?
- A: Obviously married. J-A (autistic child) is the second child. Oldest child is 10, a boy. The second child is J-A, she's 7, and then B, he turns 3 in June. I was a teacher, but stopped working after the birth of the first child. I didn't go back. My husband's a technical director at a paint company. He was a mechanical engineer at Volkswagen, but now he does practical operations... chemical work. J-A comes home every afternoon. I tried to put her into aftercare, but her behaviour worsened because it wasn't structured. She became difficult to manage, because the home is structured... but she's home every afternoon. *(Pause)*.
- R: Tell me more about your children, starting with the oldest one.
- A: J (oldest child) is exceptionally bright. He had to skip a grade because he was reading way above his age level, so he skipped Grade 2. He taught himself to read... he picked up German in Germany at like 4. Even though he's a year behind his class he is still way ahead of his class. He is very shrewd, and he can be manipulative and moody... he's going for that 10-11 age now. He really battles with J-A, there's a lot of anger that I pick up on a lot of the time. I try to show him that I express my anger too, not at her, but about her. I try to encourage him to express that anger. She will go into his room and dismantle stuff... and she takes his things, like his books, and folds them up or throws them in the pool. We have to lock all the doors and cupboards. And if you leave it open, she knows. She like senses that the door is open and runs in and disrupts what we are doing. I cannot interact with him

without having to communicate with J-A, because she needs so much calibration. He just rolls his eyes and walks away. There's a lot of stuff going on there. It's hard to know how to address it without being blatant, because he's obviously sick of his sister, but he's also growing up and trying to make sense of his sister. Because he's so bright, he sees things at a much higher level, but he still has to go through the emotional stages. He is only 10, you know. In his class, he's like the general knowledge expert and the maths expert and the expert on the war in Iraq. So he's way up there, but he's got to deal with these things on a 10-year-old level. I've got to treat him with great respect. If I bully him, he just gets worse. My husband likes to bully him. Sometimes, he just has to go... (*throws play punches in the air*)... 'Sort yourself out!' His behaviour is so good sometimes, but when you just let it slip, slip, slip and then suddenly... (*punches fist in her palm*)... We've got to be careful now, because J-A can actually cause him to completely alienate himself from us. We've got to see that he's also parented, because one tends to under-parent the children who can cope...

R: ... Since the child with autism requires so much attention?

A: Ja, so much... all my attention. I cannot even speak to them without being interrupted. J-A will see that... I cannot even help him with his homework. J-A will run in and grab his rubber, or run around and throw things in the pool. We can't leave her; she disrupts everything if she is left alone. (*Pause*). J-A is a very happy, loveable child. She is not malicious. I've seen malice in her, which is an encouraging sign... (*Laughs*).

R: Sounds like she certainly has diversity of emotion!

A: She certainly does. She cries and... she does. She is not a rigidly autistic child. She is obviously autistic, but she's got many things that make you think this diagnosis isn't right sometimes. It makes you think. But she's happy... She bounces back so quickly. When she's been reprimanded, she is remorseful. She shows remorse now. She didn't in the beginning... she must have been a bit psychopathic! She does cry now, and shows empathy. She bounces back quickly, but she is very up and down.

R: So her mood is labile at times?

A: She is very labile, yes. She was much worse... she'd throw things and have violent mood swings. With the treatment we have been doing in the last three years, there has been a great improvement in that. And then little B... He's very charming, but can also be very manipulative. He knows exactly how to use language to his own advantage. He speaks on the level of a four and a half-year-old. He's got excellent language control. A year ago, his language outgrew that of J-A. So now he teaches her how to talk. He can be very demanding as well and sometimes throws tantrums. But, because of what I've been through with J-A, I am much more aware of what he does and how he behaves and his discipline. He's got a much different level of discipline than J had, because of J-A.

R: In what manner?

A: The control that I have and letting him get away with things. Having techniques now, which I learnt through J-A to manage this kind of behaviour. This has been a very positive thing with J-A. Like this behaviour is not acceptable and now I am going to do this and this. They get smacks from time to time, but that's not the main method. I've got other ways of calibrating.

- R: That's a very interesting concept. You've said before that J-A needs a lot of calibration. What does that mean?
- A: It's like reset. Like, your behaviour is out of control now, so now I am going to hold you. So I'll sit her on my lap and hold her, until she gives me eye contact. Even a normal child will avoid eye contact, because they don't want to submit. My little niece will sit like that for up to 45 minutes before she will look at her mother. She's small, so she can manage her. She'll just say, 'You sit now until you are calm and realise that I am in charge'. They need to learn that the parent is in control and they need to learn that the hard way. With J-A, I can't always hold her, because she gets violent... she bangs her head at me or she'll kick me. So I make her stand and cross her arms like this... (*stretches arms in front of her body and crosses them at the wrists*)... and say, 'Now you stand until you can look at me.' And then she has to look at me. I can see, when she's not submitting, she'll say, 'I work' or 'I calm' or whatever she thinks I want to hear, but the quality of the eye contact is not there, it does not show submission. But when she shows submission, I know we are now calibrated. She used to get out of calibration very quickly, especially on days when she had eaten certain kinds of food. Then I often had to step in until we are recalibrated. With this one (*shows to B playing in the background*) I have to do it like once a week. They have to know their boundaries in order for them to grow and test their boundaries. They must test. The only way you know your boundaries is when you step over them.
- R: It certainly sounds as if your experience with J-A has been very valuable in this regard.
- A: Certainly it has helped. This year in January I was with a behavioural therapist in Cape Town. She actually changed our lives around, because we were getting into such a dilemma of J-A ruling the home. We weren't in control. She was in control because of her behaviour. And I had nobody to help me. My parents live next door, they moved out here to help us. But we had many visitors who'd say, 'Come out for supper.' But you can't go anywhere with J-A without a scene, because she can't eat properly and she runs around and she... she... (*throws her arms up in the air and laughs*)... It's just impossible. You can't have a normal life. That's stressful, and her behaviour was terrible. So I said, 'I have to go to Cape Town.' We spent a lot of money. I stayed there with J-A for three weeks. She had to treat my mind to say, 'You are the mother, you are in control. Do something.' Parents these days don't know how to parent. So that's been a positive thing. Even with J, I can now say, 'I'm the authority here, you won't do that.' It's that whole thing of someone's got to teach you about authority in the outside world, but not a vicious authority... you have to be confident, like a psychological authority almost.
- R: What has this training meant for you?
- A: It has turned my whole perspective around. Now this is the tutoring room where she gets tutored (*points down the hallway*). Before January, I had a tutor come in like twice a week and on Saturdays. Now if I went in that room, J-A would hit a complete wobbly and fall on the floor because I came in and she wanted to be with me. That would upset her for the whole hour. So in Cape Town, I had to go in and do a lot of the tutoring myself... I still do, because I know that this is her program and I know what she should be doing. So now I can go in at any time. When she's working with her tutor, I can interrupt them. I encourage the interruptions, because that means that she has to keep on focusing without shifting attention. I also know exactly what the tutor is doing. I can pop in there at random times and they can't get away with things any more. I am the authority now, not someone else and not J-A.
- R: You've said little about your husband. How does he get along with J-A?

- A: Their relationship is quite healthy in the sense that he'll play with her. Because I'm the one who's been to Cape Town and I'm the one who does all the reading and research, he looks at me. So I'm the authority... so he has to listen to what I say and that. Even disciplining and controlling, when he's not sure what to do, I say, 'No, you should do that now.' It's obviously stressful because he can't deal with things. But compared to some other parents, he really does well, but it's not easy at all.
- R: And you? Please tell me a bit more about you and J-A.
- A: Well, there's a lot of this love-hate relationship (*laughs*). I hate the autism, I love J-A. When I see the autism slipping away a bit, then that is marvellous, because she interacts. But when you leave her unstructured, the autism just comes flushing back. Autistic children require a lot of structure and a lot of input and a lot of intervention, extremely demanding, but I've learnt a couple of things the last two years, I suppose. One of them is that you have to be obsessively consistent. Not just consistent, you have to be obsessive about it. If you once don't once allow this, you must never allow this. But other children will learn, even despite your mistakes. You must be absolutely obsessive, and nobody in your care team, even my mother and my father, may allow that behaviour, because she will respond to the minimum level of inconsistency. Where the normal child will know, 'Ag shame, this woman just slipped up'. They'll know that; the reasoning is there. She (J-A) doesn't read those codes of interaction yet. That's the hardest thing for them to learn. She used to go into the shop... she has stopped it now because we have intervened... she used to lift up people's shirts to look at their belly buttons in the shop (*laughs*). There's this other thing I learnt to be, called the benevolent dictator.
- R: That sounds like quite a loaded phrase. Explain to me what that means.
- A: It's tough, but you have to intervene. You dictate to her what she does, but you do it because you love her and you hate the autism.
- R: It sounds to me like a "do no harm" approach.
- A: That's right, yes, but also do no harm to yourself. Because often you do no harm to the child... you ignore them... and you actually destroy everything. 'Just leave her; she wants to jump for seven hours on the trampoline. Ag shame, just leave her'. That's benevolent, but it's not helpful. It's benevolent in the sense that she does what she wants, but it will not curtail the behaviour. Autism is like... I thought about this a while ago... It's like when you wind up elastic, and you let it go, it turns into a big bos. But if you keep the tension and you maintain it the whole time, you get success. You just have to keep the tension the whole time, because, if you let go, you are in big trouble. No single person, no single couple can do that. You need people around you to help. And that's a difficult thing for me to do, because she's my child, I'm her mother and I must be able to manage her.
- R: It seems as if you felt personally responsible for everything about J-A.
- A: Yes, I went through the whole guilt thing... I was... I am personally responsible... (*Pause*).
- R: You have a sense of, 'Oh goodness, this is my child and I must be able to control her'.
- A: Yes, definitely... and of course I can't. So a sense of utter failure all the time is always there... until you realise that this is a disability, which, if you are rigid about it and you get

them young enough, you can actually remove it. Or at least minimise it, so that they can cope in the real world. Does that answer your question?

- R: Yes, thank you. It more than answers the question. Like I said before we started, just speak as things come to mind. I wonder... perhaps, if we can go back to when J-A was small... a baby. She was born three years after your first child... what alerted you... or perhaps, what was different about her?
- A: There was nothing different in J-A until she was four or five months. They say most newborn girls are ahead of newborn boys. I compared her to J. In the first four months, her milestones were ahead of schedule. Like she started to hold her head up at two days, she had an Apgar of 9 and 10. I was healthy, it was a drug free delivery, one and a half hours, no birth trauma... nothing! Huge baby, four kilos. There was nothing there to indicate that this was going to be a problem. Some women suffer and the babies are blue... there was nothing like that. With B... he was as blue as anything... I thought, 'Aagh, here we go again, another learning problem!' She had nothing like that. She reacted to the vaccine, the booster between ten and fourteen weeks. One eye squinted in; she didn't look at her hands. She was like four, five months. And of course they said, 'Ag, don't worry, all babies squint. Don't worry about it, don't worry about it'. As far as the hearing test and the vision test, they said there was no problem. But they don't test properly at such a young age. And then, after the second booster, her arm swelled up like that (*indicates enlarged size of right arm from shoulder to wrist*). The whole thing went red, and she screamed. I took her back to the clinic. They said she's fine. I know now of course that she wasn't fine, and that was probably one of the triggers... Anyway, after that she started to sleep like 16 hours at a stretch. I thought, 'Gee, I like girls. Girls are easy to manage. I can put her down and I can actually have my life back again (*laughs*)'. So J-A started to sleep these ridiculous hours and I thought this was cool. I thought something may be wrong, but I was actually very happy to just carry on. J was four, very busy and very interactive and very bright.
- R: So you appreciated this quiet baby.
- A: Yes, I am not going to deny that. I thought this was cool and this is my second child and... I can have a life and go (horse) riding. Everything seemed fine and she was an easy baby, you know, that's what I thought. She smiled, she seemed very happy. If I think back now... of course hindsight is always 20/20... when you are there, you don't actually realise that something may be amiss. And my mother thought something was amiss. She did come up from Cape Town at that time... They actually moved up when they realised about J-A. My dad retired and took his money and they moved here to support us. And without them, we certainly would not have had B, and J-A and I would both have been institutionalised by now (*laughs*). They did great! So she suspected something was amiss. She would come up to visit before every four months, and J, when he was that age, he remembered her from visit to visit. He would talk about her, and they had a relationship. But J-A just didn't want to know, she was like somewhere else.
- R: So she wasn't able to hold the memory and maintain the contact?
- A: No, not at all. So, at seven months, my little warning bells went off... but you don't want to say anything to anybody else. She said something to me at that point... You know, it is so difficult to approach a mother and say, 'There may be something wrong with your child'. It's like sacred ground, the relationship between a mother and a child. You really are... it's like a fearful thing. I really wish that someone had just taken me by the shoulders and said to me, 'There is something wrong, sort it out now! Have it investigated.' Not that that would

have helped much, because with all the medical help, that just doesn't go anywhere. No Internet at that point, no access to research about what's going on right now, and the textbooks were ridiculous. They just gave these ancient definitions that don't count any more... certainly on autism. If she had just said to me... had the courage, I think... to risk the relationship with me for the sake of the child. That's not easy to do, I know that, but you can't correct that. That's just one of those regrets that we both have.

R: You also said that you felt that something was wrong?

A: Yes, but you don't want to... you think that if nobody else can see it, it will just go away... perhaps I was drinking too much coffee... I was breastfeeding... you know, just looking for other reasons. My GP said, because we are quite an allergic family, when I breastfeed, not to take wheat or dairy... For all three children, I breastfed them each for two years, and in those two years I didn't take wheat or dairy. And I know that, had I taken wheat and dairy with J-A, she would have been far worse, because she's very sensitive to wheat and dairy now. You have to be so careful; just one little food item can be almost toxic for them.

R: Tell me more about the food and diet.

A: In the beginning, she would eat everything and anything and as much of it as she could get. She is terrible about that; she's an obsessive eater. The kitchen is locked at night; because she will just... she cannot regulate her eating. She's getting better now, because we are forcing her to speak for her food. So she has to think, 'Do I really want this? Is it worth the talk?' So she's actually analysing her feelings and deciding that she doesn't want this. So now she will stop after her first helping and take her plate to the sink after supper, which is huge progress.

R: What was her eating like as a baby?

A: I breastfed her exclusively up to seven months, nothing else. Then I took her off to my GP, because I was worried about the squint. And she just lied there, she wouldn't do anything or roll over, and she didn't try to talk. You know that noise you hear when you phone a fax machine... that noise... she used to make that noise. I used to call her my fax machine... it was a terrible noise. No pre-speech, no boo's and goo's like other babies. But she was a happy child. She laughed and smiled and hardly ever cried. She was this gay, happy girl. She was so cute, she was beautiful. She interacted at that stage, but nothing like J did. I always thought, I am never going to compare my children, so I never wrote down milestones for J. I thought it's not fair on the children to compare them day for day, so I didn't. But I wish now that I had, because I might have seen earlier that J-A is not reacting, like J said this or this. He started to talk at seven months. When he dropped something, he said, 'Ooh gone!' And J-A was lying on the floor and squinting and doing nothing. I took her off to the GP one day and he said (*imitates an angry, shouting voice*), 'Your child has got irreversible brain damage. She's got a tumour. You must rush her off to hospital right now!' It was the 12<sup>th</sup> of September 1997 to this day.

R: It sounds as if that experience has been completely imprinted in your memory.

A: It is, it was terrible. It was so traumatic... so I took her to see the paediatrician, and he said, 'Man, there's nothing wrong with her... just give her some more protein'. He said we should just give her meat. She weighed 5.6 at that time and her vestibular system wasn't functioning well, I know that now... she had low muscle tone. He took all the blood tests and X-rays and TB and muscular dystrophy and all the rest... but everything came back

normal. So he said we should just wait. It was chaos, 'cause this one here said she had irreversible brain damage... he was actually right, but you want to believe the good guy, you want to believe the one with the good news... so we did. You know, when you are on that level of coping with what is happening around you, you don't think. You can't think, 'Is this right, what he said?' Your emotions just tend to take over. And your hope lies in the people who are meant to know. Now, no hope lies in the people who are meant to know. Everything they say now, I question. So I changed paediatricians, obviously, and now his partner, he said, 'You know more about this than I do. So now how can I help you?' I thought, 'Now there's a guy with the right attitude'. Now that's excellent, because he listens to me, and he respects me, and he knows that I have done research in a particular area where he hasn't gone. So there was a good ending to that problem.

R: And what happened after that?

A: Well, he suggested that, because of her low muscle tone, that we take her for physio and occupational therapy. Cape Receive still offered that to outside people, so we took her there twice a week.

R: How old was she at that time?

A: Seven, eight months.

R: So a lot of stuff happened in a very short period of time...

A: I didn't realise how much it was to handle until now when I think back and realise that that was like the turning point in our lives. In that February, March, she was 12, 13 months... I taught her to crawl with a towel, which is one of the things they showed us. She started to walk at 17 months, which is out of average, but not out of normal range.

R: So her motor development was a bit slow?

A: It was very slow, because she was hypo tonic. We had to work on that a lot, like teach her to stand and move. She was very broad-based, she had no twisting action here (*points to pelvic/hip area*)... she had no balance... her whole vestibular system wasn't functioning well. At that stage, I fed her everything, because the doctor said, 'She needs food, give her food'. She wasn't an underweight baby, but suddenly her weight dropped down on the chart. But her physical body never showed weight loss... I think it's because he weighed her on his own scale and not on the clinic's scale. So that was obviously a concern and the doctor put it in her card... This child had a big weight loss here, now why? I stopped going to the clinic after her vaccines, and went to our GP for everything she needed.

R: In terms of eventually getting a diagnosis, how did that happen?

A: That was another two years, three years later. She was four and a half when she was diagnosed, when someone finally said the A-word to us. I don't know if she was borderline or had like overtones or undertones of PDD or autism. Why they didn't, I don't know, but nobody seemed to have the authority to give a diagnosis. We went to Germany for six months, and I started to note that she had these little seizures. Like she would sit on the floor and I would call her and she would go like this... (*blinks her eyes and drops her head forward for a few seconds*)... and then look at me. No one else could see it but me, because I would sit with her all the time. And I'd think, 'Maybe it's all the coffee, or something simple'. I said to my dad on the phone from South Africa, 'I hope it is epilepsy'. But even

then I must have hoped against hope, I must have known somewhere here deep inside that it wasn't.

R: It is amazing, that realisation that a parent has...

A: It is... and it's subtle, you can't put it into words, it's just this sick feeling. I think the third EEG that they did, they discovered an abnormality and put her on Epilim. It made her hair curl, she looked like she had an Afro... and she became enormous, like overweight. I remember in Germany, they've got this lovely bread, and she'd eat like half a loaf and I was so pathetic, I didn't even see. It was a ridiculous amount of bread and buttermilk and yoghurt that she ate. She'd make such a noise in the shops, so rather than having a ridiculous fight in the shops, she would sit in the trolley with her bread... and the gluten in that bread is so bad. And the caffeine and milk... I didn't know. From the time she was four months until she was a year she was on ten courses of antibiotics. Ten! And I trusted my doctor, I didn't think, 'Is this right?' I thought that I needed his help, and whatever he said was right. I mean, most parents are like that. Now I say, 'I hear what you say, but I don't agree'.

R: You learned the hard way.

A: I certainly did, the very hard way. She got a terrible yeast overgrowth. They did a stool sample with her in Cape Town and her yeast count was 4+. The average is one for a child. Her belly was up to here (*gestures distended abdomen*) with distension. She was bloated and fat. She weighed 25 kilos at three. Now she still weighs 25 kilos at seven, so she was terribly overweight. So that was the antibiotic story. The vaccine caused a fault in her immune system and she became sick and had all these other things that was going around that they couldn't pin. So she had that and the antibiotics and the yeast overgrowth, terribly overweight and she had an obstruction, which I wasn't even aware of at that time. She was just a picture of unhealth. But she was happy. She still made the fax machine noise and by the time she started on the Epilim she had gained about four words.

R: It sounds as if she wasn't really aware of pain and discomfort.

A: Pain, no way! She would walk around with her toe cut open and blood everywhere and wouldn't even notice. The theory of that is when they eat gluten it gets to the intestines, but half the digested proteins get into the bloodstream, peptides, and the peptides work on the opioid receptors in the brain... so they act like they're drugged. A lot of them that I still see walk around like they're drugged. The human face swims, they can't see it. So she had all these things wrong and off we went on the epilepsy road, which affects all the fatty acids in the brain, and so all the speech that she had gained she lost. And then we came back to South Africa and went down to the Red Cross Hospital's neurological faculty. He confirmed that she didn't have epilepsy and said that she had a global developmental delay. Global implies that they've got delays in everything, but she had areas where she was on par. Like her gross-motor skills at that age, she was just about two, was fine. Her gait was a bit ataxic, but she was fine... she wasn't sitting in the corner. Her gross motor was about on par at that age. So it wasn't a global delay... she had scattered skills. But they didn't pick it up. Maybe I didn't answer the questions honestly, because I didn't want to know. You cling to the hope that it's epilepsy, and the drug will make it go away. And the doctor said that this drug will control her behaviour and her moods and this will be the magic pill. So she had to have her liver tested every three months and then she would go into absolute shock at the sight of someone in white, because the German people were so brutal with her. They'd hold her down and dig blood out of her foot. She's terrified of anybody who's wearing a white suit. Even now, my doctors don't wear white coats. So we went down this epilepsy road and

when she was three we decided that this Epilim wasn't working, so we got hold of this guy in Cape Town, who's a naturopath. He said, 'Stop the cycle.' So we stopped the antibiotics, and tapered off the Epilim. We also got hold of this paediatrician in Cape Town, who has an interest in neurology. She did like R5000.00 of pathology tests. At the end of 1999, I went to Dr. Wiggins here in PE, because I was at my wits' end with J-A. Her behaviour was bad, the seizures weren't going away, she was on two drugs, and she was just unhealthy. It was driving us mad, because we didn't know what was going on. So he discovered in that interview that I was pregnant with B. He said, 'Are you mad! Did you not realise? Did you order this baby?' He carried on like that about B. He said, 'This child of yours has got a mitochondrial disorder and there's nothing I can do with her anymore and you must take her away to Cape Town.' He basically said that he washes his hands off us. So off we went to Cape Town and this is where we saw Dr. Schnedel (Paediatric neurologist). She did all these blood tests for mitochondrial disorder and Fragile X and blah, blah, blah... and everything came back normal... except for some organic substance in her urine, which we found out subsequently was because of the food she was eating. So that's where we were then, and we realised that these people weren't helping us. At that point, we started to look... it was suggested to us that maybe it was a vaccine related injury. This Dr. McKenna, he was the one who suggested this. So we phoned him from PE... he's a doctor and a naturopath. He was very anti the normal method of just dosing with drugs. So he said that we must do two things: stop the antibiotics and take her off the treatment that she was on. He also said that, in three months' time, we should take her off the Epilim, because it's not going to do anything for her. If it's a vaccine injury, you are not going to have anti-epilepsy drugs that do funny things to the brain. And many autistic children, like 33%, have some abnormal EEG, so they don't tie in with the normal epilepsy syndrome, it's all idiopathic. (*Laughs and shrugs shoulders.*)

R: It sounds terribly difficult to get to a diagnosis.

A: Ja, I understand that, and if I was a doctor, I don't know what I would have done differently. But that's water under the bridge now. I just felt that I was going crazy myself.

R: I get the sense that you doubted yourself and what you saw in J-A...

A: Yes, you want to see what you think it is, and epilepsy can be fixed. She would get treatment and go to a normal school... but in the back of my mind, I thought, 'Learning is gone... learning problems... Oh yuck, I don't want that! I want my children to be perfect!' Here J-A is with this syndrome, and J is so bright. So the doctor in Cape Town asked me about the vaccination and how she had reacted. He asked me what she looked like and whether her belly was distended. So I said, 'Yes!' I couldn't close her pants! I can tell you many funny stories... J-A had this pair of pants when she was 3, and I couldn't close them... I had to put a ribbon through to close her jeans. Now those same pants fall off her. She came back... swish (*gestures a small waistline*)... to the size of a normal child. Shocking, hey... shocking, and that was just from the gas from the yeast from the antibiotics. They just kill off all the natural flora, which causes a yeast overgrowth. There are lots of theories about how that can cause lots of brain trouble and other sicknesses. Add that to the wheat and dairy intolerance, which she also has, and we've got a badly developed brain here, because of all the chemicals. Also, inside the vaccines, there are two parts, namely a preservative and the actual virus. The preservative in most children's vaccines is mercury. And mercury poisoning and autism, in terms of blood tests, have an incredible overlap.

R: You think that those vaccinations really aggravated the situation.

- A: Or actually caused it. Because when she got that is when the turnaround came. Mercury interferes with the enzymes, which stops fighting it, which interferes with your whole immune system, your digestive system, and your brain development. Mercury spreads to all the brain tissue, kidneys and intestines. We actually managed to get this program from America with a protocol of drugs to help us get rid of the mercury. And since then, we've been doing this for 18 months now, every second weekend, we gave her treatment for the mercury. And the doctor here said, based on the amount of mercury that comes out of her, she should have been dead by now. In 1995/1996 they increased the number of childhood vaccines. One theory is that they get like a 10 dose bottle for 10 babies, and if the sister doesn't shake it well, the mercury all sits at the bottom... and then one child can get all the mercury for 10 babies! And that's the only way they can really understand where she got this from. So the mercury is flowing out in her urine at a rate that the doctor can't believe. And that's actual pathology, it's not hooah haah homeopath stuff. It's there, she's got mercury in her, and huge amounts.
- R: I would like to come back to the arrival at a diagnosis. You mentioned before that it took a few years before someone ever said the A-word to you.
- A: We took her to see the behavioural therapist in Cape Town... She was already four by that stage. We were just muddling along. I took her to about four preschools. They all said, 'Oh no, we can't handle her, we can't handle her!' It took us a full year to potty train her. She used to take her pooh and smear it all over the cot. It took the whole year from three to four. My mom stayed with me that year. We tried all the things that you do with a normal child, like rewards and stuff. We put her on the potty every half an hour and tell her, 'Good girl, good girl!' I was at my wits' end, B was two months old. J-A had been kicked out of several preschools. She was unmanageable, and I needed a break! I thought it was okay and that she was old enough, but they all kicked her out. They said that they can't manage her, she throws out popcorn, takes other children's food, she bullies them on the playground, or she wants to swing all the time. And eventually I took her to Aurora, because they've got a care centre for disabled children. By that stage I thought J-A has obviously got a disability here now. And I needed a break, so off we went to Aurora. And Aurora of course doesn't allow children in without a major interview. So Emma Booth was the lady there, an amazing woman, she's so dedicated to these children. She played with J-A for about an hour on the floor, trying to get her to do things, and she asked us a few questions. At the end of the interview, she said, 'Your child is autistic, take her to Quest.' So I thought, 'What?! She doesn't sit in the corner and rock!'
- R: At that stage, did you know what autism was or had you heard the word before?
- A: Actually, my neighbour, who is now part of my care team, she got some stuff from the Internet. She'd been reading about this other child and came across an autism site, which was actually the ASA site. So we started to tick things off, like 'Look, J-A does this and this', so we had a bit of an inkling. I just couldn't believe it, because I was so hoping for a word to give to this thing that my child has got.
- R: Were you able to accept the diagnosis?
- A: Yes, because by the time we got that list, she had been taken off all the drugs. She was on nothing, no drugs, and we had already changed her diet. The doctor said to stop the antibiotics and to feed her only things that can walk and grow. Like meat and plants, nothing else. She's healthy now. Since that day, since she was four and a half, she has not had one

course of antibiotics. She never gets sick! When she gets a fever, she goes to sleep for three hours and when she wakes up, she is fine. So her immune system... we've taken the mercury out, and changed her diet, we've taken control.

R: After you heard that word... got the diagnosis... what was it like to get the appropriate help?

A: She said to take her to Quest, and I said, 'I'm not going to Quest. It's at the bottom end of the slum in Uitenhage. There's no ways that I'm taking my daughter to that place!' It stank in there... I went there for a screening interview, and saw the other children. It was shocking. The one child just sat there with sand... (*gestures motion of trickling sand through her fingers*)... You look at all these funny things, you know... it almost didn't seem real. There was no way I was going to send my child there. But we went there for the interview, and they had the whole team there... the multidisciplinary team. We went there for the morning and spent about three hours, and at the end they said she qualifies for an observation period of one month. That meant taking her through in the morning and fetching her for one month. But then I thought, 'Okay, I'm going to get a second opinion'. There was no ways I was going to do this to my child. It was disgusting... It smelled there, this was not for my child. It was so hard... and in this family I have to bear the responsibility, I am the medical person. Every family has one, like the nurse type. And he'll listen to everything I say, so I'm the expert. It was all resting on me, I had to make the decisions.

R: It sounds as if it was tough...

A: I didn't know it was tough, because you're in it. I didn't realise that this was actually hard to do. It's just where you are at that point. Afterwards, you think that that was actually... (*gestures confusion by holding her hands over her ears and shaking her head*)... terrible, you know. So I went to get a second opinion... to Deon Schwartz. He's the guy that does assessments for Aurora. So we took J-A there, and she packed all his books on the floor and took his keys and threw them out the window. He chatted to me for a long time and asked what she does. And he said, no, there are really good reasons why I should take her to Quest school for an observation period of one month. So, there we go! Driving in and out of PE. My husband took her in... at that stage he had already left Volkswagen. I often wished he hadn't left, because he could have taken her in on his way to work and picked her up in the afternoon. So we went through that, and three weeks into it, I said to the principal that we must let her go there, because we have already cancelled her place at Aurora, and it's very hard to get in there. So that to me was like a confirmation. And she got the LSEN (Learner with Special Education Needs) number within a day. She's got a disability number... specifically autistic. So she's got this number, and if we're not earning, she can get a disability grant. But she doesn't get that, because we earn more than... it's a ridiculous amount... like R18 000 per annum. She's been at Quest ever since then. She transferred when they moved to PE. So she was structured for those hours a day, which gave me a break, and she got a better education. She was starting to get the help that she needed. Well, it's not actually the help that she needed, but it started things for us. I don't see Quest as THE answer at all, it's only one aspect, and it helps me a little bit more. At Quest, there are so many in the class, and they don't respond to so many.

R: How does J-A interact now?

A: She knows that speech is important, but she has ataxia at the same time. They are working on that all the time by breaking the word into syllables, and then they teach her to say the syllables. Like, she can't say chips, so they teach her to say ch, ch, ch, until she can make that sound. And then she'd say chi... chi... chip... chip, and then she'll start to say it... but it's a very blood wrenching process. If she wants something now, she has to say it. You'll

see on my counter (*points at counter in the kitchen area*), I've written, 'I want...' That's a visual input for her to remember that she must say, 'I want peach' or 'I want pear' or 'I want food'. I did that because she likes to sit on the counter. Then she goes (*raises her voice and points with her finger on the table as she slowly pronounces each word*), 'I... wa'... and she rolls her eyes... 'tea'. If she doesn't do it, she doesn't get. She gets furious at us, because she forgets sometimes... and that's when we have to be mentally very strong, otherwise we won't succeed. We actually have to force it out of her, because she CAN speak. She says things that are just not intelligible to other people. Her articulation is just poor, but she can string like five words in a sentence. I can pick it up, but nobody else can, so we have to work on that articulation. And since we've been doing that drilling and grilling, her speech and articulation have improved. Like, she always said Mama or Dada or Gaga, but now says Mommy and Daddy clearly. But it's not easy... it's exhausting... it's non-stop. Because every night, you have to be drilling her on her speech, and that's where the other children fall out, you see. She wakes up before everybody else, of course, like half past five or quarter to six. Then someone has to get up, of course. We lock all the doors, but she'll like put the plug in the bathroom basin and turn the tap open and flood the bathroom. Or she'll crash the pictures down. If you look in her bedroom, there are no pictures, or otherwise they are very high so that she can't reach them. There's just a little box with toys. She is very destructive when she is on her own. She does not know how to do leisure stuff. But we are working on that. Keep her structured at school and then every afternoon she gets tutored for like three hours, then she goes for a walk, then she has supper, and then has to bath...we keep her structured around the routine, and in that manner we are in control of her, and not the other way around.

R: It really sounds like walking on a tightrope... keeping a balance between J-A's needs and the rest of you.

A: And I find, if I don't get my time off, I get really angry.

R: How do you manage to get some time off?

A: I have to ask. She goes to school in the mornings, but he (*rolls her eyes in the direction where B is playing*) is also very demanding. That's very odd, what he's doing now. He'll only sit still when he watches a video, but I can't just let him do that all the time, but there's a place for that too. But he's in bed when she (J-A) goes to school. I actually keep her at home one day a week, and teach her myself, so that I can keep track of where she's going academically. Usually on a Wednesday or a Thursday she stays home with me. And in the afternoon she's structured, and on Saturday she gets tutored the whole day, from nine to five... that way she keeps learning.

R: That's an awful amount of time. Do you get help from someone?

A: I've got five people who tutor and help with her. Two of them are class assistants at Quest, one has been trained by the lady in Cape Town. They are completely underrated people, because they are actually educators, but they get classed as tea girls and the government sees them as like public health service and they actually do excellent work in education. It's not fair that they get classed as general workers, because they are way above that. Two of them come two times a week and they stay for three hours and work with her the whole afternoon. And as far as I can see they have a follow-up and then do this thing and now that thing, but I manage the whole thing. I have to know what's going on, like I have to know what her benchmark is in speech, and the only way I can do that is to keep tabs on the tutoring and the only way I can do that is by tutoring her myself as well. So I go through the whole

program with her at least once a week. My mom also tutors her for one and a half sessions a week. They've got a very simple program that they work on. So let me see: It's me, Daphne and Catherine and my mom, and Sue. And then there's A (husband). When he comes home in the evening, he'll take her for half an hour and they'll play ball, or he'll watch her swim. Or my dad will take her for a walk and I take her for a horse ride sometimes, so that she is occupied all the time and not in other people's faces.

## INTERVIEW 2: POSTDIAGNOSTIC ADJUSTMENT AND COPING

R: It seems as if we have covered most areas related to the arrival at the autism diagnosis for J-A, and everything that happened before that. I would like us to move on to the second area of inquiry, namely the family's adjustment and coping after the diagnosis. We have already touched on some of these aspects, so let's just move on from here. Firstly, I would like to ask you about the general running of the household. You have already told me a bit about your routine. Since J-A has been diagnosed, how, if at all, has the family's routine changed?

A: Well, before the diagnosis, J-A was like her own agent. She did whatever she wanted to do, and we sort of chased her around! I just ran around doing damage control. I was J-A's damage control expert. At that time, we didn't have the psychological know-how or power to say that this is not acceptable behaviour. We tried so hard. We told her how many times to get off the glass coffee table you saw now there in the corner. She used to jump on it. And we smacked her, like you would a normal child. But with a normal child, you'll smack her maybe once or twice, like J is about a one smack child, and B is about a four-smack child. J-A could be a hundred thousand smack child; it wouldn't work. Not at all, not by that method. The only way it works is, you've got to go there and set your mind to it like for, say the next three weeks, and you are just going to work on this thing. Like, when she's on the table, you've got to go there and take her off, and while you do that, say, 'Now you get off!' You have to physically take her off, because the more you speak, the less they listen. So that pathway is then made. Verbal doesn't work, it has to be physical, or visual. Obviously, you also use verbal, because that's how normal life goes on. But in order for us to have some sort of life... You'll see, this wall wasn't here (*points to wall that separates TV room from sitting area*), that little door wasn't there (*points to metre high door that closes entrance to kitchen*), and these cupboards weren't up. There were books to be seen everywhere in the lounge area. The TV was at this level (*gestures location at eye level*), but she would run at the TV and almost crash into it, and smeared stuff over the screen. Everything has to be very high up. We had to put doors in everywhere to keep her contained. We later managed to put the pool in, because she loves to swim and that keeps her busy a lot of the time in summer. So, at that level, it's better. When she had the diagnosis, she was about five, we put the pool in. And we thought, ah it's fine... we'll just let her swim. We didn't realise that that was actually a bad thing, because she only cared about this one thing. And autistic children like to just do one thing. When she started at Quest, she began to do those patternistic things that they did, the stereotyped behaviour. You always have to intervene. So we covered up all those books there, hid them away so that they weren't a visual stimulus for her. In the lounge, she used to behave like a bat in there... up and down, flying all over the show, knocking all the things down. She took the books down and tore them up. It was like, everything she saw, she had to kill. We covered that wall up, so that the lounge is now more relaxing for us all. That's why we put up the gate there, so that she can't get out when we sit down to watch a movie. She just cannot sit still, she cannot!

R: So, you can do things as a family now... like watch a movie?

- A: No, we don't. I have to cross her hands and say, 'Now you sit and watch'. I hold her hands on her lap, because she won't sit, she jumps up and runs around. I sit next to her. When your hands are crossed like this (*stretches arms out and crosses her hands at the wrists*), there is very little you can do. So the hands are crossed now, and then she knows... then she sits. This is what was helpful about being in Cape Town, you know. I learnt some techniques, which we didn't have before. So there's that, and locking the doors, and the fencing is here for her and the dogs! We have to lock the gate, because she would go out the gate.
- R: Yes, I noticed the dogs...
- A: She (J-A) is very rough with the animals, but she loves them. She'll go to the horses, she adores them... and she rides, she rides so well. She's got a horse, and I've got a horse, so we go together. She will blow on them and love them... for the first few minutes... then she starts to be rough, like smack them on the nose and see what they do. They are very good with her, never nasty... and the dogs are very tolerant of her as well. She loves them so much, she sometimes almost strangles them. Very tough, rough love. Other coping things are coming home from school. Going to the shops is a mission, because I have to have one hand on her hand. We've got to a point now, that she's big enough, that she may not go in the trolley. That's an absolute blatant rule for everybody... not in the trolley. Now, she can either ride in the front, or she pushes the trolley. Now I'm starting to tell her, 'We are going to get two butters'. Before, she had to stay in the trolley, because she would run around and unpack and open up chocolates and eat them or grab handfuls of nuts. If you left her in the shops... I would just pretend she isn't mine. Terrible, terrible behaviour in the shops and restaurants and any public place. Taking her to the shops for shopping therapy used to be impossible, now that's improving. She's not a stupid child... once she's got the rule she knows, 'Okay, this is now the rule, I'm not allowed to get in the trolley'. She is then quite happy to take the second best choice, like to ride in the front, and she's happy with that now. She's getting better at that. She's getting more tolerant of our authority... probably because we are more authoritative within ourselves too, more confident. We had to fight very hard to get her where she is. It's been hard work all the time, and you have to stay confident to manage the child.
- R: You often speak about that confidence and being in control of the child. It sounds as if that has been a big learning for you.
- A: Yes, it's been a big thing. I mean, if you look at parenting these days, it has become more "child-in-control" and less "parent-in-control". The parents are out there, working. Twenty years ago, it was an exception to have a mother working outside the home. Now it's the rule. I think it's much easier to go to work than being a mother... much easier. And with J-A, it's impossible to not be at home. Everything has changed... parents everywhere... and I've seen it now with us too, in hindsight... we were losing control too. We were losing our authority as parents. Parents must have authority over their children, otherwise it's chaos. If you look at nature, there is authority everywhere between parents and young... and we are losing that as the human species. And that is so in my face with J-A, because she challenges me all the time. I have to take that stance with J-A, because now we are making so much progress. And now I can breathe, because I know when she's going somewhere, it's fine and like my dad is going to take her for a walk now for half an hour and I can be with B or do homework with J. Or whatever, and know that she is being properly cared for. Because, what happened before we used to have a clue what to do, is that somebody would say, 'I'll take her off your hands and give you a break'. And I would know that she would come back worse, because they would let her get away with things. That's why I said that, if anybody wants to be part of my team, it's got to be obsessive consistency... everybody has got to do

the same thing. Luckily they have come to see me now as in charge of her and will listen to what I say and do it.

R: It sounds as if these people have accepted that you know best as far as J-A is concerned.

A: Yes, which is a good thing, because now I feel better and I am in control of her. There is this whole thing of authority and mutual respect. I have to respect J-A, I can't treat her like a doormat. In this whole environment of structure, I am there because I love her, not because I hate her. So it's about tough love and benevolent dictatorship. And obviously, when a child becomes like this age where J is, you stop being so much of a dictator. It's still benevolent and you are the authority, but you must also ask, 'What do you think?' I have to bring him up to that level rather than put him down. When J-A hits that stage... that's a big obstacle that still lies ahead, because the mental maturity isn't there. But we must do the groundwork now, keep her structured, keep her learning and realise her behaviour and other people's behaviour, because they only realise when you actually intervene in their thinking processes and say that. Because if I just let her be violent all the time or let her sit in the corner, she'll be excluded from society... and my purpose is to teach her how to be in the real world. Incorporate her in what we do. We can't just ignore her because she stands in the corner. Some autistic children do stay in the corner their whole life... it's very easy to just ignore them and let them stay there and carry on... just forget them at Quest.

R: You mentioned to me before that, in terms of J-A's education, you don't see Quest as "it" for her... just as a stepping stone...

A: Yes. If I had enough money, I would keep her in an eight or nine hour programme every day at home. But I just can't afford it.

R: You raise a very important point there... tell me about the financial responsibility of caring for a child with autism.

A: It's huge! The biggest expense for her now is obviously the tutoring. If I lived in Cape Town, I would pay R50.00 an hour. That's because it's specialised one-on-one tutoring, and that's what they get paid by parents there. If I lived in America, then \$45.00-\$60.00 an hour. I pay a whole lot less than that, and I say, 'This is what I can pay. Can you help me?' And those are the terms that they must agree to. My mom is great, because she does not need the money. Actually, with Sue and I... her son is 10, and he's got some learning disabilities. So we decided to swap, I am going to take a session with her child and she'll take an hour with J-A. See, I've got a maths background, so I help him with his maths, and she helps J-A with her work.

R: That sounds like a helpful social arrangement.

A: Yes, it is. That's community help. It definitely helps, because people don't know how to interact with us as a family any more... everybody has moved away. We don't have family friends any more. People stopped inviting us for meals or to go out for coffee or to go out to eat, because it's so unpleasant with J-A. We just don't have that. I don't know how this is going to play out in the future, or where we are going to find friends. The church kicked us all out; they certainly don't want us there, because J-A behaves funny in church. So we don't bother with that any more. We actually tried again, later, but we weren't very committed. They are not at all tolerant. Some people say, 'Well, then they must learn', but it's hard to be the mother and they say you can't rule your child in church... it's hard to go there.

R: It also sounds very draining on you.

A: Of course it is. I mean, who do you go to church for? Yourself, your child, or all the other people? You sit there with this major conflict of why am I here? *(Raises her voice and visibly gets irritated. Gets up and opens the door for B to go play outside.)* Right, the financial thing. The tutoring is a major expense. Obviously, she's on a diet... no wheat. So she eats rice cakes, which are like R8.00 a thing. No bread, no biscuits, no rusks, none of those cheap foods. Also no milk. No fast foods, like hamburgers. But her eating's better now, more under control. She eats cheaper stuff like brown rice, lentils and vegetables... whatever's growing.

R: And you, as a family, how have you adjusted to these eating habits?

A: We have all adjusted. We eat what J-A eats. We also don't eat spaghetti any more, unless J-A goes to bed early, and then I'll make spaghetti for J. I don't eat wheat, because it makes me psychotic! *(Laughs.)* And if he *(Points to B playing in the background)* has wheat, his tummy runs. So there definitely is gluten intolerance in the family... I mean genetically. I have come to a point now, because of the bad nutrition problems that we had with J-A, where I am almost obsessive about what all my children eat. We don't eat hamburgers. Ice cream I buy like twice a year. I'll only buy ice cream for like Easter or Christmas or something. I let her have chocolate, but I don't buy sweets and I don't buy biscuits. I make biscuits, but not often. I sometimes let her have chips. We do, now and again, go out and leave J-A with my mom, so that we can have these things with the other two. So it's not that it's never around, we just don't allow it in the house.

R: You say that you sometimes go out with the other two children...

A: Yes. We have to, it's absolutely important. That woman in Cape Town said I have to give J and B half an hour each of uninterrupted parent time without J-A every day. It sounds so little, but you know, to find half an hour for one-on-one is not easy! I often have to rearrange the whole night, and schedules change all the time with sports and stuff *(Throws hands up in the air and laughs.)* So the costs would be like her tutoring, her diet, structural things, changes and alterations to the home. Buying of equipment, keeping the pony fed... those are all because of her. The tutoring room was like a single cost. We try to think of it in this way: If J-A went to a private school, we would be looking at say R1000.00 a month. Now, J-A is costing us about R2000.00 a month, just her education, because we've got tutoring and school. So what we've got to do is just to borrow money and extend our overdraft. We'll do this for two years, then we'll have a look again. Maybe it's all worth it. I mean, if she wasn't so impulsive, she could have more of a normal life... we have to live in hope. And once the symptoms are minimised, you can be less interventive, but there is a time when you've got to be very intensive. Try to get the brain working, especially while she is so young. If it was an ideal world, I'd have my private tutoring with her alone all day. But that's not financially viable, I'd have to get a job, and then it won't be possible. So school is there so that J-A can "play" a bit with other children and have a bit of group with other autistic children. But I can't be perfect, I can't get it all right for her.

R: It is so wonderful that you can say that, because so many parents try to live by that fantasy... that they can do everything.

A: Look, I was there. Actually, last June I was so sick. I had a virus that hits the heart muscles, and I was confined to my bed for a month. That was like a turning point... I had to get help from my mom and my dad. I had to get someone to sort things out and clean the house and

feed the dogs. The doctor said that I had to do something, or I would be in serious trouble. He said that he had never seen anybody with such a low immune system. I was so run down... totally exhausted. So one tutor started coming and taking over one afternoon. I put her into aftercare at the school, but it was not suitable for J-A, because it wasn't structured enough. It didn't help at all. It gave me time off, yes, but you always have to decide whether this is good for me or is it good for J-A. And if it's not good for J-A, then it's not good for me, because I worry that I am not doing enough. So I have to find things that are good for me, very good for J-A, and also good for everybody else.

- R: So you have to be like the mind for all... a decision maker, a mother, a wife for your husband...
- A: (*Laughs*). Well, that is sort of at the bottom of the list. I think, with everyone with children of this age, your marriage has to take a bit of a back seat for a while. If it doesn't take a back seat, your children will grow up to be a mess.
- R: If I may be so bold to ask this question... how do you think having J-A has affected your marriage?
- A: Having J-A with all her problems made me, as a parent, grow up very fast. My own confidence and my own personality and like having a fighting spirit with J-A, but not in household issues. I don't take the lead in everything... I try not to. Certainly with managing the children and the household things, that's my domain. He'll sort out the financial decisions and what car we drive and when we go away, and those things.
- R: It sounds as if you have got a good partnership going.
- A: It very much is a partnership, yes. I've got my role and he's got his role. And it works well, I think. We are at the top of the wheel at this moment. We've just got to keep moving, keep kicking; otherwise we sink to the bottom.
- R: It sounds as if you've got to keep actively involved in order to maintain control. If you don't mind, I would like to go back to the family's activities and habits, and how J-A's presence has influenced that. In terms of leisure activities as a family, you mentioned to me that you've bought a boat. How do you experience doing things together as a family?
- A: We didn't know what to do. We felt so strongly that we need good family memories. If all our weekends were spent chasing J-A, the boys were going to get nothing. One can only swim so often. I mean, the pool is one aspect, but it is not enough to keep a family together. I like riding... the boys don't really like riding so much, J can ride and J-A loves it. So we had to make a choice together, and consider the financial costs.
- R: So the horses are predominantly for you and J-A?
- A: Ja, we two love to ride, and I love to ride. I've also got to escape. And often we get left behind, and I know that, if I leave myself behind, I will collapse. I... it's that thing again where I have got to take control of myself and say to myself, 'I will not clean the house now!' or 'Let Mom do supper'. And for me, that's a very difficult thing to hand over the control. It's a dichotomy... choosing to not do... and choosing your battles. That's one of the major things we do with J-A, to choose your battles. If you're not mentally prepared to follow through with your instructions to her, then don't start. Choose your battles... choose to win them.

R: It sounds as if that takes a whole lot of energy.

A: If you are not able emotionally to carry on, ask for help... get someone else to take her for half an hour. We used to like to camp and mountain climb and go on beach walks. We loved to garden... before J-A came along, we did a lot of gardening. We used to stay in the bushes and the koppies over here, but that just doesn't happen any more, because she doesn't like it. But she's getting better now. I can actually take her down to the paddock and she'll spend the morning there with us. When she was three years old, taking her out to eat was fine. Everybody didn't notice. But when it's a five or six year old throwing things around and taking food from other people's plates to eat... that becomes a problem. As soon as it becomes age inappropriate, it's not fun any more. We take her to restaurants for her therapy, not for fun. So when we take her to a restaurant, we have got to take a hundred things for her to do and sit her right up the wall and put your hands around her and say, 'You behave now.' It's absolutely not fun. So, when I go do restaurant therapy with J-A, J doesn't want to sit at our table. He's too embarrassed by her behaviour. He's at that tender age and I have to respect that and say that it's okay, it really doesn't bother me. Some things are just too difficult for him. The one day, last year, I felt so sorry for him. I picked J-A up from school and picked him up afterwards. I was on the way to J's school, and she (J-A) had undressed. I was driving, so I couldn't do anything about it. As I was driving up the hill, he just almost died. But what do you do? She's the kind of child, that if she wants to wee, she'll just go off and squat on the grass and wee. And he is very embarrassed about that. He doesn't want to invite his friends over here, especially those who don't understand her. It's tough; it's very tough for him. He's a loner, though; he's like me and like A (husband). We can do very well with our own company. We don't need people around. And he's got the two boys next door, Sue's children. They play a lot. They are also used to J-A doing funny things. Other children are just horrified; they are in shock and awe. So restaurants we don't do, so we do boats. A (husband) has always wanted a boat, and he also needs fun things that he needs to do; otherwise he is the provider and nothing else. So it's all very compartmentalised, our roles are very compartmentalised. So we had to find something that we could all do together. So the boat was that, and J-A loves the boat, because it's water splashing and random movement and wind through her hair. And she's got her boundaries... she can't step off the boat and run away! She can't do what she does if we'd like go camping... she'd run off and go help herself to everybody else's food in the tents, so we can't go camping. And we also can't do something like go for a drive, because she'll sit in the car and she'll masturbate. So we can't do that. J hasn't actually clicked what she's up to, but it drives me mad when she does that! I'm driving the car, and here she's going in the back!

R: How do you control such socially inappropriate behaviour?

A: It's actually quite funny. I've got a water pistol in the car. So when I catch her doing that, I shoot her with water! I have to!

R: (*Laughs*). Goodness, it's amazing how creative you have to get as a parent.

A: You have to find a way of thinking, 'Okay, now how will this work?' And, you know what? If our reactions become predictable to her, she'll use our reactions to get what she wants. So, for example, in the tutoring room, if she doesn't want to do maths and I put the numbers out there and tell her to match. She knows that, if she just takes her hand and shoots them off like that (*gestures sweeping numbers off the table*), I'll tell her to pick them up, and then she gets a break from doing maths. Now, if I always do that; make her pick them up; then she will do it, because she knows how I am going to respond and then she gets a break. So she

manipulates me. So we are not allowed to... all the tutors... may not react the same all the time.

R: It sounds as if everybody has to respond in an orchestrated difference.

A: In a sense, ja. Don't always make her pick it up. Some just ignore her and pick it up and carry on as if nothing's happened. So you have to be so creative, and always make sure that she is not making you behave predictably. She is very manipulative in that way.

R: Sjoe! It sounds like an incredibly tiring mental exercise.

A: Very, very tiring (*laughs*). But it is possible. You just have to strategically plan all the time. And I know now, since I've been tutoring her since January... I can almost tell what she's thinking and planning. And I know when it's behaviour and when it's inability, I can read that now.

R: You couldn't make that distinction before?

A: It was impossible, I just thought she couldn't do it. She likes to do this thing, when she's told to stand on her one leg. Now, with four of the five tutors, she knows that they know that she can do it. Now, the tutor comes in yesterday, who's been away since she learned to do that over the holidays, and J-A pretends she can't. So this tutor is struggling and catching her. J-A lowers herself to the level of what she thinks the person expects. So now, we've got to have regular meetings and report systems so that everybody knows what she is doing, and what's the baseline. But she gives me the worst behaviour, because I'm the mother and I'm not supposed to be pushing her with tutoring. (*B interrupts to get his mother's attention with a stuffed animal. Break for a few minutes.*)

R: You've told me about behaviour control and discipline, and we've also spoken about education and J-A's day care system. So weekdays, four out of five mornings, she's at the school. One day, she's at home with tutoring from nine to five. And the afternoons?

A: At least three afternoons a week, we've got tutors in. Every second week it's five afternoons, and the other week it's three afternoons. So some weeks she's got two afternoons off.

R: And weekends?

A: On a Saturday she gets taught. If we're not going on the river on Sunday's, I'll teach her for the morning. We try to keep her busy, like take her shopping. Or my mom and dad will pop over, and take her for an hour. That's all changed since February... before we were doing it all by ourselves, but now we're not doing that. We tried dealing with her, but we didn't actually have a clue.

R: You just did what you thought was best at the time, but it sounds as if you wish that things could have been different?

A: Yes, there's always that guilt and regret, but that doesn't take you anywhere. But you also have to go through it, and then move on. Just don't stay there. And then you go into the whole thing of, 'Ag well, that's it!' We became sort of fatalistic... I mean we have to carry on with our lives... because of J-A. I also know that, with some parents with autistic children, these children are very passive. They just sit in the corner. I don't know, it's a very

difficult thing... I think that's worse for the child. Maybe the family just can't connect with the child, so they put them in the hostel. You know, they are there, but they are also not there, and they don't become students of life. They just carry on without them. The sense of sorrow and loss is with you. The older J-A got, the more I realised what I have lost. When I see other moms with their children in Grade 1 and their uniforms and little suitcases and sitting in the restaurant, having something to eat... that's tough to see that and know that I haven't got that... and I'll never have that with my daughter.

R: I actually never thought of that... that she's your only female child... your only daughter.

A: It's so hard, sometimes. But she's my child, and I love her. (*Long pause*).

R: That's what's most important in the end, isn't it? I've asked you more or less everything I wanted to about the family's routine and adjustment after J-A's diagnosis. I would like to know a little more about the impact on your other children and family members.

A: We're always worried that something's going to fall off.

R: Something's going to fall off?

A: There's no support available for siblings. There's no psychologist that I know of, yet, who understands how autism affects the siblings. There's definitely a need for that, but it must be appropriate. The affect on the siblings is, I think, the hardest. But he (*points to B*) is fine, because he has never known anything else, being the third one. He hasn't known it, the loss. He's actually more attracted to abnormal children than normal children! He just thinks that's how life goes... so for him there's no loss. But J... he has seen how she (J-A) has changed our lives. At times, I think we must take J to a psychologist, just to make sure that we've covered all our bases and he can talk to someone outside the family, you know... because I don't want him to have problems because of J-A. It's unfair, and we want to avoid it. It's just finding the right kind of help... we don't want to traumatise him any more. Like he feels he's now being watched or something.

### **INTERVIEW 3: PRIMARY NEEDS, CONCERNS AND SUPPORT SYSTEMS**

R: Okay, that covers quite a bit about the impact on your family and your adjustments. I think we can move on to the third topic, which is about needs, concerns and support systems. You've actually already told me a bit about your support systems... your care team and your parents living next door. I actually want to explore that more with you. With everything that you have been through with J-A, specifically, who would you regard as the people who helped you most or supported you most?

A: How do you mean?

R: I mean in terms of managing her, understanding her, and also supporting you emotionally.

A: I don't think really anybody. It's been a lonely road, because I've always been like the authority. And being the one with the most knowledge... stumbling around in the dark, yes... but being the expert, and always being the strong one. Being the oldest in my family, always having achieved on a higher level than anybody else... always being there at the top and taking challenges.

R: So you are basically the "coper"?

- A: Yes, I am a copier. But there are the odd days when I don't cope and I can now ask for help, which is a big thing. I've learned to know myself well through all these years. The more I need help, the less I am able to ask for help... the more I feel that I can't cope and I need to prove to myself that I can cope. The kind of people who I call Job's comforters are the people who say, 'No, it will get better next year... When she gets to this age it will be fine.' Those aren't helpful. Sometimes I want people just to say to me, 'It's okay, I know you're struggling; it's fine, I understand. Let's put her in the car seat and go for a drive.' And don't say to me, 'I'll take her off your hands so you can feel better.' It makes me feel worse, because they are in fact saying that I can't cope. I don't want people to feel sorry for me and think I can't cope, but the help that they give must be constructive help, like to take her for a walk and to talk to her while they go. That's real help. I don't want an emotional cushion for me... yes I need that and it has an advantage... but if I have that at the cost of J-A's behaviour, I'd rather not have it. Some people used to say to me, 'No, she's fine with me at my house'. I don't actually want to hear that. Anybody who criticises how I behave with J-A or how I deal with J-A, who doesn't actually live with me in my house with J-A, then I'll kick them off. That's not on. They have no right to talk to me about how to parent her, because they should come and live with me in my house for a week... and know how it feels. Nobody can know how the mother feels. You can think, but you can't actually feel that feeling. It's a 24-hour job, and the constant responsibility. But it's better now, because people recognise that I need time off, because now another person has said that. You always know that, but to actually say, 'I need help now,' I think I did it about twice in all the years. Like, 'Mom, I really need a day off here. Can you help me out?' For me to actually instigate that was a big thing. Now, I know that, with my own limitations, how destructive I am to the whole set-up when my own limitations have been exceeded. I get very irritable and very highly-strung and tense. And when I eat bread or something with wheat, I know that it's even worse. (*Laughs*). I really got to watch my own diet. We take a lot of Vitamin B and keep a healthy diet and try to keep our nutrition up.
- R: You mentioned to me before that, before you were able to ask for help in such a practical manner, you actually had a physical "shut-down"...
- A: Ja, I did. I used to break into these crying sessions and get depressed... not depression... and just felt this blackness, like this is not a good day. I don't have many of them now. J-A used to make me feel like that, because I wasn't in control of her. And now I know, 'I'm not going to worry about it, because today is a bad day, and tomorrow will be better, because I'm still in control.' And you've got that mindset of, we know where we're going, number one, and knowing what she must achieve and what she can achieve... I've seen her do things. People with whom I deal now do what I ask them to do without questioning me all the time. I accept criticism, as long as it comes from a position of knowledge and understanding. So don't tell me I must not do this or that when she misbehaves at the table and you don't know any better. J-A has now got to eat separately from us, because she can't behave at meals. I've now intervened and taken control and decided that we're going to stop this. One thing at a time. For now it's eating slowly and normally without screaming or throwing her food around and without throwing a tantrum and without gobbling, by herself, without us telling her to do that all the time... without too much verbal input. She's got to behave on her own, with it being her choice. Once she can do that, she can come in once, maybe twice a week. It's tough, because the evening schedule is so tough. So, if I give her her food at six o'clock, there's no way that she's going to bed at half past six. So we eat half an hour later, but then she wants her food. It's really not easy. And she can't wait... delayed gratification is not an option in J-A's case. If she sees the food, if she sees me dishing up the food, she throws a tantrum, because it's not coming fast enough. That's our last major

behavioural problem, because she behaves better in the shops now. She still needs intervention, but she knows when we're in the shop, she's got to walk and hold my hand. We can do that, and then she behaves, but with meals, we're not there yet. So we did the shopping thing, and it has improved... not that it's going to stay improved if we keep her away from the shops, because obviously it's very tempting to just not go there, because it's so hard. Or lock her in her room and just leave her, we can't do that either.

- R: In terms of finding true emotional understanding, it seems to be a lonely and difficult road...
- A: Nobody knows how to help properly. They all feel desperately to help, but they don't know how to. All I've wanted all these years is for someone to give me a hug and say, 'I know that it's tough for you and I know you're doing your best, even though you're having a bad day.'
- R: It sounds as if you just need some recognition?
- A: Ja, just recognition. But nobody gives you that recognition, just nothing! It's tough, because I have to be strong on my own.
- R: You've mentioned your parents before...
- A: Yes, they've been some help. But there's some trouble there too, because they say, 'Ja, she's fine at my house and just leave her with me.' And then they'll let her run around and get away with things that I don't let her do. And then she'll come home and be difficult.
- R: So, you didn't find that kind of help useful?
- A: It was good for me, but it wasn't good for J-A, and therefore, in turn, it's not good for us. That was tough, but that's improved now, because now they know, if we go to the shops, she's not allowed to sit in the trolley. It's terrible, because I have to keep on reminding them. The other day, I shouted, 'Mom, get her out of the trolley!' And that's horrible, but I have to do it because it's best for J-A. It always hurts to keep people up on this high level of awareness all the time.
- R: I was just thinking, it sort of goes with the territory for grandparents to spoil grandchildren, and they can't actually do that with her.
- A: Exactly. It's very tough, because my mother has chosen to do tutoring with her. It's very tough for the mother, and grandmother, to be an educator. In this kind of environment... it's such a dual role. There's always this split of where does your mother heart come in and where does your educator role come in. You've always got to think where you are and do the tough love because you hate the autism, but you love the child. I do ... I do sometimes get so cross, especially if I haven't had enough breaks, or we're having a particularly up-hill time, you know. And when you let go, that anger is terrible... terrible anger. And as soon as you've got anger, she has gained control... she has won. What I've learned in the last sort of shortish time, is not to be the victim in the autism. Don't say, 'Shame, poor parents', because you are just going to end up in a quagmire. Don't feel sorry for yourself, because you'll just end up being the victim. It's like women who are being abused... you don't have to be abused; you are choosing that... to be a victim.
- R: I once heard someone say, that the first time you are a victim, but the second time you are a volunteer!

- A: *(Laughs.)* That's the whole point; you have to choose to be in control of your child. It's sad; because you do take emotional abuse from the child... not that they do that willingly. You just have to take control... you have to take control.
- R: I would like us to get back to support systems. You've spoken before about the helpful and... well, less helpful medical professionals that you've been involved with. As you think back to your life with J-A... the whole diagnostic process and afterwards... getting a place for her to go to school... finding people to manage the educational program and to help you... what do you wish had been done differently... or perhaps, what can you suggest for the so-called helping system to do better for parents?
- A: Well, I suggest that there should be much more of an overlap between medical and educational people. The doctors look at the clinical symptoms, and the educators look at the behaviour. The doctors need to look at the behaviour, and the educators at the clinical symptoms, and they need to marry the two.
- R: It sounds as if they are too compartmentalised...
- A: Yes, they are too compartmentalised. And it is not to compartmentalise, it's to link it. Because they don't come up with a blood test and then have a diagnosis... instead of looking at the behaviour and taking the DSM-IV and look. Your opinion doesn't count. They say, 'I'm a paediatrician, I'm not a psychiatrist, therefore I can't do anything... it's not my problem.' Overseas, diagnosis requires a whole team, a multi-disciplinary team. They call it a MDT. And all those people get together, and they approve the diagnosis. But in this country, there is no teamwork in that aspect. There is no developmental centre that I know of where you can come out with that diagnosis or a specific PDD... and early enough for your intervention to be really successful. Because all research has shown that early intervention in this behavioural thing is the biggest part of recovering. There are some systems in America, autism centres, where those things are now happening.
- R: Yes... from what you said, it took years for you to just know what you're dealing with.
- A: Ja, four and a half years! And the symptoms were there from pre 18 months. At seven months already, I thought that something was odd. But nobody had the courage to say, 'Look, there's a developmental problem here. Go, and do some research on this.' What they don't want to do, certainly the medical people, is that they don't want to empower the parents, because it's almost like they are threatened. They won't say, 'I think it might be this, let's discuss it. What do you think? Go read up about it and come back in a month and tell me what you think.' There's nothing like that, no teamwork. Because obviously the mother... and the father... but mainly the mother, is with the young child the most. They are the ones who know that child. They are the true scientists. They observe, and then they conclude all the time. And they don't have anyone to tell those conclusions to. The true science occurs here, at home. And the doctors don't want to know all that. The parent's opinion is obviously negated, in this country certainly. It has certainly been my experience. And I pick it up and say, 'Look, this is not what I want. I want to move my child from you to someone else, because this is just no joy!'
- R: What I'm picking up is that you almost have to step out of that position of thinking that the doctor is "the knower" or the expert. As you said before, you went to that paediatrician thinking, 'Well, you are the doctor. What is wrong with my child? Help fix it.'
- A: That's it. What can I give her? And you find that they're unequipped. Mentally, or educationally, or they don't read enough. And I know that there are so many syndromes and

disorders with children. And that's fine, I accept that, but then they must say that they don't know. But then they must say to me, maybe, in the back of their minds they know about this and I must go read up about it. Just bring in the parent as an authority, not as a client. 'Pay your money and off you go!'

R: So the "experts" don't need to know everything, they must just know where to find it.

A: Exactly... exactly. That empowers a parent, and as soon as the parents are empowered, they take control of the situation. Don't send them down the wrong road! Don't tell them that the pills will make it all go away and you know at least in your heart as a doctor... well probably those doctors didn't know that something was amiss... they didn't suspect something to say, 'Look, I think it's this. I'm not going to give you an outright diagnosis at this point because we first need to see. Let's have a look, do the research. See what you think.' This is how this new guy that I'm with now... he's got that kind of approach. He'll say, 'You know more than I do about this because you've done the research.' And he'll read the research that I give him when I say, 'We've got to do this now.' And then he'll say it's okay, he'll support me. And there should be a psychiatrist or psychologist or medical person on board with the educators. They need like a case manager, someone who can integrate the whole lot...

R: So that each one does not exist on their own island...

A: Exactly, because that's what's happening. So this doctor will look at the leg and this one will do this and that one does that, but no one will look at the whole child. Or do this blood test, which means nothing, because you've got this other problem here. And everything affects everything else. If the child's eyes aren't right, or your vision is swimming around, your behaviour is going to be funny. So, they'll test the ears, but they won't test hearing... whether the perception is correct in the brain. It's not a complete assessment. I know when we were in Ireland, she went to see a paediatric neurologist consultant lady, and she said that, if we were living in Ireland, we'd have a team of nine professionals dealing with her every week, and you get a home program for her. I know that there's a lot of bureaucratic problems with that system in Ireland, but the thinking is there. It's a medical overlap with the education. That's what's lacking in South Africa. They need to open up their minds to other people's opinions: parents, educators, OT's, speech therapists, and look at the whole case. Having a case manager will be excellent. We need an autism centre. So, if you suspect the child is autistic, this is where you can go and this is what you can do. That will be good. Sometimes I think I can do that. I can set up something like that and just manage it for other parents. I've been there, I know what they're going through and I know that, anything that I say to them, they are going to take offence at. Because I walk around in the park, and I see all these children with signs of autism, and I haven't got the courage to go to that mom. I saw a child the other day, walking around totally toe-walking the whole way, and that's one of the obvious warning signs. And there's this other woman, who lives nearby, whose friend is very concerned about her child. But the mother just doesn't want to know. The child is like terrified of garage doors and things. But you just don't want to know. So I think, maybe more publicity. Put it in the newspapers, like say, 'Developmental problems: Early warning signs.' Short, sharp, snappy articles... because there are so many children with problems out there. But the media always take the controversial stance, it's about sensationalism. That's lacking. Denise and I always talk about getting a resource centre going and say, 'Let's get doctors involved!' But I haven't got the emotional resources. I've got my own hands full with J-A. Maybe later... but I try to help people just from my own experience... just where I come into contact with them.

- R: What about the other parents at Quest, have you had any contact with them?
- A: There's not really a forum for that. At school, there's been one or two. At birthday parties, we get together informally, but that's not a support group. That's another severe lack. It will be fun to get together with other autistic parents and laugh about the quirks of your child!
- R: It's interesting that you talk of "autistic parents".
- A: I know. Autism is so pervasive, it flows into everything... it becomes part of who you are. It affects how you raise your children, how you run your household, what you eat. It affects where you go, what you do on holidays. I had to go to America last year, but I couldn't take J-A with to my brother's wedding. Because I know, if I took her, she would have destroyed the wedding. And I wept and wept when I left her here. This is like my daughter! I could take my baby and I could take my oldest, but I couldn't take her. That was really hard, but I know that I couldn't take her. And that's so tough to do... to know that you deliberately leave her behind because you can't cope with that situation.
- R: That reminds me of the loss you spoke about in the beginning.
- A: Yes, it's a loss of shared activity and of normal family life. But that's my issue... it's within myself. I tell myself I've got to become mindful of the positives. The one thing I think of is that she won't have too many boyfriends and all those kinds of things! She probably won't... I know there are problems with sexual development... but she probably won't go through that whole dating thing when I have to think, 'When is she coming home?' and have to worry! So that was like, 'Wow, sjoe!' (*Laughs*).
- R: That tends to be a nightmare for any mother, hey?
- A: Exactly. But normally, I would hate to have a teenage daughter in the house. With all the temptations that are out there. Boys are bad enough. Boys are probably easier, I think. The other thing that concerns me is helping her to understand the whole menstruation thing... because how do you explain? But maybe, when she's at that age, it will be a bit easier. She'll have a bit more understanding. At that point I will just have to... well, we'll cross that bridge when we get there. I've thought about it. I know that some parents just give their daughters hysterectomies to avoid that whole thing. I can understand why they do it, but there's no way that I could do that to J-A. Because that means that you've just totally given up hope. But there's always the fear of sexual abuse, especially with a non-verbal child.
- R: Because they can't really tell?
- A: Ja, it's terrible. Absolutely terrible!
- R: In terms of further suggestions...
- A: The publicity thing is really important, to take away this big veil of secrecy and fear. It is fearful, but let's face it, it's there! And children are coming up by the dozens... look at Quest's waiting list. And imagine how many children are living in the townships with this... who are getting tied to trees and locked in outside rooms, because the parents can't cope. I mean, what do you do? You are in trouble, you are seriously in trouble if you've got no money. There is nothing there... no free state services for disabled children.
- R: I thought about the health system when you spoke about the services in Ireland.

- A: Yes, having a health system that actually runs, that's interested in the individual, and that's not looking for how much can I take for myself and how little work can I do. They've got a system that's actually interested in the whole child and population development, rather than financial control, or just giving the child a pill so that he'll be healed.
- R: Finally, as a last question, I want to ask you about your concerns for J-A and her future. You've mentioned the whole sexual development thing...
- A: Yes, helping her understand her monthly cycle. Also, will she be independent? How independent will she be? Obviously, the more we work now, the better the chances that she will be. I believe that very strongly. And to make sure that we equip her with skills that she can use for an independent life... whether it means sheltered employment in a workshop environment or grooming horses or working in my dad's garden tunnels or packing things in a factory or whatever. Can she do that and will there be resources for her to find something? There's nothing really now. In terms of sheltered employment, there's Lake Farm here, and Camp Hill, which is for severely autistic people in Hermanus. It's far away, and it's not what I want. I've come to a point where I've accepted that she will probably stay with us for a good long time... longer than she should. She probably won't marry. Just being realistic... she probably won't marry and she probably won't have children.
- R: That sounds like another loss.
- A: I don't know. I probably don't see it as a loss because I don't see myself as a grandmother! (*Laughs*). My boys are there... Whether or not they'll marry... yes, that would be nice. I'm not there yet.
- R: So, even though you are planning ahead, you also just take every day as it comes?
- A: Ja, exactly. Like, what are my plans for the day? Like, for example, I need to be able to cook supper in the morning, so that when the kids are here in the afternoon, I can be there for them. The real time is now, but you've also got to plan ahead, so that you can have the moment. See, what I can do, like when I'm cooking, is to say, 'Now come, J-A, you peel the carrots'. That could take like half an hour, and in that time I need someone else to be there for B.
- R: Now that you've mentioned cooking... I'd like to know about J-A's self-help skills, like making something to eat.
- A: She can do some things. She can go to the toilet by herself... but sometimes she doesn't manage with the toilet paper. She's got over the thing of unrolling all the toilet paper and blocking up the septic tank. For a long time, we had the toilet paper up very high, out of reach. But that didn't really work, because she went early in the morning when she wakes up and get to it. She's learnt now to only take a small piece. Sometimes she doesn't know what to do with it, and she just drops it in the toilet! But that's another step I've got to take and intervene and go with her every time and show her what to do. But I'm not doing that now. She's got bladder control and bowel control, certainly. She undresses herself, but needs help with laces and buckles and things. She's learning now to bath herself properly in the bath and you wash your arms and your face... but that's a major thing every night. She enjoys herself too much in the bath. We must teach her that she must get out of the bath properly without leaping out and messing on the floor... or running around wet through the house. She's too big to be running around naked now. We must teach her to dry herself and dress

herself; she's got to learn to brush her teeth. We're working on that now, she's not independent yet. In terms of self-help skills, she will never starve! She knows exactly where to find food. She can butter her rice cakes now, and we show her where the fruit is. But we still have to intervene, because she never knows when to stop. We make her speak for the food, like I said. But she is young, and she is still learning...

R: In terms of needs and concerns, we have basically covered both. On the other side of the spectrum, what gives you hope for J-A and her future?

A: Well, the fact that she has learnt so much in such a short space of time. The fact that she has responded so well to getting rid of the mercury. Maybe, if we get it all out of her, these problems with learning will stop. We've certainly seen it... there's been a huge improvement since we got rid of most of that mercury. What gives me hope is the progress that I've seen since we've been doing this. The interventions actually do something. They don't take away the autism, but they have certainly made things better with her behaviour and they help me to manage and to know that I'm doing this, and this is not a punishment. This is an intervention, for her good and for our good. But again, it's on a day-to-day basis... some days are just terrible. And at moments I just got to lock her up, because I can't be with her. And I know that, if I deal with her, I'll deal with her inappropriately.

R: It sounds like a constant challenge to deal with a child with such high demands.

A: It's not nice. Once, she went through this stage where, every time she went to the toilet, she would wee on the floor. I had to clean the toilet like five times a day. I was so tired, and you get so angry at things like that. It sounds so silly, but when it goes on and on and on... Like on Thursday morning, I flipped out again. I took her, and put her outside the house, and I locked the door. Now what I should have done, rather, the correct thing to do, is to tell her, 'This behaviour is unacceptable, J-A. Now you go sit on the couch with me...' and do a holding on her. But that meant that I had to stop making breakfast for the rest of the family, I had to stop doing what I was doing, I had to intervene in my own behaviour.

R: Sometimes you just don't have that emotional energy...

A: I didn't. And A (husband) was so cross with me, because he said, 'It was 10 minutes after you woke up, and you are already like that!' But that was the end of the holidays. I've had her the whole holidays. She was here from Monday for the whole week. And I had two tutors come in three hours at a time, and I had her the one day. But I had her during all the meals, and her behaviour is worse at the mealtimes, and I have her during all that free time that is not structured. And when I do teach her, I've got this (*turns her head in B's direction*) to interact with as well, and the household to run, and the mess and the dogs and the horses... all going on at the same time. And I admit, I made a stuff up and I did the wrong thing, and I can't correct that. He was very angry with me... it's easy to criticise... but I almost disregard that, because he hasn't got a clue. Because he's not here 24 hours a day.

R: It is encouraging that you can admit to a mistake and not feel that you have now failed as a parent.

A: But now he (husband) has got a difficult time with that, and he's also got to learn. Look, I made a mistake, and I admitted it. It is an ongoing learning process, and it never stops. And autistic children teach you more than you teach them. Before I had J-A, there was no way that I would give any time of day to any disabled child. 'You weren't supposed to be born', I'd say, 'You should have been put down at birth!' That's the kind of way that I used to

think. It hurts... there are days when I feel sorry for myself... I do... it's getting better now, but... (*Laughs*)... I don't get stuck there. So what I do is, I have the Aurora children, who used to be in her class, the really bad cases, like children who can't walk or sit and dribble all day long, they come every week to ride the ponies.

R: That gives one a bit of perspective, hey?

A: Ja, ooh! J-A can function, she can run, she can jump, she can ride a horse. Yes, she drives me mad, but she can cope! That also helps me cope, to keep the perspective. Sometimes I think, would I choose autism? If you had to say you have a disabled child, what disability would you choose?

R: That's an impossible question to answer.

A: Yes, it's frightening... frightening! Would I choose it again? And I sometimes think... not always... that I would choose it. Maybe because I know it, maybe because it's the only one with hope. Certainly, it is the most stressful... I can't think of a more stressful environment to raise a child. And just... it's picking at your weaknesses all the time. She just won't let you be. When I talk to A (husband) and don't look at her, she'll know. She'll quickly run and go get that book that she's not allowed to. She watches, and she'll wait until she sees a weak point and then she'll get me there. Wicked and terrible, sometimes. Then you just go, 'Ag, this is too much.'

R: I suppose, sometimes you get so angry, that you forget that you are dealing with a disability.

A: I know, and you've got to fight the disability, not the child. And sometimes, like last night, she didn't want to go to sleep. So she called me, 'Mommy, sleep! Mommy, sleep!' She wants me to come and lie with her. Now I don't do that every night, because then that becomes a pattern. So, eventually, I went there... and she loved me and hugged me and said, 'Aah, Mommy, aah!' She's just like a normal child, you know, looking for that affection. And to remember that that's my child, she's my child, and the autism is something that we have to deal with and intervene and try to get the child out of it.

R: Wow! (*Sighs*). Just listening to this... I really don't think one can comprehend unless you live here.

A: You can come and have a try! (*Laughs*). Nobody wants to come visit here. My in-laws from Johannesburg come for a short while, and they think they are being very helpful if they take her for a walk! They haven't got a clue. They always think they've got a clue, but they don't.

R: Well, from my side, I have basically asked you about everything that I wanted to. Just before I switch the recorder off... is there anything that I haven't asked that you'd like to say or think is worth knowing about parenting a child with autism?

A: I think there should be more support for parents. There is so little time these days for other people... to hear what other parents are thinking and doing. You speak to the teachers, and they are so bound up in method and legislation. Like, I wanted to go to J-A's school the other day and not be a teacher, but just be a facilitator in the classroom. And they wouldn't let me do that, because it's not part of the policy. Now, they can all benefit from that. I can benefit, the teacher can benefit and J-A can benefit, but the policies are there and say that I can't do it.

R: That's hard, I suppose, for people to think outside of the box.

A: Ja, and they can't do that. And with autism, you have to think outside of the box. You've got to be ten steps ahead. I think that, if people are just more open and honest with one another, a lot of suffering will be alleviated. Everybody goes down this lonely road by themselves, and it's not like they are the first persons to do it. Maybe it's just the whole social structure these days... it's so categorised, like 'This is my corner, don't you dare meddle!' And they're all struggling along on their own paths, which are similar paths. And I think of these mothers that I've seen with their children, who has obviously got autistic signs... and I don't have the courage to go up to that mom and say, 'Hey, my child was like that. I've been there.' And I don't even know why I don't do it, because I would like my pathway to be useful to somebody else. Otherwise, what is the point of all of this? Why? I mean it changes the individual, but that's very isolated and a waste of your time. It helps me in my little corner, but what's the point if it doesn't go any further? You also need to get to doctors and say, 'Hey, open up your eyes. This thing is more common than you think, and help to empower parents!'

R: That is certainly a powerful message. Thank you very much for the time you spent with me to share this helpful information.

A: It's a pleasure. It's good that someone listens to the parents.

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**INTERVIEW TRANSCRIPTS**  
**PARTICIPANT B**

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**BIOGRAPHICAL DATA**

<b>Pseudonym:</b>	B
<b>Sex:</b>	Female
<b>Age:</b>	38 years
<b>Occupation:</b>	Game Farm Manager
<b>Highest level of education:</b>	Tertiary (Hotel Management)
<b>Home language:</b>	English
<b>Marital status:</b>	Married
<b>Relation to autistic child:</b>	Mother
<b>Autistic child:</b>	D, Male, 9 years old. Has two younger brothers, aged 8 and 5 years.
<b>Date/s of interviews:</b>	11 April 2003 and 25 April 2003

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*(Prior to starting the interviews, the researcher went through the information letter that was distributed to participants, with consent forms, prior to the commencement of the research. The researcher further explained the aim of the study, the manner in which confidentiality and anonymity would be ensured, and asked research participants to complete and sign the departmental consent forms to audiotape and transcribe the series of three interviews.)*

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**INTERVIEW 1: EXPERIENCES UP TO AND INCLUDING THE DIAGNOSTIC PROCESS**

- R: How long have you known that D has autism?
- B: Since he was about 20 months... 22 months.
- R: Was he diagnosed at that age?
- B: He was diagnosed at 23 months.
- R: One of the luckier parents, in terms of getting a timely diagnosis...
- B: Absolutely. But... it wasn't actually told to us, it was said, 'Perhaps' or 'With autistic tendencies', but we knew that it was autism.
- R: I would actually like to talk about that later and hear how that came about. Firstly, I would like to just ask you to tell me a bit about your family... like the family size and birth order of the children.
- B: D is our eldest son, and I have two other sons. N is 8, and G is 5. My husband and I have been together for long... 4 years before we were married, and we've been married for 11 years.
- R: Please tell me about the characteristics or personalities of the different family members.
- B: My husband and I are both babies of all the children... the youngest. So we've been allowed to do... we've had no pressure on us and we've been allowed to do more or less what we

want with our parents and siblings and whatever! We both like home a lot. My husband's family are very close and they all live in South Africa. My family... I was born 15 years after my closest brother... and they're all over the world... but I communicate with them via e-mail. My husband's father passed away before we were married and that brought his siblings even closer. We see them regularly. We're all quite sensitive. Particularly my middle child. D is sensitive about certain things; N is very sensitive to everyone. He's my most sensitive child. And G is our baby... we're not having any more... he doesn't care about anyone, but himself.

R: I suppose it's quite appropriate for a 5-year-old to be a bit self-centred!

B: Ja, but he will always be self-centred! To each his own, you know... he's allowed to.

R: Tell me more about D, his personality, and his relationships with the other family members.

B: He gets along very well with the other two children. N and D are very close. He talks about N at least 20 times a day at school, they tell me. And N taught D how to speak; he potty trained him, because they were developing at the same stage. N has now overtaken D, and he finds him a bit boring. So they don't play together as much as they used to. But now, D is playing with G, because they're at the same stage. I'm sure he will outgrow him, and then D will start doing his own thing. So they are close... the brothers are close. N is very protective over D. There was a time when they were little... I mean N could talk before he was two, properly, because we were just trying to get D to talk. N could actually talk before he was one. And we'd go somewhere, and he would say, 'This is my brother, D, and he is autistic.' That is how he would introduce the family. So he is always trying to excuse himself and he always asks, 'Will D ever come right? How does it work?' So it worries him, whereas G has grown up with it, it is not an issue.

R: But your second child, N, he also grew up with D after the diagnosis?

B: Ja, he was born before we knew. He was a little baby. But N takes everything on himself... he's just that kind of person. He takes on responsibility. He has told us that D will live with him when he's older. All of that... and I mean, I have never asked him to look after D or anything like that.

R: N sounds like quite a responsible little man.

B: Yes, but it's not a good thing. I mean he worries when I drive to PE that I am going to die, and then what is he going to do? I mean he's just like that... like my mom. So I can recognise it, and I see that it's not healthy a lot of the time. They fight... N never fights with D; he protects him all the time. But G and D fight for my attention, or whatever. And N and G fight; N will never fight with D. And D hasn't been fighting for a long time, only about three years... I think when G started being a threat and fighting back, he has learnt how to push and shove and screech.

R: So D was quite a passive child before that?

B: He is very loving. He is a very loving, placid child. Emotionally, he's my easiest child, because there are no demands. N can tell me, 'I hate this or I don't want that or I'm worried about this.' G can have a tantrum... D never has tantrums.

- R: I suppose that's part of the diversity of autism. On the one hand, you can have such a tense and fussy little baby, and on the other side there are those who are just in their own little worlds.
- B: Look, I mean he could scream a place down if he was over-stimulated, like a shopping centre or something. But I mean anyone can.
- R: I suppose that shopping with an autistic child can be quite a challenging experience.
- B: It's strange, because it's his favourite thing in life. He loves shopping, and the escalators and lifts and whatever. But then, it can get too much for him, and then he just flips out.
- R: What happens when he flips out?
- B: He bites his finger when he starts getting anxious. There's a huge callous on his finger, because he does that when he is excited or happy or worried or whatever. When he's highly emotional. And then he'll start saying the same thing over and over... like, 'I want smarties', or whatever. And when he repeats things, you can hear that he's getting more and more anxious. It will maybe get louder, or then he'll have something in his hand, and he won't give it to the cashier. You know... just like high anxiety and losing control of what's going on. But, I mean, when he was a baby or a toddler or a four-year-old, I used to phone my local Spar and say (*lowers her voice into a whisper*), 'We are coming today! We are coming shopping.'
- R: (*Laughs.*) That's sort of like preparing the locals!
- B: Yes, and 'You are not going to do anything out of the ordinary.' D used to scream the place down. If he put something in the trolley, it was his... and he found it very difficult that it had to go onto a table and be scanned and then given back. So he used to stand at the checkout, screaming.
- R: The whole time?
- B: Yes, for the whole 20 minutes or however long it took to ring up. But we would just hold him... hold his arms down, because he would try to get all the stuff back. Eventually, I got him to realise that we have to pay first. So even now, he'll say (*speaks in a fast, anxious voice*), 'Let's pay with the money! Let's pay with the money!' And it's always the end point that's the problem. The actual being in the shop and selecting the goods are fine. It's when they are being handed over and then being handed back.
- R: I would like us to go back to when D was an infant, a baby and a toddler. Tell me about your pregnancy with him and how you eventually realised that something was wrong.
- B: Look, we were dairy farmers. We weren't where we are now. My husband and I were dairy farmers near Plettenberg Bay. And I was working at a nursery; a plant nursery... and we were hippies! And I didn't even go to a doctor when I was pregnant. I was very happy, and I thought I would have a home birth. You know, not at all concerned. Everyone has babies every day, no big deal. When I was eight months pregnant, my husband and I had been to breathing classes with a sister who worked at the local hospital. And I just woke up one morning with pain in my lower back, and that night I had felt very strange.
- R: What do you mean with feeling strange?

- B: I was very emotional, and had a lot of back pain. And I went to the Knysna Hospital, and I sat in the queue with about fifty other ladies, waiting to see the doctor, because we don't have a medical aid. And they made me wee and took my blood pressure... but that's what they do when you're pregnant. And there was obviously something wrong with me. So they said, 'You're in labour... at eight months... You're showing signs of pre-eclampsia. There's something in your urine, you're blood pressure is sky-high! What were you doing?' So they were shouting at me, and I was feeling (*covers her eyes with her hands as if to indicate fear/anxiety*)... I remember thinking, for my baby, 'I'm sorry!' The first conscious thing and realisation that everything might not be okay. Because before then, I hadn't had a care in the world. And then they broke my water, and they put me on a drip, and they left me with about eight other women in labour for about 12 hours. At 7 o'clock, the doctor came on, and he said to me, 'Things are not going well. Your blood pressure is too high. Your baby is in distress... you need a Caesarean.' So they whipped me out and gave me a Caesar... But I had real complications, like my heart stopped. Several things happened, and the whole thing took about two hours. D had an Apgar of 2, 2, 6... and he was blue... he was very blue! I don't remember going down to the ward... it was quite late at night, like 10 o'clock or something. The next morning I woke up, and asked, 'Where's my baby?' They said, 'He's in the incubator over there.' I got up, went to the incubator, and said, 'I want him with me.' And I noticed that he was blue, and I thought that something was wrong. Then I started asking people, and they said, 'No, he's just a blue baby... It was a difficult birth, he's going to be fine, we're giving him extra oxygen through those little tubes and he's in the incubator.' And they were tubing him, and I said, 'No! I want him with me.' So I ripped him out and I signed this thing and they gave him to me in the bed. I started to try to breastfeed him, and then there was a lot of panic and doctors and they were quite angry with me...
- R: Because you took him out of the incubator?
- B: No, because I hadn't been to a doctor while I was pregnant. Because I had high blood pressure, and I had it throughout my pregnancy, they thought. And my liver and my kidneys had collapsed, and I had pre-eclampsia. They were basically just saying, 'You are irresponsible!' and whatever.
- R: It sounds as if that was quite a punitive experience.
- B: Yes, it wasn't nice... But they told me that D was fine, which was my main concern. I didn't care what they said about me.
- R: Did you believe them at that stage... when they said that?
- B: I thought that he was blue, that's all. He didn't have jaundice. I saw he was still blue, and he stayed blue for a long time... but he looked fine and I didn't quite understand and I didn't go into it. I mean, he looked perfectly healthy. He was small, 2.5 kg's... But I mean he looked perfectly healthy. He was just small like a prem baby. It took him about three days to learn how to suck properly.
- R: You were adamant to breastfeed him?
- B: Ja, but I mean, I got lambs to suck. That is what my job had been before on the farm. So, I just did not give up. They said, 'Give him a bottle... Give him a bottle!' But I said, 'No, I'm breastfeeding. He's staying with me. He's sleeping with me in the bed. I won't squash him. Go away, leave me alone!' And I stayed, because my blood pressure didn't go down, I stayed in the hospital with him for seven days. And he stayed in the bed with me. Then we

went home, and then... I was very like, 'I want to do this on my own!' My family wanted to fly out, and they were worried, and my mother and my sister and my brothers... but I said, 'No.'

R: You were determined to do it on your own...

B: Ja, with R (husband). I can remember thinking, in those first two weeks, 'He sleeps a lot!' Because I had looked after my nieces, and I know what babies are like. He slept more than normal. He was very good... too good... content. He didn't do this (*gestures wringing movement of hands in front of her face*)... babies do that. He kept his hands still. He liked being held a lot. He didn't like being put down on his own. I found that, even when he was older, that he was easy to console. I used to love breastfeeding him. He wasn't fussy; he wasn't difficult. He used to... it's quite funny... he used to pooh once every two weeks! But there are babies who do that; they just absorb all the breast milk and they wee and everything, but they just pooh every two weeks. I remember, later, when he was on porridge, probably a year or so, he wouldn't take a bottle. So he just wouldn't drink for a long time. No water, nothing! But he was eating vast quantities of fruit and vegetables... and then he started taking the bottle. It took about four weeks that he wouldn't drink... not from a spoon or a cup or a bottle. So that change was very difficult...

R: As it often is with children with autism...

B: He really found it difficult to hold his neck up. He only sat at about a year. Then he could properly hold his head up. His head was really wobbly. You had to support it, or put him on a chair where his back was supported. Then he crawled and then he walked. He was late, like three months later than what I thought was normal for babies of his age.

R: How did you understand that, or what did you attribute it to?

B: I thought that he might have had oxygen deprivation at birth, which caused the delay. And we used to have a clinic sister that would come to the farm in a kombi. And I used to say to her, 'He's really slow!' But she always said, 'Don't worry! Everybody is different, and boys usually take longer than girls.' And I've got four nieces, so I've only looked after little girls. So she said, 'Don't worry... he's fine.' And then she'd test him and weigh him and inoculate him and do everything.

R: So, according to her, he was fine... seemingly?

B: And then, we could just not understand that he wouldn't smile. He had not smiled before. I would call him and call him and call him and call him... and he would not answer. We started thinking that he was deaf. But then, we would open a packet of chips five rooms down, and he would be there! (*Laughs.*) So we'd think, 'Are we going crazy?' I used to sing a lot to him, and he could sing the tune I was singing, but he would not respond to his name or commands, like 'Put the cup down' or whatever. And he was quite busy... very active. Then N was born... D was 16 months. He loved N from the word go. He loved to hold him and interact... he also started to smile at him. And then we decided, we've been to the clinic and whatever, we never had any time with D or N on the dairy farm and with the nursery... and we were now going to find out what was wrong with D. I happened to meet this professor of paediatrics, who... I've been ill as a child, and he recognised me in the shop in Plettenberg Bay! We started talking, and he asked whether I've got children. So I told him about D and N, and I said that I think that there may be something wrong with D. So he said, 'Well, bring him to me and I'll have a look.' So we went there... we went to see him at his

house, and he said, 'Yes, there definitely is some developmental delay there. I can't tell you exactly what it is, but what I recommend is...' See, we couldn't afford anything private... He said, 'Go up to the children's hospital in Johannesburg, and go see Dr. Joan Wildman.' He organised that for us. So we went there, and stayed there with R's sister in Johannesburg. We stayed there... and it took about four or five months, because we had meetings, and then we had to go and have a CAT scan, or an ear check, all at the Johannesburg General Hospital... genetics, blood, urine... all of that kind of stuff. And then we'd wait for the results and they all got together or the psychologist would watch him play or climb up steps.

R: What was that like for you?

B: Terrible... absolutely terrible! I could not do it. I could not do the hospital part. R had to do that. I initially went with him, with N, because we had absolutely no one that we could leave our other child with. So we'd go with N and D. D started getting upset or he didn't relax. They'd often give him some kind of sedative, like a syrup or something to calm him down, because they wanted to put electrodes on his head or wherever, and it would hype him up.

R: So he had an abnormal reaction to the medication.

B: Yes... and I used to just go and sit outside and R would have to stay with him. I could not handle that at all. I didn't mind seeing Joan or questionnaires or play therapy or whatever, but I didn't like the medical interventions. And after all of this she said that it was very difficult to give us a prognosis and she would like us to go and be re-assessed when he was three at Red Cross in Cape Town or back to her or whatever. She said PDD... Pervasive Developmental Disorder, with autistic features. I can remember feeling relief... like huge relief that he wasn't deaf!

R: Did you know what autism was... or autistic features, what that meant?

B: I had a friend, who had had a child, a young boy, whom we all thought was autistic, or what we thought was autistic. I thought I knew what it was, but I still don't know what it is! But he liked playing on his own; he didn't interact well; he needed a lot of support socially and emotionally, but his speech was good. This child that I had contact with, he was at that stage 10, my friend's child. With D, I can remember feeling relief that at least we know what it is, at least we now knew how to start working with him and doing a home program or something. At least he wasn't deaf and we weren't barking up the wrong tree or wasting time or whatever. And then I started getting cross, because I thought that I should have managed my pregnancy and the birth better and should have been more assertive about it.

R: When you say you got cross, do you mean that you got angry with yourself?

B: Ja, like it's my fault that this happened; it could have been different. But then I thought often that it might have happened anyway... I mean, you never know. You often have that, you know... like some months you feel okay about it and some months you wish you had done this or that or the next thing.

R: It sounds like quite an emotional experience... a lot of ups and downs.

B: They were quite good to us. When she told us that D had PDD with autistic features, then they send us, the whole family, to a psychologist. She talked to us about it, and said that we are going to feel guilty and angry. So she sort of prepared us for what to expect... she was very nice. I wasn't as... I accepted it a lot easier than my husband did, I suppose because I

had much more contact with D on a daily basis than he did. I think that he felt quite isolated... he kind of isolated himself from it. He almost pretended it wasn't happening. And he would refuse ever to discuss sending D to boarding school or away... you know. We were always going to keep him with us and look after him. But I mean, he was a 2-year-old boy, and it's difficult to think about that at that stage. He often pretended that it wasn't happening and that it would definitely get better and that it would go away... like it was just an overreaction. He thought he would grow out of it or that something would change.

R: And in terms of your understanding of what was going on?

B: I didn't really know what to expect. As I look back on it now, it was hectic. But when you're in it, you don't really know. You just do it.

## **INTERVIEW 2: POSTDIAGNOSTIC ADJUSTMENT AND COPING**

R: We are actually moving over into the second interview topic now, which is about how you responded, adjusted and coped after the diagnosis was made. What happened in the family... I mean how did you cope in terms of setting up a daily routine.

B: It was very difficult, because we had resigned. So we were unemployed, and we were living with R's sister. We got the diagnosis, and we realised that we were going to have to rethink what we're doing... we couldn't do dairy farming, because we would never see the children. So we moved in with R's other sister, who lives near Knysna. I started helping her... she grows herbs. And I would stay at home with the children. I had these little home programs that I'd do with him.

R: Did you develop these programs on your own, or did you have some help?

B: Yes, I did it on my own. Very simple things, like dressing dolls or washing hands. Very easy stuff... singing songs, trying to hold a pencil. He was two at that stage. I wasn't extremely strict about it. D was always a good kid, but they were very busy at that stage, once N started crawling. We used to call them the "mini movers". What they'd do is, if you didn't watch them, they'd go into a room, and they'd move every single object in that room out into another room. And that became one of his obsessions... moving things. R started looking for a job. Things were starting to get hectic... the children were ruining everybody's life. I wanted to go be with my parents in Portugal.

R: So you felt a need to be around your parents and family at that stage?

B: I just felt that I'd been relying a lot on R's family, and I actually hadn't let my family in. I felt it was a bit unfair to them as well, to my mom and dad. They knew about D from the start, and they were really involved, but they wanted to be more involved. So I said to R, 'Let me go to Portugal for two months, and you sort your life out here. When we come back, we'll have somewhere to live and know what we're doing, and you'll have a job.' And just before we were going to Portugal, our GP, our old GP from Plettenberg Bay, phoned us and said, 'A friend of mine just bought a game farm near Graaff Reinet and he needs a couple to manage it, and I thought of you.' So we went for the interview and then we flew out.

R: You went to your parents in Portugal?

B: Yes, the two boys and me. R stayed behind. About a month after we had left, R was offered the job. So when we came back, R had moved to Graaff Reinet, to where we are now.

- R: Tell me about the two months in Portugal. Did it also help you to take care of yourself?
- B: No, my parents are old. My mother's an emotional wreck, so it was more like me taking care of them. Not really my dad, but I had to do a lot of hands-on stuff. But it was more about not feeling guilty about having excluded them.
- R: How did your parents respond to D?
- B: My mom was very close to him when we were there, and my father. They are very loving, touchy kind of people. Strangely enough, we were there for two months. D and my mom got very close. Then we came back, and we didn't see her for a year. Then she came to visit us, and D would have nothing to do with her!
- R: Did he not remember her?
- B: I think he did. I think he was furious that she had abandoned him. He would actually go up to her and push her away. But he did recall who she was, because we've got photo albums, and he'll say, 'That's Granny Darly', he was doing that at that age. So they were good, but they worry. They worry about us and the future and what will happen, and I don't really. They are all worried and concerned and trying to help and support.
- R: I would like us to go back for a moment to your actual management of the household at that stage. You had a second young child... things such as a daily routine...
- B: Chaos!
- R: What about meals, bath time, bedtime, behaviour management?
- B: It was chaos. I can't actually remember. I can't remember N learning to walk, talk, anything... he taught himself. I actually can't remember... I had two very young children in nappies.
- R: Is it actually difficult for you to recall anything from that time?
- B: I cannot remember. I can only remember being very, very tired. And I can remember R taking a lot of strain, because he thought that I didn't love him any more. I was with the children the whole time. I was controlling the children... feeding, cleaning, changing nappies, stimulating or whatever. I cannot remember much at all.
- R: Did you find D to be very demanding of your time and energy?
- B: Both D and N, they were both demanding. When they both started crawling and walking and running around... it was like having twins. Because D would make N do things, and N would make D do things. They'd spur each other on. Then, when we got to the farm, it was much easier. Much, much easier...
- R: In what way?
- B: We've got a huge house. We didn't have many things, very few bits of furniture. And we gave them complete freedom. They'd walk... they still do... they'd walk for five kilometres, the two of them. Or they used to play in the river with that much water in it (*gestures depth of about 15 centimetres*). So there were many nice things for them to do, and there is lots of

space. They've got complete freedom, and I was more relaxed, more settled, and we had a stable income. Everything was just easier.

R: In terms of D's development and education, what happened with that?

B: When we got to the farm, about three months after we'd been there, I met a woman in Graaff Reinet who had a Montessori playschool, and I thought that I'd like to send my children there. She said that D could come, but not N, because he was too young. So I said, 'If N can't go, then I'm not sending D.' Because he wouldn't go. I mean, he didn't do anything without N. So she said it's all right, N can come too. It was just socialising, teaching him to sit down at a table... teaching him to concentrate on one thing. And Montessori was good for him, because it is so behaviourally orientated. And sitting in a ring... I remember that children were horrible to him, older children. And that upset N. But in terms of work and stuff, N was streaks ahead of D, like with word recognition or numbers and everything. And then she closed, so I took the two of them to Union Preschool, and I didn't like them at all. They didn't like D, and I felt badly treated by the teachers and the institution and whatever. They had big classes, they didn't understand the problem... They didn't want to understand the problem. It's a normal mainstream preschool. They just treated me badly and they treated my child badly. So I took them out of there, and I sent D... I decided to keep N at home... to W. P. Preppie, which is an Afrikaans school, a preschool... and I found them great! Much more accepting. They had two other children that they did not know what was the matter, but they were obviously attention deficit or something. I had good staff working in my home, helping me with cooking and cleaning and whatever, and they accepted D. I mean, a lot of Xhosa people, they are amazing like that... they just accepted how he is. The one lady, J, used to go with D to this preschool and sit next to him, just so that he would behave. He wasn't able to follow instructions, so she would tell him herself. Because he would find it difficult, if someone stood there up front and say, 'Let's all go and have our break,' or whatever, he might not be listening and be like a thousand miles away. But if someone just looks at him and he knows that they are telling him, then he'll do it.

R: So, he needed a lot of individual attention.

B: Yes, one-on-one. A lot of one-on-one attention.

R: So, if I understand correctly, he would be at the school until late morning. Would he be around the house the rest of the time?

B: Ja, but he only went twice a week. Sometimes once a week, because we are far from town... We are an hour and a half from Graaff Reinet, so he's used to travelling.

R: What was he like at home at that stage?

B: He was busy. I honestly can't remember. They used to disappear for hours on their walks.

R: What was that like for you... I mean, would you worry or just knew that they were off playing?

B: It was very strange. I initially worried, and we got one of our trackers to follow them. And they used to know about him and they would get really irritated. And they just had certain places that they went to, and they were always there... so that was fine. But I had a couple of times... I mean, one time I can remember, I thought that they were dead, both of them. I

could not move, I went weak at the knees. And I radioed my staff to go and look for them, and they found them about eight kilometres away. I was pregnant with G, on my own on the farm, R wasn't there, and they had vanished! And they couldn't swim, and there were big dams.

R: And all the animals and snakes and stuff?

B: That doesn't bother me. We've got rhinos and bushbuck, but that does not bother me in the least. I am nutty, I'm telling you. I am more scared here (city). If D disappeared here, I would die. If I had to lose him in a shopping centre! For me, the openness and animals and snakes and water and whatever are not so bad as someone taking him, or a car. It's all what you are used to, I think. His sense of direction is unbelievable. Still, to this day, he will come and tell me now that he's going for a walk at eight o'clock in the morning, and he'll come back at eight o'clock in the night... And I do worry when it's ten o'clock at night! And he has come back in the dark. But I've got to give it to him. We are very lucky that he can do that, because he is letting off steam. It is very healthy for him to do that...

R: It sounds like an idyllic lifestyle!

B: It is for him. He is very lucky. But that is why he finds it very difficult to settle in here. Because the change is so enormous.

R: How did it actually happen that he ended up here at Quest?

B: It was the Eastern Cape Autism Association, a woman called Dianne. I went to meet them at Quest in Uitenhage. They only had five children in the school, and they gave me a home program. I was good about it some days and not so good about it on other days. I mean, I am not so much into routine. I am not into routine, which is a problem for D, I know! That's what he would prefer, but my house runs more on chaos. My line on it is that D has got to learn what the real world is like. He's got the structure and routine on this side, and at home it's sink or swim. If he wants a sandwich, he must make it himself. Or if he wants to go for a walk, he has got to come and tell me and go for a walk. I am not going to say, 'Eight o'clock is bed time, blah, blah, blah...'

R: How does he respond to that lack of routine at home?

B: He's fine. He's absolutely fine. He is easy to take anywhere. I mean we can go on holiday to the Beacon Island and he is used to just fitting in with what goes on. But we realised that D needed some therapy, so we advertised for an OT to come stay with us on the farm. So we got hold of this lady, but it was not good for any of us... It was horrible for her and for us...

R: In what way?

B: I found it very difficult to enforce that structure in my home. And D wanted to be with me, so he resented her. It happened to be in our house... she stayed in our house. So, he would see her coming, and then he'd run to me and cling to me and she'd say, 'Let's go do some work.' I would walk with him and go sit at the table and, you know, for an hour or so. He just did not enjoy one second of it. I know that D keeps his life here (at school) and at home completely separate. It's like he is two different people. He will not wear anything at school that he wears at home; he will not bring anything from home to school. I had to buy school clothes and home clothes. If I talk about school, he tells me to be quiet. He will not talk to me about anything that happens at school. It's very difficult for him to mesh the two

together. I noticed that already when he had the OT. So, it didn't work out, and then she left. Then, when he was 5, the lady from the hostel phoned and said, 'Should I put your name down?' So I said she should put my name down, but R said no way! But they phoned me again later, and I thought, 'Well, okay, let me give it a bash!'

R: You said that your husband wasn't keen on the idea.

B: He was furious. I took D against his wishes. But I sensed that D was getting frustrated. I could not give him an enriching situation at home. He was not learning any more from me. I now had two other young children, N and G... I couldn't give him all the attention he needed any more. I also thought that he was getting to that age where he should be in a structure and start learning to read and all that stuff. And I could not do it. I did not have the time, and he did not want to be with anyone else. My argument with R was that I had to give him a chance to realise that he could live on his own. That he can survive without me. If he knows that, I'll be happy. He can come back and live with me when he is older, but I want him to know that there is life. Because he felt like an extension of my body. He never, ever left me. He would sleep next to me. He was on my lap constantly. I would get into the bath; he would get into the bath. Now, when he comes home for the weekends, it's still like that. He still follows me a lot, although he does go out on his walks. He is much more with me than with the other children. But I only noticed that when he left. Because I was so used to it, I didn't know any different. So I brought him down to Quest, and stayed with him in hostel for a month. It was terrible. I mean, I am very affected by how places look and feel. I just thought, I cannot project onto him how I feel. I've got to give him a chance to be on his own. After a month, I left, and we sent one of our nannies, a staff member, to come stay with him. They used to carry him screaming in the morning. And then I was there in the afternoon and we would go off shopping or do something fun. And then Lindy would do the same with him for a month, and then we left him.

R: I would like to ask you a bit more about raising D and the demands it made on you as a parent.

B: I think raising D had more of an impact on my husband than it did on any of my two other children. They did not know life without D, whereas R did. He really struggled with it, because D was with me the whole time. He would actually get cross with me and say that I was obsessed with D. He said I only wanted to be with D. I wasn't always with him, he was always with me! There is no other way kind of thing. With N, I think he was ignored a lot. He was a coper, and I was barely coping with D and with both of them.

R: It is interesting that you now talk about coping. It sounds as if the coping consisted of giving D 100% of your time.

B: No, I don't give him everything he wants; I find it difficult to discipline him. I speak to him, but I can't shout at him and I can't change the pitch of my voice. Because, when I do, he gets very upset. And then it escalates into a complete breakdown. He'll start wailing if he thinks I'm really cross. I find it extremely irritating when he repeats the same thing over and over again when he wants my attention. So then I'll say, 'Oh D, just shut up man!' And he's fine with that.

R: Does he stop then, when you say that?

B: Yes, he does. It's terrible, because my 5-year-old also now says, 'Oh, D, shut up man!' And D will listen to him. So we all do it. I smack them, all of them, when they fight or when

they're naughty or D's naughty, he gets a smack. He gets very upset by a smack. It's not a hard smack or a beating or anything like that. He will usually stop doing what he's doing straight away. And then he withdraws and kind of pulls himself together. He bounces back quickly. He's fine, he's not a sulker. He will often say to me, 'Is Mommy cross?' before I even smack him. Like when he has been pushing me or something, and he can see that I am cross. He will ask me if I'm cross, before I show him that I'm cross. So then I'll say, 'Yes, I am cross because of this... So now don't do it again.' And then he won't do it again.

R: It sounds as if he is quite emotionally attentive.

B: He is very emotionally aware. He will know when I'm irritated. Only me, not really anyone else. But recently, since last year, he has been getting closer to his father, which is excellent. They play together, and he actually wants to go on a ride with R, which he never ever wanted to do before. My husband responds well to that, they have a good time together. Recently, he took D somewhere for about two hours, and then he came back and said, 'Okay, now you take him!' I've had enough kind of thing. So I think he is starting to realise what it can be like with say an eight to twelve hour day. But he has never had that before.

R: So you have always been the primary caregiver?

B: Yes. When he wants something, he'll ask me. Unless I say, 'I'm busy now, go and ask Dad.' Then he will go and ask his dad.

R: Well, that covers about everything I wanted to ask about adjustment. Just, in terms of his education, you have mentioned that his home and school lives are quite separate. Do you still have any educational programme at home?

B: No. At home, he loves me to draw for him. So we draw and he likes recognising letters. So we look at books, and we've got a lot of SMILE toys or puzzles. Or a pegboard. He is free to use them and play with them and put them back, but I don't have a set time when we sit down and do anything like that. He's got his own TV with videos. He loves watching videos. So he'll watch videos and take them out, or listen to music by himself. He'll go make himself some hot chocolate and go to his room and put a video on and watch it.

R: He sounds remarkably independent.

B: I still dress him, I shouldn't. He dresses himself at school, but he's slow. But that's my fault, because I don't let him dress himself at home. And he loves packing bags for going away or for picnics and things like that.

R: So you go on picnics as a family?

B: Yes. We always do everything together; I don't care what other people think. We go to the Spur as a family. When we go somewhere, it could be fine, but it could also be not fine. And we never knew whether it was going to be fine or not fine. And he could deteriorate in a hurry. So we used to be always on edge. If I think that I have taken D to Portugal five times. D and N... I used to take them on a plane and we used to go via Athens and Morocco and I think I was insane. I was absolutely insane, what I did to myself! I mean, Heathrow, with D and N going completely mad. But I did it, and it wasn't that bad! I wouldn't like to do it again, but I can say now that it wasn't too bad. And I found people to be quite understanding. Not so much now that he is older. But when he was 2, 3, 5, it was okay. I mean, you see other children crying their eyes out. They don't go, 'What's the matter?' or

'Can I help you?' With D, he does not get angry or break things. He is not destructive or aggressive, he just gets terribly upset. He weeps and gets anxious and is easily stressed. The other thing that upset me is that people would get really offended, because he would take his clothes off. He loves water and super tubes and swimming pools, even though he can't swim. And then he realised that you go faster with no clothes on, so he would try to get his costume off, even when he knew he was supposed to wear it. So if we went somewhere like that, people would get offended.

R: I suppose it would be regarded as socially inappropriate in so-called society.

B: Yes, but not to me. So I would get into huge fights with mothers who told me to put his clothes on. But now, we are fine. I manage to keep his costume on. At home, he doesn't have to wear it if he doesn't feel like it, like when he goes swimming. We've got a pool, and he can do whatever he likes to. He also likes wearing my clothes. (*Laughs*). He likes to wear some of my dresses, because he likes the touch of the fabric. One of D's favourite places is the jacuzzi at the Beacon Island Hotel, and we have never stayed there! But we have to walk in there as if we are staying in one of the rooms and use the jacuzzi and sauna and heated pool. He jumps in the pool and splashes people. And people get irritated, like when a dad is trying to teach a little girl to swim. And D can't swim, but he is very confident in the water.

R: That low fear response is often associated with autism.

B: Yes, but D will never jump into the deep end of the pool. He is aware that he can't swim. There are certain people that we can go to that he likes, where he is more relaxed.

### **INTERVIEW 3: PRIMARY NEEDS, CONCERNS AND SUPPORT SYSTEMS**

R: Tell me a bit about your social system, like family and friends. Your support systems.

B: Look, we got married and had children when none of our friends had children. None of them were married, so we just used to take our children wherever we went. We live on a farm, so if you go somewhere, you often stay the night. So that wasn't always easy, but now people come to visit us. We go to R's family once every six weeks. Then, often we go camping at Cape St Frances. I mean, we know what autism-friendly places are. We go to autism-friendly places! We go to Mozambique for four weeks. We don't go out regularly. I mean, we go out to eat say once a month. We go home, or we go to friends.

R: Do you have any nearby friends?

B: I've got one close friend who stays in Graaff Reinet; she happens to be our doctor's wife. I don't know anyone else in Graaff Reinet, because I always come here (Port Elizabeth). I go to Graaff Reinet maybe once a month. So we are geographically quite isolated. But I am very friendly with our people who work on the farm. They are my friends and they support me a lot. I trust them with my life. R and I had to go away to an auction or something, and we left all three our children with the ladies on the farm. They know my children quite well, and they understand D also. D also loves them. R's one sister, who has a herb farm, is also very close to D. My family is too far away.

R: And in terms of more formal support systems? From the beginning of your life with D, what was helpful or less helpful about formal helping professionals?

- B: Well, initially I needed someone to say, 'Yes, well, you should be concerned. If you are not happy about it, check it out.' Don't just say, 'Don't worry about it!'
- R: It sounds as if some people disregarded your concerns as just being an over anxious mother.
- B: I think there are lots of over anxious mothers. I'm sure there are, and it must be jolly irritating. But I think someone should be given a chance to state his or her situation. And often, it's very difficult with people in the rural areas, because only the primary health workers have got access to those families, and the message is not being relayed. So there needs to be better communication between ... the sisters in the kombi's must listen to the mothers. And often those mothers can't even dream of going to PE or Joburg, I mean it is just too costly. I think there are thousands of autistic children, thousands, in the Eastern Cape, even in PE, in the locations.
- R: It sounds as if you are very sensitive to picking up autistic signs in people.
- B: I see autistic people everywhere, EVERYWHERE! Old, young, middle aged, whatever. Look, I think we are all a bit autistic, some just more so than others! I'm not very sociable. I'm not good in a crowd with many people. I was quite weird as a child, with separating fantasy and reality. My family is completely cuckoo, and so is R's!
- R: In what sense? Do you mean that they are just alternative?
- B: No, my mom is a manic-depressive, so is my sister, and my one brother. They've been on treatment most of their lives. R's mother is depressed, even though she has never been treated, and so is his sister. And eccentricity on both sides of the family. I don't mind if D dances on the table at suppertime, I really don't, but I know that some people will be very upset by it. As long as he knows that he can only do that at home, it's fine. Because he is not offending anybody. He is just letting his hair down, and that is okay...and he does differentiate between what goes down there and what doesn't.
- R: You've said before that you try to not think too far ahead, but I would like to ask you, as you think of D's future, what concerns you most?
- B: I would hate for D to get depressed. I have seen what depression can do. I mean, my brother only started to get depressed in his thirties. Will D wake up tomorrow and be depressed? I don't get depressed. I don't know why I don't get depressed, I just don't. Everyone else gets depressed in my family, but not me! So I am a bit afraid of depression. But I know that people with autism are susceptible to depression, and it's very difficult when they get to that teenage stage, that social stage of forming relationships with other people other than his family. He is very close to his brothers, and his brothers are going to have girlfriends and I am very concerned about whether he is going to be able to form relationships with other people of his own age. If that could turn into an abusive kind of thing. I mean, some girl could develop a crush on D, and not realise what she is getting herself into.
- R: So you are not only thinking of what a relationship could do to D, but also the person that he forms a relationship with. So it sounds as if his sexual maturation and whatever goes with that are areas of concern for you.
- B: That's what I am most concerned about at the moment. I am not really concerned about where he is going to live, or what he's going to do. I just want him to be happy. I want him to be able to say, 'Okay, I want to go to Lake Farm' or 'I'd much rather prefer to stay with

you.’ You know, whatever. He can do whatever he wants to when that time comes. I know that he will always need me, throughout his life.

R: So you have come to accept that he will never be completely independent.

B: Yes. I don’t think he will ever be able to go live in a flat somewhere. He will probably need to live on the farm, where he can let his hair down every now and again. You know, that kind of thing. I don’t think he is ever going to be able to do a 9-5 job.

R: So, in terms of practical things such as living arrangements and financial independence, you know that he will never stand on his own.

B: No, I think it will be extremely stressful.

*(Respondent requested that the interview be ended at this stage and continued on another day, since she came to fetch D for the long weekend, and wanted to leave at break time.)*

### **INTERVIEW 3 CONTINUED**

B: What I can recall that I wanted to say last time is that the medical report, like a diagnosis, should be at a much more hands-on level. With the clinics that go into the rural areas to see children. There should be like a checklist that they ask at every time they see you for a vaccination or whatever. Like, ‘Is your child sitting?’. A sort of developmental screening, but a very basic one. Like, if your child gets two crosses, there should be further investigation. I also found that going to assessments and occupational therapy and speech therapy... that was extremely stressful for me, and extremely stressful for D. Because what I felt, he felt.

R: For the moment, I would like to ask you more about your personal experience of the stressful nature of these experiences. What made it stressful?

B: What made it stressful is that I know what my child is like at home. But when he is in front of strangers and in a new environment, he is not like that at all. Even when I sent him to school here. Now D is verbal, he has been speaking since he was two. Well, he did not speak for the first six months, whatever they did, he did not utter a word. So, we would be sitting there and we would be playing and the whole family would... they tried to make it as relaxed as possible, but I would ask D a question and he would not answer because he knew that he was on show or that he was being performing or assessed or whatever, he would not do it. Like even build a three-block tower... and I know that he could do it! And I found the scepticism of people very upsetting, like they would say, ‘Now you said that your son could do it, and now he is not doing it.’ I found that extremely stressful.

R: It is almost as if your observations were not true.

B: Ja, and then you start thinking, ‘Am I going crazy now? Can he really do that?’ And then you go home and try it again and see that yes, he can do it! And then I also started thinking that maybe he would resent me later on. Maybe his not speaking for six months or whatever is showing deep anxiety and anger, and when he is a teenager he may decide that he hates me, because I put him through that. So that was a big stress in my head. Am I doing the right thing? The whole time, with each assessment. Shouldn’t I just leave it? Bungle on in the darkness or should I put him through this? And also, with this school, letting him go and sending him to this school. And I still don’t know if I’m doing the right thing. Well, I can

see that he is developing and learning, but at the same time I don't want to emotionally... I always want a strong connection with him and I want him to know that I have always done things that I think are best. And even with normal children, there is resentment, where you think that your mom did not give you enough attention or she sent you here... And he can't vocalise that. He can't tell me, 'I hate what you are doing to me'. I remembered something else I wanted to tell you now. He was incredibly sensitive with his head and his hair and anything to do with his hair... tactile intolerant with things like brushing his hair or washing his hair... like I have never taken D to a hairdresser, I have never taken him to the dentist, ever. I can't, that's got to be R's department. Hairdressing, I can't do... I used to cut his hair, but it would take like three people to hold him down. And he would scream the whole time. Washing his hair was the same thing. R and I would have to hold him down in the bath and wash his hair, and he would go completely hysterical. And my other children copied that, so I had three children that you could not go near their hair to wash or cut or whatever. Now that has all changed, they take him from school here and now he's absolutely fine at the hairdresser. And now he actually enjoys washing his hair. But it is actually just to confront that thing and say, 'Okay, I'm not taking this any more. This is going to happen, it has to happen. You can't go around looking like a Rasta. I am going to cut your hair and wash your hair.' And try to explain things to him and carry on, even though he is screaming blue murder. But things like that I found extremely stressful, that I couldn't rationalise in my mind, like why should it be so scary for him or painful or whatever? This is nonsense; I've got to do it.

- R: So it sounds as if actual limit setting, saying, 'Look, this is enough now,' that is very hard for you.
- B: It is very hard for me, especially because it is traumatic for him. It is not, like I can explain it to a 5-year-old. Most children don't react so violently to mundane things, like shopping or eating out or watching a video or washing their hair, or whatever it may be. It causes such a bizarre and traumatic reaction that that is hard to deal with. I don't think I was ever completely relaxed when D was a young child, because I never knew when the next trauma was going to happen. And I think with that added to the tiredness is the reason that I can't remember much about his early childhood. Getting through the day was just a daily struggle to survive. I mean, in the last two weeks, I've been thinking about it, and I can't remember. I can remember certain incidents and whatever, but I can't remember the day to day of it.
- R: And that, in itself, is also a way of coping. That you just screen out what is too hard to remember.
- B: It's like selective memory!
- R: Absolutely. Not to be judged for its effectiveness in any manner, it's a way of coping.
- B: I also know that I took it upon myself. I took the responsibility on myself, I wouldn't let anybody else have it. Not even my husband, it was my responsibility and I handled it and dealt with it how I saw fit. I ignored my husband a lot, and my other children, but specifically R. I mean, he was like number 6 in line, get in the queue, you know, maybe he would get some of my attention then. And that caused friction in the marriage, because he thought I did not love him enough or whatever. And I felt that I was just so busy loving that I could not be bothered to love anyone else.
- R: You mentioned to me, if I remember correctly, that D was physically so close to you that he almost felt like an extension of your body, and that your husband found it extremely difficult

to stand second to that. It sounds as if the affection was just not there... you said it caused friction... Please tell me more about that.

B: We are a very loving family. Like now, we still all sleep in one bed. We've got like a king-size bed and then two beds next to that and five bodies sleep in that bed when it's not school time. And R is also very affectionate to the children, but it was always me and D and the latest child and then R on the one side. I think what R missed most is just the conversation and just the two of us, because I used to collapse. When the children fell asleep, I fell asleep. When they woke up, I'd wake up, and then it was go, go, go. So we never had time alone, and we could not leave them with anyone else. People were nervous or, I don't know... we just did not have that kind of a set-up. And we were quite isolated, so when we went on holiday, we went as a family. And then we couldn't like arrange a babysitter or whatever. They would have torn the place down. And, what used to happen, is that we used to argue. Mainly at night, when the children were sleeping, when I was tired. He used to just say that I was obsessed with the children and that I ignored him and that I didn't care about him or whatever, and I just used to agree. Yes, it's true, I can't or I don't care or whatever.

R: You just did not have the energy to argue...

B: Ja, I am just doing what I have to or whatever and then we'd talk about it and it would be sort of over, but not resolved. And it is only since D came to boarding school, the last 3 years or whatever, that we have had time together as a couple. So, it put a lot of strain on our marriage. And now, soon, it's going to be just the two of us at home, when all three children are at boarding school, and that's also going to be very interesting. Because I know that I use my children as a shield. I know. When I don't want to do things... I'm not a social person... so it was very easy for me to say that I don't want to or I can't or whatever. I'd just stay at home with my children. They just wouldn't blend or whatever, and more so with D. I couldn't, because D won't, and he always wanted to be with me. So it was perfect. I had the perfect alibi kind of thing. So I didn't mind at all if R went out for the weekend, or to PE or fishing somewhere for a week. I was absolutely fine, and it bothered R that I didn't mind, and he is jealous of my relationship with D. But not so much anymore, because they are starting to have a strong relationship. But that is only in the last year. He is starting to form a relationship with his father now. Before, R was out. It was only me and N, and then R's sister, but with R he would not have any kind of relationship. R is social, enjoys company and belongs to a cricket club. This club and that club and he goes fishing with people, and I am a private person. I prefer being on my own. Sometimes this causes conflict. For example, R plays cricket, every Saturday there is a cricket match. All the wives and the children pack up their cars and they go for the day to watch cricket. I don't want to do that! I don't want to pack up my three children, who are all difficult, into a car... go and sit somewhere with people who I don't really know and don't really care about, and watch R play cricket. I'd rather stay at home and have some fun (*laughs*). But, you know, then R will feel hurt that I wouldn't go. So, it's a compromise thing, you know.

R: And now, with D at boarding school, how are things now?

B: Well, now I still don't often go. I mean, he can understand that I don't really like it. But I do go sometimes, and sometimes we all go together with D, because people have got to know D. I remember, I can't remember how long ago it was, we went to the Spur. We had always done it, we had always taken D everywhere with us, but this time he was at boarding school; he was not there. And R said to me that it is the first time that he had relaxed this year, and D wasn't there. And I had never known that, because he is a very calm, slow guy, and he doesn't tell me if he's feeling tense or whatever. So I had never... I was always so busy with

my anxiousness or one of the children or taking it all on myself, like I'm doing everything and organising and I'm so tired... I never realised that he is also feeling it, but in a different way, and showing it in a different way. Now I know, and N does it in his way and G does it in his way. The whole family shares the autistic person in the family.

- R: One other thing that I want to pick up from the previous interview is your geographical isolation. You mentioned to me that it was very difficult for you to get help or organise babysitters- it just wasn't part of your set-up. In that sense, you may also have been more isolated in terms of support systems, both formally and informally. Please tell me more about experiences that you have had with D and experiences that your family may have had.
- B: I don't feel that I've had support at all, from family, because we live in an isolated place, and our family doesn't often come to visit us. So they haven't... it takes a long time to form a relationship with an autistic child... So there are very few family members who have a relationship with D... only really R's sister. Even, I remember when I was pregnant with G... that was five years ago... I had an appointment with the gynaecologist, and we left D and N with R's sister, and D screamed for the whole 2 hours that we were gone, like hysterical screaming. And she said that we must never do that again. So he could just not stay with anyone else. My very good friend in Graaff Reinet, whom I left him with when I had a baby already... so a year and a half after that... he got anxious and then he just started pulling things out of her cupboards, and she couldn't control him, and she found that quite scary. So she also said please, I mustn't leave him there again. So I've never felt like I can leave D anywhere other than at this school. Now, he will go with R on a game-drive or on a walk or whatever, but he has never spent a night with R without me. He has only ever been at school, or with me. My other children are fine to leave with other children or adults... I can explain to them and they understand. I have left the children at home, we have gone away for five days, and my staff looked after the children. They have been my biggest support. They understand D, there's a relationship there, he's in his environment at home, and they know what he's like. I could leave him there... there's nowhere else that I could leave him other than at school or at home, with or without me. And now, he will choose to stay at home rather than to come with me, like when I go on a walk. I don't know... I think many parents who stay in the city with a difficult child isolate themselves even more. Because there are so many people who can criticise or query or whatever. You just get so sick of explaining to people that your child is autistic. And I had hardly any of that, because the people that I came across were either controlled, or knew about him. Either guests who are coming to visit us, or friends, or friends of friends. But when you are in a city, you constantly have the pressure of meeting strangers or explaining yourself. I would have my situation any day, rather than have to deal with all these people.
- R: You do have quite an interesting set-up on a game farm. How does the family deal with clients who come to hunt or view game on the farm?
- B: We are private. Away from the guests. We have a man, a worker, who stays next to us. He has a family of three teenage and adult children, and they are unbelievable. They know D, they've known him for ages, and they are very concerned about him and caring and supportive of him. So if he goes and runs through their house and does all sorts of things, it's absolutely fine. His behaviour has improved, though. That also used to make me very tense, with D's behaviour when we had guests or when I was working. Because he always wanted to go with us, so I would try to slip away from him, and then he'd find out where I had gone and arrive there! So it was tense, it really was not easy. But at the same time, he kept me from having to go to dinners, which I don't like doing. So, if someone said, 'Come and join us for drinks', or 'Come and have supper with us,' I'd say, 'No, I can't.' And I'd

have an excuse, which I don't anymore. With other things now, he's absolutely fine. When people come, he'll go on a game drive with us... he loves going on a game drive. He's quiet, he knows what to expect, it's fun for him. We have always included him in what we do. I mean, everyone who plays cricket there knows D and doesn't mind if he runs onto the pitch. People know him, so it's fine. The guests that we have there know him. The hunters that we have there, I don't have that much to do with anyway. But it used to be tense for me to try and do all my shopping, organise all the food, and have everything running, with D clinging on to me, because that is what used to happen. I used to go in to town, and a shop list that would take me two hours would take up to six hours, because I had two young children, and then they wanted to wee, and then they wanted this, and then they wanted that. And it is very easy with an able child, like with G I can go shopping and it is easy. And he knows that this is the basket for the guests and this is the basket for us, and there's a difference, and he can't eat from that one and that kind of thing. D still doesn't really know. So... that was stressful... but other than that it is easy and we have a lot of time together, just as a family on the farm. Although, most weekends, we have guests. So, when they (D and N) come home, there are guests, and holidays there are guests.

R: But everybody has learnt to adjust to that...

B: Ja, it is not stressful at all anymore. It used to be, but it is not anymore.

R: In terms of the formal support systems available to parents with autistic children, what is your perception of the professional help available to parents who don't have medical aid or don't have the money for private health facilities?

B: I think it is very poor... shocking actually. I think that there is very little education on the general public's side. People don't know that there is something wrong with their child. When they find out that there might be something wrong with their child, they deny it. So they ignore that there might be something wrong with their child; they think that it is going to go away. He is just being naughty, or whatever; it is not a problem. I think that mothers, or parents, don't know what to look for. And a lot of health care workers don't know what to look for. And that needs to be approached very sensitively and quickly. The earlier, the better. If there's a problem or they find out that there's a problem, get the parents used to the idea that there might be some kind of a problem, and that there is something that can be done about it. It is not like a brick wall that is now, like, this is it... your child is going into an institution and you are never going to see him again, which I think is what a lot of people worry about. What is going to happen? I happened to stumble across a state mental institution in Kirkwood, and I almost died! I will rather shoot my whole family than send my child there, or admit that there was a problem if that is where he'd have to go. That would be more hell than dying today. And that is what is available to people who cannot afford to send their children here (Quest School). So, it is dreadful. People should have home programmes, rather. But then they can't have home programmes, because the child is staying with an illiterate grandparent or both parents are out working. I mean, it's a real catch 22. But if you get it early enough, it is easier than if you leave it until the child is bouncing off the walls and then the only place for him is a mental institution, because places like this aren't prepared to have them. And I also think that parents and children with problems... and I know that this is difficult... should not be assessed away from their home environment. I don't think you get a true reflection at all. I think there should be a team of people who, if a problem is picked up, they go and see the family at the family's home. And a lot of the time, the family can't get there, it would just be too expensive to come to PE and stay here for a week and have your child professionally assessed. There should be someone who has like a broad view of developmental problems in children, who goes out into the

field and assesses problem children in an area, and who can give advice to affected parents. I mean, that is how I wish it could have happened to me. That my reports to the clinic sister had been taken seriously and that someone could have come to my home and seen my child. That would have cost a quarter of what it cost to the state, because I did not pay for my assessment. It was done through the state. It would have been much less traumatic, and we would have had an answer quickly. Instead of waiting almost a year, which is how long it took. But I know that that is also difficult. We just don't know what to do a lot of the time, because parents say to themselves... I mean I knew that there was something wrong with D and I expected the fact that he was autistic, but 90% of the parents that I know thought that there was something wrong, but then they refused to accept it. And a lot of them still think that they can make it right. A lot of it is just about accepting, it is about how you accept people generally, or yourself, or whatever. I think many people take having a family member with a problem as a criticism or a negative thing, rather than as a positive. That is what I have always tried to tell my children. I mean, they know autism better than everyone that I know, and maybe one day they can use it to their own advantage and work in that field and help other people like that, rather than view it as, 'We couldn't do this because of D'. Rather take it into a positive.

R: Thank you. We have spoken very extensively about everything that I wanted to ask you. Is there anything else that you would like to say before we end?

B: One thing is last year I was quite surprised, because we often arrange for D to come home and we weren't picking him up all the time. He would get lifts with people that he knew and who lived in Graaff Reinet. One weekend it happened to be a couple, who were guests... the owner of the farm who landed in PE and hired a vehicle. They agreed to give D a lift, and D loves going in a car. He knows where we live, and he has no problem with travelling at all. I arranged for them to pick D up and I notified the school and then told R that I had made this arrangement. R said to me, 'Did you tell them that he is autistic?' And I hadn't told them. That is the first time that I hadn't actually said, 'Oh, by the way, he is autistic. He's not going to have a conversation with you.' Because they had asked me how old he was, and I told them that he was 8 and that he was going to Quest School. This is the first time that I didn't tell someone who he was going to be in contact with. I found that interesting, that I hadn't told them. And it had upset R that I had not told them. He told me to phone them and tell them. So he hasn't fully accepted D, that's how I interpreted it. It is still like it's like 50% important to R that D is autistic. So it's like 50% of the whole. To me, at this stage, it's about 20%. So then I did phone them, but I felt that it was unnecessary. I mean, they would have worked it out, like if they said, 'D, do you want to stop for lunch?' or 'D, should we turn right here?'. They would have known very quickly that something is wrong, because he wouldn't speak to them! I don't think of him as only autistic anymore. He is becoming his own person.

R: Thank you very much for sharing your thoughts with me. I really appreciate your willingness to participate in this research.

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**INTERVIEW TRANSCRIPTS**  
**PARTICIPANT D**

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**BIOGRAPHICAL DATA**

<b>Pseudonym:</b>	D
<b>Sex:</b>	Female
<b>Age:</b>	31 years
<b>Occupation:</b>	Fire-fighter
<b>Highest level of education:</b>	Grade 12
<b>Home language:</b>	Xhosa
<b>Marital status:</b>	Married
<b>Relation to autistic child:</b>	Mother
<b>Autistic child:</b>	A, Male, 6 years old. Has one younger sister, aged 12 months.
<b>Date/s of interviews:</b>	15 April 2003

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*(Prior to starting the interviews, the researcher went through the information letter that was distributed to participants, with consent forms, prior to the commencement of the research. The researcher further explained the aim of the study, the manner in which confidentiality and anonymity would be ensured, and asked research participants to complete and sign the departmental consent forms to audiotape and transcribe the series of three interviews.)*

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**INTERVIEW 1: EXPERIENCES UP TO AND INCLUDING THE DIAGNOSTIC PROCESS**

- R: Now D, What I'd like to start with firstly is what it was like for you from the time of your child's birth – up to when he was first diagnosed. Okay? So what I'd first like to ask you is if you can just quickly tell me about your family – like how many children, husbands, names, what they do, how old they are and what they are like – what type of people they are. Okay?
- D: I didn't have like close siblings. I grew up with my grandmother. It was my grandmother and the other sisters, like relatives you know. I never grew up in a close family. My grandmother was a harsh, a very harsh person, and then I didn't have my close sisters like my mother and father and stuff. It was my cousins, but we had very good relationships. Everything was going right up until they left. They went to stay with their parents and then I was alone with my grandmother and my grandmother was selling stuff. She was busy at home. There was nobody like family because it was like a shebeen. She was selling liquor you know. That kind of life is busy. We never had a home on our own because there were always people drinking and all that, up until I moved out. Then I gave birth to A, you see. There were two.
- R: And his father, where did you meet him?
- D: Oh I met him – he just came to my house, I think he was having a friend staying close to my home and then I met him that time he came to my house. He introduced himself and then the relationship continued. It was 1992.
- R: And then you fell pregnant and you had twins?

D: Yes, I fell pregnant in 1996 and had twins. The other one couldn't make it. I had a very – at that stage I was pregnant I was happy. L was looking after me – A's father, up until I had problems with my...my stomach was so big and then I had to go up and down in hospital like they were giving me injections saying that the baby wanted to come out, but the time was not right - it was too early. I went three times. They admitted me three times in hospital – they were giving me injections. They were saying that they are retaining the pain, because it was too early – the lungs are not yet fully developed for the baby to come. So it was difficult for me. I was having – having a difficult time to breathe, and then eventually I gave birth in Provincial Hospital here in P.E. A was born. They were both born normal birth, but even that time I had problems. There was no doctor, there was a nurse and a student nurse and the other one I think was a staff nurse. So afterwards I was experiencing problems when I was giving birth. They called a doctor. They had to use forceps, but I think A came out normally. It was the second one that they used forceps – they pulled him. I was also getting tired so they had to pull him out with forceps. A was all right. The other one, they took him to...he was in hospital – they were both in hospital that time. They give him oxygen, the other one. The other one was sucked. The other twin, they gave him oxygen and then after some few times they said no he is not all right, they were both boys. They send him to special care.

R: Intensive care?

D: Intensive care. He was taken to Intensive Care, and then after a day he passed away. I was feeling concerned about A at that time. I started to panic. I was loving him, sitting with A, but I think the hospital also was so negligent. A was all right, but then there was this baby also. There was another baby – they keep on switching surnames. There was Mofu, and then my surname was Mafu. They were switching the tags. Giving A the – he was not sick, but he was getting weak and the other problem I couldn't breastfeed. There was nothing coming out from my breasts, and the nurses could not understand that there was nothing coming out. I was telling them that there was nothing coming out from my breasts, but they were forcing me to breastfeed. I could see that A is not getting enough. He was losing weight. I told the nurses, but they said 'No, it's you, you are panicking because of the other one'. But eventually I told my husband, A's father, I want to go home, because I can see that I am going to lose this one, because his sugar is getting low, because he's not getting enough to eat or drink. And then we told the staff nurse at hospital that no we are going home. They said no, A is not all right, but we can go home if we feel we want to. As we are going home I noticed, no man A is changing. He is getting weak. And then we drove back to a specialist, Dr D. He's a paediatrician, he is working in New Brighton. We went to him and then he said A was weak at that time, he was weighing 2.5 and his weight dropped to 2.3 or something. He was getting weak. He was not responding - Dr D, I went to Dr. D's rooms. I put him on the table. Dr D looked at him like that and he asked what was wrong with the child. I said, 'I don't know, we are coming from hospital', and then he pricked him underneath his foot. He was not responding. He said no, we need to go to hospital. Do we have money? He asked us what hospital would you like to go to. I said normally we can go to Mercantile – but I didn't have medical aid at that time. I was not working, but we eventually go to- my husband had R1000.00. They said we will need about R1500.00 for admission before they can take that child. But the child was admitted. I was treated all right. They find out his sugar was dropping. He stayed in hospital, Mercantile Hospital, for two days under observation. And then he came back. I thought that everything seemed fine. He was growing, everything looked normal, but after a month he was having like asthma, like chest problems. I took him to hospital. He was admitted, I think he was admitted when he was about a month or so. Towards two months he was admitted in hospital, during that 'cause when he was turning two months, he was admitted

for chest problems. He was treated and then he was up and down now in hospital for chest problems, getting anti-biotics, everything and then they gave us Nebuliser. Dr D now he was being treated by Dr D, he was a specialist, also a paediatrician, working in Durban Road. He was treated by him. But he was all right, he grew fine. He was responding normally like a normal child. I didn't notice anything wrong about him, up until he was..... Because he was making sounds, he was responding as a normal child. Even if he see something on TV, going to six months, seven months, he could dance and do that, he could respond to music. He could say some words like 'iminwe'. There was this song "Iminwe", and he would hold his finger up. He was repeating that song, he was dancing. And then all of a sudden when he was turning, he was about two years, one year something, I notice, no man A is not the same like the other kids. There was another child next door. They were growing up together, but he was a little bit behind than A, say about four months, three months, but every time I am comparing A to that child, there is something wrong with my child, and he is busy. He doesn't respond well. I will call him. You could see that he can hear you, but he will take his time to respond to what you are saying. Sometimes he will respond, sometimes he won't even take notice, as if he can't hear. I took him to eye to...to ear specialist, they said no there's nothing with the child, his ears are fine, he can hear.

R: You thought he was deaf?

D: I thought he was deaf because he was not like responding everytime I am talking to him, but you can hear, you can see that he can hear, but you don't know what is wrong. And I took him to Dr D. I explained to him, no man I've noticed something wrong with A, and he is not eating most of the food. He's not eating, he is just...that time he was eating mealie meal and he was like eating....there was this...in the chair he will find something like cotton in the chair. He will every time sit in that chair like playing with this cotton, such a long time playing in this cotton, and he was having this sound....uuuuuuuu. Every time he was having this funny sound, and the speech was not developing. My other one was that his speech was not developing normally. And then I talked to Dr. D. Dr D also noticed this thing. He suggested that I must take him to Red Cross in Cape Town because he was suspecting something, but he don't want to say it. I took him to Red Cross in Cape Town and then he referred me to the doctors there, but I am just forgetting their names. And then I came back, the doctors sent a letter. They said that they are suspecting autism, but it's too early to tell, he's very young to say, to tell what is wrong, but I must wait. But he was getting very hyper-active. He was very, very hyper-active and strong for his age. And he was playing alone. He didn't have time for his peers. He will just go there, maybe he will just play outside. They will play there...I took him to crèche even, just to check what might be wrong. Even at crèche they could not take care of him, they said no, uh uh, they cannot take care of A. He was coming home dirty, because he is playing. He's very much hyper-active, he's playing alone. They must look for him when sometimes they can't find him. They will find him maybe playing with the dogs and dog's bowl, and dog's kennel. He will play there alone. And then we came back from Cape Town. Dr D also sent me to other psychologists and to speech therapy. They were all saying now, no, A is autistic. So by the time he was... and the other problem, we couldn't take him out of the nappy. We could see that he couldn't tell what is wrong with him, like he didn't know how to go to, to say he wants to go to toilet, he will pee in his nappy and then the bottle also.

R: Didn't want to give it up?

D: No, he did not want to give it up, he didn't want to eat, it was the bottle, and the mealie meal. He was not eating anything else. I was concerned, that was my worry also. And

then we heard about Quest. At the age of two now, he was turning three years. I referred him to Quest. Dr D referred me. They said that they dealt with kids with autism. I took him to Quest, but they said he was a little bit young for them there to attend school. They were going to assess him next year; I must send him when say he is four. But they could see that he was, he belongs there. I took him there and then he was there up until now. He was at Quest, they were in Uitenhage at that time.

R: Did you, when the doctor first said he suspected autism...did you know what autism was?

D: Uh, uh, I didn't know. I didn't know what was autism, up until this day because it's confusing. There's a lot of things, like when I was reading. The doctors, they are also contradicting with autism. Some will say this, some will say it's not like a proven thing, like when you have got a fever you will say, 'No, my headache is like this', the kids they don't look the same, but the symptoms, when they are telling you about the symptoms, some symptoms you see, like A is not that, like that, autistic if I can say. He is hyper-active, very much hyper-active. If he can like.... (*gestures that the child should settle down*).

R: Calm down?

D: Calm down and listen, he's destructive. He was destructive living there.

R: When you say destructive, did he break things?

D: Ya, he was, yes, he was breaking things and he was like taking food out of the cupboards, throwing it outside. He was doing his own thing, as if he is a child who does not get attention. He's looking for his attention like to, grab everything he is doing. One other thing, you can see that his mind...he knows what he is doing, as if he is trying to get your attention or what, I don't know. Something else, if, like he don't know you, he will behave. When I come back, let's say I am at work. I left him with someone new, he is not like used to him too, but they will say 'No, there's nothing wrong with this child. He was sitting here. I said A do that, he will do that. A, there's nothing wrong with the child, it's only you'. He's picking up from people, he's got his, like ... 'My mother, I know maybe she's soft, and then I will pick up on her'. He knows what he is doing. There is another mind that says 'No, this child is all right'. He is very much aware of what he is doing, but you don't understand what is this behind this autism.

R: It sounds as if it was a very difficult time for you.

D: It was a very difficult time understanding. I couldn't understand it. What is autism? Because, as you can see, the child – he looks normal...

R: Ya...

D: He looks normal up until he can do some things like take the speech. You can notice that there is something wrong with the speech. He's got the words, né, but he can't sit down. If he can like, say, sit down, learn to listen. He can stop that hyper-activeness and then he can learn. Even if I am taking him to a speech therapist. He is all over the place, he's all over the place. You can't .....his mind is everywhere, his mind, he can't sit down, he can't concentrate. They lack concentration. You can't sit down and then you can teach him this and this and that. But there is, he's got some speech, but don't know what is keeping it inside....there is something inside him.

- R: It sounds also as if it's difficult for you to understand him at times.
- D: At times, he is very difficult to understand him at times. Because you can't put, you can't like have a normal conversation like we are doing now, like sitting and then we talk. But he was having.....his eye contact was not that...because they say that autistic children they....(pause).
- R: Avoid eye contact.
- D: Eh, but you can see that he is sometimes he don't want to look at you, he will look all over the place, but he is good at times.
- R: He is learning?
- D: Mmm, he is learning now.
- R: How did you feel about him having this autism. What did you feel or think or what did you want to do when his doctor said, 'Okay, I think your child is autistic'? What was that like for you?
- D: It was very difficult. At first I didn't understand what autism is.
- R: You felt confused.
- D: Yes, I felt confused. Even though they were explaining it. I thought they were saying he is slow, he is a slow child. Maybe he is going to develop as the time goes on, he is going to develop. I took it like that. But as the time goes on, I saw, no there is nothing, no improvement. There is some improvement, but he is slower than I thought. Sometimes, I must just live with it. That A is not going....he is not normal. I did not want to say it at first, he's not normal.
- R: It's almost as if you didn't want to believe it.
- D: I did not want to believe it, no, I really didn't want to believe it, I thought maybe there was...sometimes in our culture we think no there's something wrong with the ancestors. You know, our culture, there's something wrong, maybe.
- R: Like amafufunyana?
- D: No, not amafufunyana.
- R: He was a bit small for that.
- D: He was a little bit small, you tend to think that maybe there's something to do with evil spirits maybe....my grandparents.....
- R: Someone put a bad spell on you?
- D: Yes, or my, my.....(long pause).
- R: Grandmother?

- D: Family or grandmother, they didn't do like, there's something like you have to slaughter goats or those things. Maybe there were, there was things that they didn't do.
- R: To honour their ancestors?
- D: Yes, now it's coming back to me, because they always say, no, it will come back to you, not to your child or to your gran, whatever. What your parents didn't do, it will come back to your grandchild. I was thinking like that. I went everywhere, to sangomas, to everywhere, I was looking for help – to traditional healers and to the doctors.
- R: That's a very interesting part that I have not heard from any of the other parents. Can you tell me, just to help me understand..... What did some of the sangomas tell you? What was their understanding of what is wrong with your little boy?
- D: With A. Some of them, they told me there is another auntie, né. It's, I'm just forgetting names now. She told me that she saw nothing wrong with A, and she promised me, let's say at the age of five he will start to speak. But she don't see him like a normal child. She can't tell why, she can't tell why. But she also said to me that I must go to this uncle and then this uncle is going to give me something to help A, because it has something to do with ancestors and all that stuff –they must do....
- R: Ceremonies?
- D: Ceremonies and all that. I went to this man. Sometimes they are charging too much money. You go to the person and then he asks maybe this much, and then you don't go back to him because you don't have that money. Not that you don't want to go because you don't believe, né. More or less they were talking the same thing, that I must do this and this and that for A to be all right. They don't see him as a normal child. They see him as a normal child, but there is this thing that they can also can't tell. Lets say they will always refer to ceremonies and all that.
- R: So they also, some of them didn't understand what was going on?
- D: Ja.
- R: They couldn't really say specifically what was wrong?
- D: The last one I went to, she said A is going to be all right. It depends on me. It depends on my family and me.
- R: That's a big responsibility.
- D: Um, and the family, it's family stuff and ancestors.....you must do....work, you must slaughter goats and like I cannot explain like I was speaking in my language. I cannot explain it to you. And so you can understand it, because there are lots of things involved.
- R: Many traditional things?
- D: Eh, traditional ceremonies.
- R: Did you have other children after A?

- D: Yes, I had a small baby. I've got a small baby, one year old.
- R: Now?
- D: Now.
- R: A boy or girl?
- D: A girl.
- R: A girl. How has it been for you with the new baby? How is A getting along with her and with your husband?
- D: He is jealous. A is jealous. He knows that there's blood relative. He's related to this one né, but he will smack her or push her. He's always doing things as if he's lacking attention. As if he's lacking attention, because you can see that he can...he wants your attention...if he's looking at you, and then he wants you to look at him, that he is doing this and then he will smack this one, or he will push the other small baby. He will push her, he is jealous.
- R: How.....sorry, did you want to say something else?
- D: Ja, like with my experience of A, I am scared, like every time looking at the baby, I don't want to miss out, like A, let's say like I am comparing her with A. Looking every time whether there are no signs of autism or....
- R: So you are very careful and alert that there may be something wrong with your second child?
- D: Eh, I'm very like feeling that guilt, because with autism you've got that guilt all the time as a parent. Is it something you have done, or what is it? What makes this child like this? A looks as if he is someone who is lacking something, you see. I try to give him love. Everything I give him, it's as if he's lacking something. He's crying out for something. There's this special thing that he wants, and you don't understand. And he's very clever. He reads. He can write his name, he works on the computer, he counts, but you don't understand what is this thing that he needs.
- R: So it's very difficult to make contact with him?
- D: Mm, very difficult.
- R: And your husband, how does your husband get along with A?
- D: They are getting along well. He is worried sometimes. He makes him panic, like he can't take it. A is doing something, like something wrong; he'll want to smack him. You can see that he is worried inside né, he is worried, but he can't like understand. I don't think he really understands A. Because Dr. D said you mustn't give A anything. We tried everything. We gave A Ritalin. I don't think it's working. It's not working, because it will keep him, let's say he will sit down and do nothing for let's say three hours or four hours. After that, the Ritalin is out of his system. He will be more hyper-active. He will jump high, jumping. You can see that there are other things, maybe there's something doing in his mind also, it's making him so hyper-active. And then we also tried Respidol.

I also don't think it's working. They think that they are making him more hyper-active, he's very much hyper-active.

R: So the medicine, he's actually responding strangely to the medicine?

D: Eh, he's responding strangely. He will sit quietly and then like, lets say he's behaving lets say for three hours or four, after that he's worse than before, and everywhere. But with Ritalin, he doesn't eat. When he gets Ritalin he don't want to eat. He will sit, but he won't eat. He will sit. You can see his brow is heavy, he wants to sleep. And you also don't feel right when he's like that. You don't want him to be very busy, but you don't want also him to be like a zombie. Don't want to feel guilty to give him drugs. As if you are drugging him. But his father wants him to be, he said if he can sit still and do nothing, not be so destructive all over the place, he will be all right. But I said no, I think we must just accept him the way he is. But, ja, it's so tiring with him. This business it's very much tiring. You can sit the whole day with him because he doesn't sleep during the day, he's up and down, but at school here he behaves. But they were also complaining he is hyper-active. He is hyper-active, worse than before. But sometimes I think he is growing. Maybe there will be that time, a cure.....something to.....(pause).

R: Calm him down?

D: Calm him down.

R: Does he stay here in the hostel at school?

D: Yes, during the week. We take him on Fridays. We cannot keep him, he won't learn at home, because I don't have that control over him.

R: You, when you say that you don't have control over him..... It sounds as if it's difficult for you to manage him, to discipline him.

D: Yes, to discipline him, it's difficult for me.

R: What do you do normally, when you try to stop him from doing something?

D: I don't know. It doesn't help to talk to him. Sometimes I just have to smack him.

R: So he gets a smack on the bum?

D: Yes, mm.

R: Does he respond to that? Does he listen then?

D: Ja, sometimes, sometimes he wouldn't listen. Sometimes he listens, when I have to smack him so hard, he will stop. Like if you just smack him, 'No, A', he won't listen to what you are saying. You have to be very harsh. You have to use that voice with him. You can't speak like, 'No, A' (softly). You have to be 'No, A' (loudly) and you must make sure that every time you make a noise, it's going on your mind as well as the parent.

## INTERVIEW 2: POSTDIAGNOSTIC ADJUSTMENT AND COPING

- R: It sounds hard for you to do that. In terms of the first interview you have basically, you've just spoken through everything that I wanted to ask you, thank you for that. Now, secondly, if we can go on to the second interview, I want to ask you more about after you got the diagnosis, what it was like afterwards. You have told me some of it, but I've got some specific questions, okay? I want to ask you about the running of the household and the general routine of the day. I specifically want to know the daily things that you have, such as meals, bath-time, using the toilet and going to bed and doing things with your son, and fun things that you do as a family. What was difficult, what worked? How was that for you? How is it for you and the family, for you as a parent?
- D: You mean after the diagnosis?
- R: Ja.
- D: Everything changed because we have to now..... The doctors like, they suggested this structured environment. Everything changed now, we have to do things according to A's ways. Like we had to change our times like trying to, like....
- R: Get a routine?
- D: Get the routine. But it was not easy to follow the routine, it's not easy, it's very difficult. It's not easy, even today. I am used to him. But it's not easy to follow that routine, to have everything, because sometimes you will take, let's say, you will wake up, let's say...he wakes up very early, he wakes up, let's say six o'clock. Six o'clock, quarter to six, he wakes up early. Then you have to wake, and you go to the kitchen. If he wants to, let's say, porridge and pour for himself. He will take a bowl and pour for himself porridge, or he will want you to cook, he will switch on the stove, he calls it 'cook, cook, cook'. You will see that he is hungry, and then we make porridge. He will just eat, not finish it. He will go to something else. Your whole, like day.....it's so....
- R: Mixed up?
- D: Mixed up, it's not like that routine. He is doing this, he is doing that and then you go to bath him. Sometimes when I want to keep him busy I just run the bath and let him like take everything in the bathroom and let him play there as long as he wants to.
- R: He likes the water?
- D: He likes the water, play, play with it. He splashes and gets everything wet, and then you must know you have to suffer the consequences. It's not easy man to follow the routine with him. You just make your routine, but it's not...your life is not the same any more when you have got an autistic child.
- R: What makes it difficult? How is your life different?
- D: You don't go visit friends. And you are scared to go to public places with him because he will just... Like he will be more excited than say, let's say you go to Greenacres. He will be wild. Go all over the place and people start looking at you. Some of them, they think, no this is a spoilt child because he will take this, he will take this, he will take this, and they won't understand. If he wants something he will make, he will cause that .....

R: That tantrum.

D: That tantrum, everybody must look at you. He will throw himself on the floor and then he knows that you can't stand that, and then you ended up buying him that thing. What I have noticed about him, he is aware of his doing. He is very much aware of his doing, that's why I said earlier on as if he is lacking something. He is aware if I'm doing this, I will get away with that. If I'm doing this, I will get this, if I've done this I will...it's very difficult. Your life change, you don't go even to churches. You hardly go to churches, you can't go with him, and you keep on changing people's nanny because they don't understand him. You keep on changing people, you don't have one people at home looking after him –they won't understand him.

R: So it's difficult for you to get someone at home to look after him?

D: Um, to look after him. They don't understand him.

R: You also said you don't go visit friends. What makes it difficult to go visit friends or to have friends?

D: At a friend's house, it's better in your own place. He's destructive, he will break some other people's things, you see? It's difficult in that way. And you won't have a conversation when he's around. You won't like sit or relax. You won't relax with your friends. Like, he will be all over the place. You must always say, 'No, no, look A there, look A there'. You decide, no, you must rather keep him at home.

R: It's very difficult.

D: Um, it's very difficult. Rather keep him at home. You can't let him outside also to play with other kids, because he will go all over. He will go everywhere, although he knows where he stays, but he don't know his way back. I don't know whether he knows his way back, or he doesn't realise now that I must go back home, or it's late now. One time we were discussing it, last week. His father and me said, 'I wonder if A can come home?' Can we let him, let's say he was outside. We didn't know where he was you see. But he was playing in the park. We decide no man, one day, one time we will hide, né, and let him play, and see at what time he is going to come back. Or is he going to come back, or where is he going? Just follow him, but we will hide. We just let him play alone. We'll hide and follow him every steps when he's outside, what is it exactly what he's doing. When is he, has he noticed, no, now it's dark. I must go back home, or what?

R: And what did he do?

D: No, we didn't have that time now to do it. I just, I panicked. I panic, I just went to fetch him. He was playing with other kids, and then I thought normally he is not used to go to this other side. Maybe he will get lost or what, I panic, I just went there to take him home.

R: So it also sounds as if you constantly have to watch him because he doesn't realise something's dangerous, or anything like that.

D: Um.

- R: Okay. Is there anything that you can do as a family that A and his baby sister and you and your husband that you can do together?
- D: Like, when we are reading a book, he will participate. Like when you say 'A, kiss the baby', then he will do that. When we are sitting watching TV, he will just want to watch his own programmes. Like he's got his special programmes, like Popeye and all that. He will watch that and he will laugh alone there. He will laugh. Let's say if I am watching my own programme, he will change the TV, he will watch his own.
- R: So it's very difficult to do something as a family?
- D: Yes, as a family, it's very difficult.
- R: It sounds as if this one little child takes over the entire house.
- D: Ja, you can put it like that. Because you must do everything in his way. And if you will say no, I'll just leave him alone, your house...because he finds his way to destruct everything, it's very difficult.
- R: You have often said to me that he is very busy. So it sounds as if he makes lots of demands on your time and energy. How do you manage to cope with that? In other words, how do you also take care of yourself, how can you just manage that?
- D: Like I say, during the week I am taking him to school. That's my time I will sit at home, but weekends if he is at home and holidays you must know that you don't have time for yourself. Or, I must just sleep, and lock everything out, and lock him in this room. I must know this is the room, I will just sleep. He will come and jump on the bed, make sure that I am waking up. He will wake me up, but I just, you know sometimes I am getting used to it, to the fact that he will run all over my body. I will just sleep. Even if I am working night shift I will know I want to sleep during the day. I'll just sleep, even if he is doing that. All of a sudden I will just see he is also sleeping next to me. I am just shutting everything out. I just tell myself, no I must just.....no, I just ignore him, as long as he is in this room with me.
- R: So you know he can't go out and hurt himself or hurt someone else?
- D: In this room he will destruct what is in this room, but there's no danger into it. I will just listen....but another thing – he behaves when he is with his father. He is, like giving him hard times, but to a certain extent....not as bad...he is very bad with me. He's very bad, he knows which way you think. And that's why I said they see their targets, their soft targets. They watch out for their targets.
- R: Clever.
- D: But you don't want, as a mother, that's why I said earlier on, you always have that guilt. Even if I am smacking him I will end up crying because I wonder what is wrong with this child. Is it me? Am I too soft? Sometimes I just want to hit him because you are just saying to yourself, is it you, you are too soft, or what is it? Or you just hit him and then you realise, this is wrong at the same time. You see you have got that guilt, that guilt in you.
- R: It sounds as if you still have it in you.

- D: There's that guilt, you don't know what to do.
- R: So, in terms of your own energy and your own time, it sounds as if you try to get your rest during the week, and then you sometimes just screen out whatever is around.
- D: In my mind also, sometimes I sit and think that I also need therapy, because I can't concentrate also.
- R: You feel that you also need it?
- D: Sometimes you sit home and you need someone. You need to speak to someone, because it's so demanding.
- R: You cannot do it without help.
- D: Ah, ah, you cannot do it without help. Although I have done it up till now, but sometimes it's...there are other things like...I'm doing fire technology at work. I can't concentrate on my work. When I want to write something, you know what to write, né, but it's just, your mind is everywhere. You just, ever since you've got A in the house everything is not the same. You also don't, like feel the same anymore, because of A.
- R: It does change you, having a child with such difficulties. In terms of just after you got the diagnosis, it sounds as if he was and still is very up and down. It sounds to me as if, in terms of his education and day care, you have had some help. Has he only been in Quest or has he been in other places?
- D: No, only in Quest. He's been here since he was diagnosed.
- R: You said he was in crèche for a little time.
- D: Yes, only for a little time. But then they said that they could not keep him there, and he was still too young to go to Quest.
- R: So in that time in between, did he stay with you at home?
- D: Yes.
- R: You also mentioned to me that the nannies changed all the time. Can you just tell me a bit more about that. Did you find that they were ill-treating A?
- D: As a parent you become very much aware and defensive like when you've got a child like that. You know, like as if you know he's sick. You don't want to tell yourself he's sick. And sometimes you don't want other persons to like tell you that your child is not all right. He's sick, he's not normal, like you don't want anyone to like ill-treat your child or...you are very much aware. And then A he can't speak, so I try to watch every move. Like his face, got a pinching something, I will ask 'What happened here?' They will say 'No, maybe something else'. I will start to notice, is this one hitting my child or what. You tend to be very defensive and you can't keep someone when you are like that because you know that your child can't speak and he can't express himself and tell you what is this. And you can see the child ..the person looking after him is not right. He will tend to be scared, to be withdrawn from that person. Autism child, they are very like...you can notice

something is not right with them. They are very sharp and you know as a parent, you become also very aware of things like that. You take notice of that.

R: It sounds as if....

D: You also, I don't know how to explain...what were you going to say?

R: It sounds as if you have learnt to understand him in other ways.

D: In other ways.

R: Other than talking.

D: Yes, in ways other than talking.

R: Because you can see when he is scared or when he's happy with someone. I have asked you also about how do you control him, his behaviour and how do you discipline him. You have told me sometimes he listens, sometimes he doesn't. So it sounds as if it's also very hard to find a way to control him. What does your husband do? You say that A...he listens to him more easily. What does he do to control A?

D: He tells him.... it is the way he talks to him. He's always like, if he's had enough, he will tell him, 'No, A'. A knows that voice you see, but even....though he knows the voice to him, né. Even when I am saying that, he doesn't want to listen. He won't listen. He disciplines him. He will tell him 'A, I don't want you to go out', they went out. He is sitting in the car, he left him in the car. 'A, I don't want you to go out.' He will sit, although you are watching, and then he wants to sneak out, and then he will sit. I don't know, as I told you that they see their soft targets, né.

R: He knows he can get away with Mommy. Ja, he's clever, hey? He sounds quite a clever little boy. You have told me that you grew up with your grandmother, not your parents. In terms of other family members, how has A's birth and him being in your family – how has it affected other family members?

D: I don't understand.

R: A has a little sister of one year. How do you think it's affecting her, or your husband, or his family, and your family. How has this birth, having an autistic child....how is it affecting your other family members, that you are aware of?

D: As for my family's side, ja, I can say that it's affecting them né, because when you go, we don't go there a lot – but they don't have like that contact with A. Even if we stay, they don't have that like sharing the family stuff. They affect him in that way, they don't, they can't like relate to A.

R: Do they just ignore him?

D: No, it's A who is ignoring them. He's ignoring them, like he don't realise that they are family or he can't like differentiate between them as normal other people in the outside. He's got that thing, he knows his sister. Although sometimes she will look at him as if she is trying to understand what is wrong with.....the baby will look at him, she won't cry né, but she will be thinking, she's got those questions, what is wrong with this.....she wants to

play with him, but A only plays by hitting the child or by doing something wrong. She will be scared. She's not that scared of him, but although she finds that, 'No, I must protect myself from this one'. You will see her running with A coming, running...(*imitates screaming sound*) she cries all of a sudden without A touching her....and then with his, his father's side of the family, his father's family. Ja, I can say they are getting along well, because he's used to that side, because he grew up on that side. He knows them, he knows the granny, L's mother, he knows the other sister that's staying with them and Av (cousin) because he will pick up their names, he knows, he will pick up Av's clothes, or shirt or T-shirt. He will know, he will say, 'This is Av's', or he will say 'Av'. He says now this belongs to Av. Although, sometimes you can see also it's affecting her also, because he cannot go. She likes to show off 'This is my cousin'. He cannot go out. Like go to play, the other kids will tease her, say 'No, he can't speak' or A will smack another child. And then they will say, 'No, A is not normal'. It's affecting Av also because she wants to go with A like to show off to a friend.

R: Is Av older than A?

D: Yes, she's thirteen.

R: Does she stay with you?

D: No, she's not staying with me, she's staying with her granny. A's grandmother. But we like to visit them a lot, we are always there most of the time. It's affecting everyone because you don't have that normal life. A normal child you could go to shops, because even if they went to shops they must come back carrying A at the back, A is jumping up and down. He wants to go, he wants to go all over the place. Maybe he wants to grab something in the shop. He doesn't, he knows sometimes they must take, but he don't know that you must ask from the shopkeeper to give you something. He will just grab it.

### **INTERVIEW 3: PRIMARY NEEDS, CONCERNS AND SUPPORT SYSTEMS**

R: In the last interview, I want to ask you specifically about what you think the parents of autistic children need and what their concerns are. Also, their support systems. Firstly, what I want to ask you, as you think back to everything that you have been through with A. What do you think you felt most uncertain and most alone about? Also, what did you really feel you needed help with? What made you feel alone and uncertain?

D: You cannot be sure, like, you feel alone because there's no certain diagnosis, like say, this is what is wrong with the child with autism, or some of them say no you must watch the diet, although even the doctors and the dietician, they are contradicting –because they will take, like an autistic child like my child A, to a dietician. Some will say no you must, like, not use sugar. Some will say no you must do away with gluten, or some will say no you must not give them wheat products or so. And it's very confusing for you now as a parent, because they don't say like the same thing. Or, they can be sure this is not right for an autistic child, né. Like sugar, you know, as a parent you feel no, it's making them more hyper-active, no you must not give your child that, too much sugar. Although the doctors, they are also not.....I feel like autism I can say here in South Africa it's not like well-known. It's not like every doctor knows about autism. And they don't make.....you will say too, let's say someone will ask what is wrong with your child. You say 'No, it's just autistic'. They will ask, 'What is that?' No, it's not everybody know what is autism. I think it's like, high time it must be like AIDS story, it must be something that is known by

everybody. It's whereby you can get some help, because some will come with their versions, some will come with their stories and others will come with their stories. And I think also there are a lot of children outside....although it's not, it's not like, it's not something that is known.

R: Do you find yourself, when you look at other children, do you find that you are more sensitive to noticing, or picking up signs of autism in other children?

D: Ja, I can say, because there is a child of one of my family, she's three né, she can't speak. Her speech is not yet fully developed yet, and she, she is withdrawn in some other ways that you compare him with your child. You find maybe he's got autism because I'm thinking that maybe this child has got autism although he is quieter than my son, because my son is very much hyper-active. Yours, he's more like withdrawn. I can say, you can just see he is autistic because I feel autism it's more like they're withdrawn. They're so withdrawn, child, they are like alone, like playing alone. There is something wrong with that child. Although that woman is not yet ready to... it takes time to acknowledge what is wrong as a parent, to acknowledge what is wrong with your child. Although you might have signs, picking up some signs, but no, to accept it and then to go.....

R: To get help.

D: To get help, it takes time. Sometimes you just want to go, 'Uh -um, there is nothing wrong', although you know that something is wrong and there is a problem.

R: So, ja, you also said to me that sometimes, for a time you didn't want to believe that anything was wrong. So that's what you mean with it takes time. Ja. Okay, um, in terms of also taking care of yourself and your own needs, can you tell me a bit about what you think parents of children with autism need also for themselves, to take care of themselves?

D: I think you must get together....parents of autistic children, you must get together and then you share .....what is your son doing now? And what is...you must get those gatherings, and then....

R: Sort of like a support group?

D: Yes, a support group and it's good to have Quest, like school where they can take care of your child. Let's say, during the week, but although it's very much expensive, and it's very expensive to raise an autistic child, because they are breaking everything in the house, they're destructive. You have to buy things over and over, and food. Because as I have mentioned, the diet -sometimes you buy everything, you just do everything. Everything that you think is going to help your child, you just buy, you just spend.

R: Like expensive toys?

D: Like expensive toys, because some of them, they will say no, buy like play station, to keep him busy. Buy a play station because they like that. Those games, something that is going to keep...maybe it's working for your child, it's not going to work for my child. But my child is very difficult, he can't stay in one place.

R: Sit still to play the game?

- D: To play the game, you ended up buying it, thinking that it's going to be helpful, né. TV games, you buy that TV game. He will play with that thing, take it home. A few seconds, thirty minutes, it's too long. And then afterwards you find that thing broken, he breaks that thing. He will want to see what's making that noise inside. He's so inquisitive.
- R: He will take the thing apart?
- D: Yes, he wants to see inside.
- R: You told me that it's quite expensive because you have to replace things that they break. Their education, is that also expensive?
- D: Education is expensive. Because here at hostel, you are paying about R950.00 a month. The hostel fees and the school fees also....and the school fees it's R200.00, so it's expensive.
- R: A month?
- D: A month. We don't get subsidies from the Government. We don't get subsidies. It's very much expensive to raise an autistic child, but although.....(long pause).
- R: Medical costs, do you have a medical aid or your husband?
- D: Yes, I've got medical aid.
- R: Now?
- D: Yes, its expensive also, so you must try...you see Ritalin, it's two hundred and eighty something. Sometimes you run out of that you must buy it out of your pocket. Sometimes the medical aid the funds are finished, you must buy out of your pocket. It's expensive to raise an autistic child.
- R: If you look at say this local Port Elizabeth area, how do you feel about the resources and the support systems that there are for parents? What is your opinion about that?
- D: I don't think.....support group?
- R: Support systems.
- D: There isn't. As I've told people, they don't know about autism.
- R: So you think there's a big need for that?
- D: There's a big need, but we must have like even if parents of autistic child they go out, and make people aware of autism. They don't know autism, there is no support. Even if, like I was looking for a grant. They just look at him and say no, there's nothing wrong with your child. And you're working, you are not supposed to get grants, because they say if you are working you don't get grants. And there's no support. They don't know autism, and most of the doctors also, they don't know autism.
- R: You have mentioned to me though, about some paediatricians that you've been to, and also Red Cross. How have those people been to you? Have they been helpful? What do you

wish they would have done differently? What did they do that was helpful? Tell me about that.

D: I think Doctor D was the one who introduced me to Quest. He was very much helpful.....he introduced me to Quest. He told me like I mustn't give anything to A, nothing. No medicine, nothing. I must just accept him as he is. He will maybe change as the time goes on. He's not bad, there is a hope for him to change, although he is not sure yet. Because there are cases he mentioned, let's say not here in South Africa, where they keep overcoming that autistic.....

R: As they get older.

D: Yes, as they get older. His got that hope for A. But as the time goes on. He's always fully booked, I can't get hold of him. I went to other doctors and then they tell me no they are not aware of that condition. They will say, 'No, give him Ritalin, give him this, give him that'. I've tried one doctor in Dora Ngiza Hospital, one of the sisters there. She told me that if you don't give this child something, you want the child to end up wandering in the street? You must control, because the child is very much hyper-active. You must control, you must give him something to control his brain. You mustn't just let him do.....(pause).

R: As he wants?

D: Yes, as he wants. You must control. You must have something to control him.

R: It sounds as if she was quite punitive, almost, towards you. Telling you what you are doing is wrong.

D: Yes. And then I've noticed one day Ritalin is more expensive, they don't do much. I tried also the diet. I've got that little. I don't have that. I'm doing things for shorter time and then said no, this is not working. I don't have that patience.

R: It's hard for you to stick to one thing.

D: One thing, especially diet. It's very difficult the diet.

R: The food that they must eat is also very expensive.

D: Expensive, its difficult because what, everything has got wheat in it, and then the diet at home, and my family is so, it's like not so happy, you know. Each time I'm worrying about his weight. When I give him those rice, rice crisps, he just, is going to be more difficult. It is not nutritional. It's not enough for him. Rice, rice cakes, rice cakes, rye bread and all that. And no butter, no chips. You feel, no man, I am depriving this child. You don't know whether you are making him more sick or what.

R: It sounds as if it takes incredible discipline just to stick to that.

D: It needs a very disciplined parent.

R: In terms of A, we're getting to the end now. In terms of A's future, how do you see his future? What are the things that you worry about? And then also, what gives you hope for A? Both sides, the good and the bad.

- D: Sometimes, I'm looking at him and I wonder where is he going to end up. As an adult, what sort of adult is he going to be. Will he be able to work, or will he be in the streets, picking up things. Sometimes I've got that hope. He needs just education, but is it going to be normal education, or is he going to stay here in Quest? At the end of the day, what is Quest going to do for him? Although they've got that structured environment for him, but you wonder up until when. Is he going to be able to fend for himself? I wish he can get like something, or play sport or something. Something that he's going to build.....going to mould him to be someone, you see.
- R: Independent.
- D: Yes, independent. I wish he can be independent. And my husband said once to me 'I'm worried, I wish I can have another child. Just a boy to look after A'. Because sometimes I'm looking at him I'm worried.....sometimes I was thinking of moving to Joburg because one of my family in Joburg he said there is a lot of improvement, the people there, they are quite aware of autism, and the schools, there's a lot of facilities and all that. But it's no good, where are you going to get a job, or money to take a child to those schools. You are going to be alone there, and it worries me to keep him here at Quest, as if you are neglecting your child. The people, they ask you 'Where is A?' And we are here in P.E. You see how that sounds? And my child is not staying with me. But at the end of the day you are worried about him and you think he is safer here. He's getting like discipline and.....(long pause).
- R: Special attention.
- D: Special attention and becoming the A he was and.....although they are not fully like developed, they are not like the other kid's towns and pre-schools, but I think there is hope. They are trying.
- R: What gives you hope for A? What do you hold on to for him?
- D: I can see he is a bright child. I am hoping that they can help him so that he will improve and overcome this or what, but I don't give up hope. I'm always hoping for the best.
- R: Thank you very much, that is all the structured questions that I have. This is the last open question. Is there anything that you would still like to say that you think is important to know about what parents go through, that I perhaps have not asked?
- D: It is so difficult, even at home, sometimes it's so hard, because you don't have the normal life, you and your husband, when he is around. There is always destruction.
- R: So it sounds as if it also affects your marriage.
- D: Yes, it does in a way, because you can sometimes see that the father, sometimes he is blaming you. You are not strict, you are too soft, you are not disciplining the child enough, or I don't know.
- R: It sounds as if he is not as supportive as you would like him to be.
- D: He is supportive, but there is that complication regarding the child, because although he understands this problem, I don't think we are both ready, or we telling ourselves no, even if we are trying everything, this is a problem we are having, A is our problem. We have to

deal with it. A is not going to change you see. We don't get that time for ourselves, we must just accept him the way he is.

R: So, the acceptance is still difficult?

D: It's still difficult. Sometimes he is blaming me, the father. Although I am saying, I've got hope, there's that hope that A will be all right. Although he won't be normal my child, but the father just wants to give him some drugs, like.... I don't want those things for him. It's where we don't agree.

R: So, it's also disagreement about specific aspects of his treatment?

D: Yes.

R: Thank you, I really appreciate it.

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**INTERVIEW TRANSCRIPTS**  
**PARTICIPANT F**

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**BIOGRAPHICAL DATA**

<b>Pseudonym:</b>	F
<b>Sex:</b>	Female
<b>Age:</b>	39 years
<b>Occupation:</b>	Occupational Therapist
<b>Highest level of education:</b>	Tertiary
<b>Home language:</b>	Afrikaans
<b>Marital status:</b>	Married
<b>Relation to autistic child:</b>	Mother
<b>Autistic child:</b>	J, Male, 9 years old. Has one younger brother, aged 7 years.
<b>Date/s of interviews:</b>	23 April 2003

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*(Prior to starting the interviews, the researcher went through the information letter that was distributed to participants, with consent forms, prior to the commencement of the research. The researcher further explained the aim of the study, the manner in which confidentiality and anonymity would be ensured, and asked research participants to complete and sign the departmental consent forms to audiotape and transcribe the series of three interviews.)*

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**INTERVIEW 1: EXPERIENCES UP TO AND INCLUDING THE DIAGNOSTIC PROCESS**

- R: Eerstens wil ek met jou gesels oor julle ervarings vanaf J se geboorte, tot en met die tyd toe julle uiteindelik geweet het wat hom makeer. Voordat ek daarby kom, wil ek eers net iets weet oor jou gesin in die algemeen. Jy, jou man en die kinders en die karaktereienskappe van die verskillende gesinslede, asook die verhoudings tussen die familielede.
- F: Okay. Ek dink die heel belangrikste van ons gesin is dat ons 'n baie rustige gesin is. J is die oudste. Hy is 9. Dan het ons vir I. Hy is 7; hy word nou in Junie 8. C (husband) het sy hele skoolloopbaan as traumaties ervaar, want hy is disleksies. Maar dit het 'n ongelooflike impak gehad op die manier hoe hy sy kinders hanteer. Hy is 'n absolute rots van 'n mens. Geduld kom vir hom natuurlik, sorg, en geweldig baie begrip. As ek moedeloos raak; hy raak nooit moedeloos nie. Hy raak eenvoudig nooit moedeloos nie. Hy is fantasties ondersteunend. In hoërskool het hy absoluut floreer. Hy het sy meestersgraad cum laude geslaag. Hy het akademies uitgeblink, maar daardie swaarkry aan die begin was 'n goeie ding vir hom. Soos ek sê, hy is die rustige een. Die een wat die meeste agter die kinders aanhardloop en wat die sagste is. My kinders draai my ook heeltemal om hulle vingers. Ek is vreeslik ingestel op my kinders. Ek het as student reeds met kinders gewerk. Ek het ook met autistiese kinders gewerk, maar ek het nooit geglo dat ek ook eendag 'n autistiese kind sou hê nie. Dit is heeltemal 'n ander situasie. Ek weet nie regtig wat J se karakter is nie, dit is baie moeilik om te sê. Ek weet nie hoe sou hy gewees het nie. I word deur sy onderwysers beskryf as 'n kind wat ongelooflik simpatie het met kinders wat swaarkry, wat vir my verstaanbaar is van dat ons maar so in die huis moet leef. Ek weet dat by die meeste van my vriende met autistiese kinders draai die gesin om die autistiese kind. In ons gesin draai die gesin om die normale kind. Ons probeer alles doen vir hom, en J word daarby ingeskakel. So, ons is nie 'n gesin wat uit mekaar uit val of swaarkry omdat ons 'n autistiese kind het nie. Ons voel geweldig geseënd en gelukkig, want ons ervaar ook die vreugde van hoe dit is

om 'n gewone kind te hê. Dit is vir ons traumaties wanneer ons byvoorbeeld verjaarsdae het en ons kan ons oë toemaak en die hele winkel koop vir ons jongste kind, en dan kry ons niks wat ons weet ons oudste kind mee gaan speel nie. My man onthou nog, die swaarste wat hy gehad het, is dat die enigste ding wat hy vir J kon kry, wat hy weet wat J mee gaan speel, kon hy by die afdeling kry waar die goed vir honde en katte verkoop word. Hy kon daar ietsie kry wat daai kind mee gaan speel. Haai, weet jy, dit was traumaties vir hom. Ons het nou al vreeslik ver die pad gestap. As jy hierdie onderhoud met my gevoer het toe my kind 5 jaar oud was, het ek heeltemal anders met jou gesels. Maar, omdat my kind nou 9 is, het ek al ongelooflik ver gekom. En nou het ons al op 'n punt gekom, ons probeer nie meer partytjies reël vir J nie. Dit is net vir almal traumaties. Ons geniet ons jongste kind se partytjies. Met die oudste kind nooi ons net die mense met wie hy gemaklik is, en ons probeer... ons slaan nie meer onself daarmee nie. Ons het geen skuldgevoelens oor niks nie. Goddank weet ons niks van dit maak 'n impak op hom nie. Ek weet God het hom vir my gegee. Ek weet nie waarom op aarde nie. Ek weet dat hy 'n doel het met sy lewe, en ek is net die mens by wie hy hom gelos het om te probeer om daardie doel te bereik. So, ons voel nie meer oor sulke dinge ontsteld nie. Ons probeer ons bes vir J gee, as gesin, maar ons gaan ook byvoorbeeld sonder hom weg. Ons sal sekere vakansies met hom gaan hou; ander vakansies hou ons sonder hom. Hy hou so 4 dae met 'n vakansie, en dan begin hy uit mekaar uit val omdat sy roetine versteur word. Hy het 2 permanente "nannies". Hulle slaap eenvoudig in. Hulle ken hom, hulle weet hoe om met hom te werk. Een is voltyds by die huis; die ander een kom in as huiswerk ook nog moet gedoen word. Ja, toe hy jonger was, het ons 2 voltydse "nannies" gehad. En my ma het ons ook ontsettend baie gehelp, maar ongelukkig het sy nou ook 2 beroertes gehad en sy is ook nou heeltemal buite aksie. C se ouers help ook waar hulle kan, maar hulle is albei reeds in die tagtig. En dan het ek 'n paar dierbare vriende wat ook oorkom.

R: Jy het genoem dat dit baie moeilik is om J se karakter te beskryf. Kan jy asseblief vir my meer sê daaroor? Is hy baie wisselvallig, of is dit net moeilik om hom te verstaan?

F: Hy kan baie kla, soos nou (*J makes moaning noises in the background*). Soms het hy dit gladnie, ander kere het hy dit baie. Hy is baie labiel met sy emosies. Hy kan oor enigeiets uit mekaar uit val. Hy kan vandag eet; môre eet hy gladnie. Maar hy is ook baie kalm. Hy is gladnie destruktief nie. Hy kan doodstil sit vir ure. Hy is geen probleem in die huis wat dit aanbetref nie. Ek hoef nooit in die huis agter hom aan te hardloop nie. Hy sal doodgaan van verhongering, want hy eet nie self nie. Jy weet, met die 3 maaltye op 'n dag. Hy leef van Kentucky, of sagte hoender. Ek kook vanaand weer hoender, ek hoop maar hy eet dit. Hy is saggeaard, geweldig saggeaard. Hy is emosioneel ontsettend op my ingestel. As ek hartseer is, is hy oombliklik hartseer. As ek met hom raas, val hy uit mekaar. Dat almal vir hom moet lief wees, en vriendelik moet wees as hulle na hom kyk, is vir hom vreeslik belangrik. Hy is ontsettend ingestel op gesigsuitdrukings. Bitter min obsessies. Ag, hy is baie lief vir 'n bal. Hy sal na Barny video's oor en oor kyk. Hy hou nie van geraas nie. Ek dink byvoorbeeld sy klassie in die skool is nie vir hom geskik nie. Dit is te woelig en te aan die gang; hy het 'n baie rustige huis. En daar is dit vreeslik raserig. Niemand skree en gil ooit op hom nie; ek dink hulle praat net hard met hom daar. Hy het aggresiewe gedrag by die skool, wat hy nooit by die huis het nie. Toe hulle dit vir my geskryf het, het ek gedink hulle praat van 'n ander kind. Hy kompartmentaliseer geweldig. Met sekere mense sal hy met 'n bal speel, hulle mag dit heen en weer gooi. Ek mag dit glad nie doen nie. By sekere mense eet hy alles. In sy huis eet hy net sekere goed. By my vriende tree hy heeltemal anders op as by my. As sy juffrou met hom winkel toe gaan, gaan hy winkel toe. By my weier hy om uit die kar uit te klim. Dit is eienaardig, hierdie by party mense doen hy dit; by ander mense doen hy dat.

R: So, afhangend van wie in sy omgewing is, is sy optrede verskillend.

- F: Ja. Maar ‘n ontsettende aangename kind.
- R: Ek weet dit is soms moeilik om te onthou, maar ek wil graag teruggaan na nege jaar terug, met J se geboorte. Ook die tyd voor J se geboorte.
- F: Ons was in Venecië, ek het swanger geraak in Venecië. Ek dink dit is waar dit gebeur het. En toe ons in Londen is, net voor ons terugkom Suid Afrika toe, was ek baie, baie siek. Ek was naar, jy weet. Maar ons het ook baie rooiwyn gedrink en “geparty” (*Laughs*). Maar in elk geval, dit was nie dit nie. J was normaal in alle opsigte. Sy “scans” was alles normaal. Wat my gepla het op sy laaste “scan”, was dat die een helfte van sy brein aansienlik kleiner gelyk het as die ander helfte. Die dokter het my gerusgestel en gesê dit is verskriklik normaal. Maar sy het vir my gesê alles is normaal. Ek was ook heeltemal normaal. Ek het normaal geboorte gegee. Hy het geelsug gehad, maar sy Apgar was 8, 9 en 10. Hy was in die broeikas net vir ‘n rukkie met die geelsug. Hy is geborsvoed tot op 6 maande. Tot toe was daar niks verkeerd nie. Ek het toe agtergekom dat, as hy luister, dit is asof hy nie sy naam hoor nie. Ek het gedog hy is doof. Almal begin daar. Hy was by spraakterapeute. Hy het hipersensitiewe gehoor. Ons hoor op 15 desibels; hy hoor op 5. Ons raak bewus van dinge tussen 5 en 10, maar hy hoor skerp op 5. Dit was vir ons vreeslik moeilik. Sy oë is getoets. “Sluggish pupils”, dit is al wat hulle kon uitvind. Die neuroloë het al die “scans” gedoen; “brainscans”. Die neuroloog was Frieda Van Rooyen, kinderneuroloog, hoog aangeskrewe; ek en sy het amper ‘n vuisgeveg gehad. Ek het haar amper aangerand, want sy het vir my gesê dat, as daar een ding is wat seker is, dan is my kind beslis nie autisties nie, want hy maak te warm oogkontak en hy is te warm in sy manier met mense. Hy is nou nog so warm en hy is geweldig vriendelik. So sy het my totaal op ‘n dwaalspoor gesit, maar ek het geweet op 2 jaar en 9 maande my kind is autisties. Almal het gedink ek was mal, maar ek het geweet daar is groot fout en ek het gedink dit is die fout. Hy het toe begin by ‘n dowe skooltjie; Joan Jorritsma het ‘n skooltjie gehad in Pearsonstraat. Hy het ‘n spraakdefek gehad, maar die skool is toe gesluit. Vir 5 jaar het my vriendin elke week na my huis toe gekom en hy het taal terapie gekry; nie spraak terapie nie, maar taal terapie. Hy het vreeslik goed daarop reageer emosioneel, want dit was vir hom lekker as die tannie daar is, maar hy het nie regtig gevorder nie. Hy het op daardie stadium nie gepraat nie. Net woorde, soos nou ook maar. Toe, op 5 jaar, het ons hom Pretoria toe geneem. In Pretoria het die psigiater wat met hierdie tipe goed werk en die sielkundige en die OT en die hoof van die skool daar; dit het hulle presies 5 minute gevat om te sê hy het kinder-autisme; die doodgewoon ordinêre autisme, redelik ernstig, maar ook nie heel ernstig nie. Hulle noem hom ‘n pratende autis, want hy kan alles vir jou sê wat nodig is. Hy kan enige ding sê as hy dit nodig het. En hy kry nou by Frances Slabbert spraak terapie, en hy bou nou al 3-woord sinne uit, maar by my doen hy niks nie. Hy praat nie, hy doen niks nie, maar hy is nou weer ‘n ander kind daar. Ek dink dat, as hy in nood is, kan hy ‘n hele sin uitwurg! Maar hy doen dit nie. Maar hy laat my ook alles weet wat hy wil hê. So dit is basies hoe ons agtergekom het. En ek het uitgevind, natuurlik, dat hy “point” nie, stel ook nie belang om na sy boetie te kyk nie. Hy het sulke slap polsies gehad, so hy het nie homself aangetrek nie. Hy het baie laat dit gedoen. Sy “potty training” was ‘n bietjie laat, so 3 en ‘n half. Toe het hy geregresseer. Toe het hy verlede jaar weer in sy broekie gegaan. Dit was vir ons traumaties. Ek het nie geweet, slaan ek hom of gil ek op hom, of wat moet ek doen nie. En dit het net weer weggegaan. Jy weet, jy weet nooit met hierdie kinders nie; hulle is ‘n “surprise packet”. Een dag, een ding; môre ‘n ander ding. Ek weet nie, ons hanteer dit net eenvoudig. Dit maak dit vir almal rustiger. Ek raak nie gespanne dat hy moet eendag heeltemal reg wees nie. Ek weet dit kan gebeur, want in die Here se hand kan enigeiets gebeur, maar ‘n mens moet ook realisties wees.
- R: Spesifiek het jy vir my genoem dat daar spesifieke tekens was om hulp te soek, byvoorbeeld dat hy nie gepraat het nie en julle het gedink hy was doof. Wat was van die ander tekens?

- F: Hy het nie gereageer op die omgewing nie, hy het nie probeer maatjies maak nie. Hy het nie eers sy boetie raakgesien toe sy boetie van die hospitaal af kom nie. Hy het bo-oor die baba geloop; hy het nie eers gesien daar is 'n baba nie. Ek weet met my vriendinne het die ouer kinders gehelp, soos om die melk te bring. My kind was op 'n stasie van sy eie. Hy het weggeraak in die tuin. As ons op 'n plek gaan eet, dan raak hy net weg. Hy het nooit omgekyk om te sien of ek ook kom nie. Hy het ook nie "geworry" of ek kom nie. Hy het nooit sy hande na my uitgesteek nie. Hy het nooit normaal met speelgoed gespeel nie. Hy was gefassineer met waaiers en hy het alles gespin; die wiele van 'n kar gespin en alles probeer draai. Hy het af en toe 'n bietjie gewieg, en dan het hy altyd 'n stokkie voor sy oë geswaai, of 'n strooitjie, of sy tandeborsel. En hy was apaties. Hy het nie homself probeer aantrek nie. Hy het nie homself probeer bad nie. Hy het nooit probeer om self te eet nie. Hy wil nou nog nie. Hy vat my hand, dan sit hy my hand op die vurk, dan voer hy hom met my hand. Behalwe as ek sê (*talks in a loud voice*): 'Eet nou!' Dan kan hy alles self doen. Hy kan ongelooftlik onafhanklik wees.
- R: Ek wil jou graag meer vra oor die tyd van die diagnose. Daardie stadium van wanneer jy vermoed, maar is ook nie doodseker nie; jy kry nie die afirmasie van pediater of neuroloë nie. Jy het in die verbygaan genoem dat jy op 'n stadium amper vuisgeslaan het! Wat was jou ervaring, as ouer, gedurende daardie stadium: jou emosies, denkpatrone en gedragpatrone?
- F: Die eerste krisis kom as jy besef jou kind is nie soos jou vriende se kinders nie. Ons het almal babas op dieselfde tyd gehad. My kind was spesifiek geweldig aantreklik, baie, baie mooi. Baie van die autiste is besonder mooi; hulle het amper so 'n "angel look". Ek weet nie wat dit was nie, maar dit was vir my traumaties, want almal het my in die winkel gestop en gesê: 'Jy het die mooiste kind.' En ek het geweet iets is nie so lekker nie. As ons na partytjies toe gegaan het, het hy sy hande oor sy ore gesit en opgegooi van die klank. Dit was te raserig en die kinders het te veel gehardloop. Hy het verskriklik opgegooi van alles. Hy het "projectile vomiting" gehad tot op 3. Hy het al 3 sy etes opgegooi vir 3 jaar. Jy het hom gevoer en hy het opgegooi. Alles, alles het net uitgekom. Toe vat ek hom dokter toe en sê ek is seker daar is 'n kleppie wat nie reg is nie. Toe sê die eerste dokter ek moet nie so 'n gesonde kind in sy kamer in bring nie, want die gesonde kind gaan net siek word (*Laughs*). Die tweede dokter het gesê my kind is verstandelik vertraag, wat reg is. Hy is verstandelik gestremd, tot 'n mate. Die meeste van hulle is. Maar dit was nie die hoofdiagnose nie. Met ander woorde, hy is nie vir Merryvale geskik nie. Hy is nie 'n verstandelik gestremde kind wat na daardie skool kan gaan nie, want dit is nie sy primêre diagnose nie. Dit is nie die opvoeding en sillabussies wat vir hom gaan werk nie. Die manier van hantering in die klas, ek het geweet dit gaan nie vir hom werk nie. Hy was vir "brain scans". Hy was 100% reg. EEG's wys geen epilepsie nie. Niks nie. So ek sit met hierdie kind wat so gesond lyk en die dokters het nie geweet wat aangaan nie. Ek het so emosioneel geraak in daardie tyd. Ek het probeer boeke lees in daardie tyd, maar dan het die boek my net ontstel, geweldig. Dat my man 'n boek oor autisme by die huis aanbring, dat ek dit in die drom gooi. Ek wou net nie, want my kind is nie autisties nie! Ek het ook maar deur "denial" gegaan.
- R: Het jou man vermoed dat hy autisties is?
- F: Wel, ek het mos vir hom gesê ek vermoed dit. Ek is op en af, en hy is ook maar op en af saam met my. Ek is meer professioneel in daardie sin, en hy het my nou maar net gevolg. Dit was 'n krisis. Ook 'n krisis in ons huwelik. Ek dink jy val of uit mekaar, of jy "jel". Goddank het dit vir ons gewerk. Jy het 'n krisis. Nou is jou kind 22 maande. Dit is 'n krisistyd, en nou het jy 'n pappe babatjie in die huis. J sien sy broer nie raak nie. Ek weet nie hoe ek daardeur gekom het nie. Ek weet nie, maar ek weet net dit was traumaties. Ek het

later dokters gehaat. Dokters kon vir my niks beteken nie. Uiteindelik het ouers vir my iets beteken. Quest skool het vir my ontsettend baie beteken. J was 2, toe is ek Quest skool toe.

R: Wie het jou verwys na die skool?

F: (*Laughs*). Ek het myself verwys. 'n Vriendin... 'n ander arbeidsterapeut se tannie was 'n onderwyseres by Quest, en hulle het 'n program gehad, of jou kind nou autisties is of nie, dit is 'n program wat werk vir kinders wat sukkel. En hulle het my opgelei hoe om met J te werk... dan moet hy sit op sy stoeltjie, en leer om te fokus vir 5 minute. En hoe om dit op te bou na 30 minute, met 'n beloningstelsel. Klein goedjies, soos jy vat 'n smartie en jy deel hom in 4. Dit is net 'n soet smakie. En so het ek en J begin blokkies bou en patroontjies naboots. En ons het foto's geneem van objekte in sy lewe, soos 'n skoen en sy tandeborsel en jou oog en jou mond, en so het ons begin om te sê: 'J, dit is 'n ...' Dan sê ek alles en ek sê ook 'mond' en dan moet hy net sê 'mond'. Dit is eintlik egolalia, maar ons het egolalia gebruik om hom te leer praat. So jy werk in die probleem in om die resultaat te kry. Toe het ons nou maar begin, en elke nou en dan gaan dit vir maande goed, dan val dit weer heeltemal uit mekaar uit. Ek het so depressief geraak, want dit is maar traumaties. En wanneer jou vriende begin praat oor skoolklere koop, dan "worry" jy nog, want jou kind kan niks doen nie, hy kan niks doen nie! Jy verloor jou vriende, want almal gaan uit op uitstappies en hulle gaan naweke weg en jy weet jou kind kan nie, want hy maak die heelyd daardie geluide en hy swaai goed rond. Heelyd gaan daardie geluidjies en dit irriteer ander mense. En hulle kan in restaurante gaan eet met hulle kinders en jy kan nie, want hy raas nog te veel. Ons het nou 'n fantastiese vriendekring, en dit is maar basies soort van dieselfde mense. Maar dit is 'n opvoedingstaak vir jou vriende ook; dit is maar vir almal traumaties. Jy onttrek ook nog. Ek dink daar is meer van my vriende wat vir my meer sou wou beteken, maar jy onttrek ook nog. Nou is dit nog moeiliker, want nou lyk die kind ouer, en mense is minder gemaklik. Aan die ander kant het ek gevoel dat, as ek nou met J by Pick'n Pay gaan loop, kan mense dadelik sien iets is fout. Almal kyk, en weet jy, ek kyk ook. As daar 'n gestremde kind is, kyk ek ook. Jou oog kan dit nie mis nie, so ek laat mense toe om te kyk sonder dat ek vies word en dan gaan ons aan. Dan weet die mense dit. As hulle jonk is, dan lyk die kind stout, dan het ek vreeslik kwaad geraak. Maar nou dat hy ouer is, kan mense sien die kind dink tog op 'n ander manier. As ek praat van ouer, bedoel ek hy is nou 9, hy is lank en groot. Die mense kan mos nou sien geen seuntjie van 9 gaan huppel en daardie geluide maak nie. So hulle aanvaar... ek dink hulle dink maar hy is verstandelik vertraag. Hy het nou die dag... dit was interessant... ons was in Port Alfred... my man het gholf gespeel. Hy het een van daardie karretjies gehuur, toe ry ons agter hom aan. Dit was so lekker, J is baie lief vir ry. Toe ry ons 3 nou in die karretjie agter hom aan... dit was so lekker. Daarna gaan eet ons toe gou in die gholfklub. En nou kan ons net... jy moet vinnige kos bestel. Kos wat nou kom en dit moet geëet word en weg wees. Want hy is dierbaar, as ons stoksielalleen daar gesit het, kon ons vir ure daar gesit het. Maar omdat daar nou ander mense daar was... ag, hy wieg op sy stoel en maak sy geluide en hy staan op en af, toe raak hy (*looks at I watching TV in the background*) vreeslik "embarrassed". Toe is dit die eerste keer dat ek agterkom my tweede kind raak "embarrassed". Nou, ons het soort van 'n uitgangspunt, dit is okay om "embarrassed" te raak. Dit is okay, dit is nie lekker om so 'n boetie te hê nie; dit is vir niemand maklik of lekker nie, maar ons leef ongelukkig daarmee saam, en moet die beste daarvan maak. So dis "all right" om "embarrassed" te wees. En hy vertel vir almal by Graeme... hy is in Graad 2 by Graeme... toe hy in Graad 1 was, het hy vir almal vertel sy boetie is in Graad 2. Ek weet nie wat hy nou sê nie; hy sê seker maar sy boetie is in Graad 3. Maar jy weet, kinders is ook so pragtig. As sy maatjies hier kom speel, sê hulle: 'Hallo, J!' en niemand kyk weer na hom nie. En hy wieg en raas en niemand "worry" nie. Hulle speel reg rondom hom. Hy wieg op en af en hulle sit maar hulle video's en kyk en niemand "worry" nie. Ek dink dit is meer die ouers wat bekommerd is. Maar ek dink ook ons huis

sukkel en spartel nie rondom J nie. So hy (*second child*) voel nooit ooit afgeskeep nie; hy voel baie spesiaal.

R: En in terme van sy verhouding met J?

F: Ag weet jy, dit gaan moeilik. So moeilik as wat dit nou maar vir enige maat is om 'n verhouding met J te hê, so moeilik is dit vir I. En J is soms lelik met hom, in die sin van as hy nou vir J gaan koeldrank ingooi of as hy vir J 'n paaseier bring, dan wil J dit nie hê nie. Dan sit J dit net neer. Maar sy hartjie het gebreek aan die begin. Nou "worry" hy niks meer nie. Hy sit dit net neer en sê: 'Ag, Mamma, gee dit net vir J as jy onthou, asseblief.' Ja, dit is baie hartseer vir hom omdat hy nie werklik 'n ouer boetie het nie. Hy wil so graag 'n ouer boetie hê en deel van 'n gesin wees, want ons is nie in sy oë 'n gesin nie. Ja, ons is baie opgebreek. Pappa moet met hom gaan fliëk, want iemand moet by J bly. Oor naweke het ons nie altyd 'n "nanny" nie. Nou die dag, met die Splash Festival, het ek gesê: 'Nee wat, gaan julle maar.' Hy het so gehuil, die trane het oor sy wange geloop. Hy wil hê ons moet gaan. Ons moet gaan. Toe het ons nou maar gereël en toe gaan ons. Ons het J maar in die kar vir 'n uur gelos. Ons het vir hom lekkers en goed gekoop en vir die karwag gesê: 'Hier sit 'n kind. Kyk na hom, ons sal jou goed betaal.' Radio aangesit, vensters oop. Hy sit na die see en kyk en ons kan vir 'n uur uitgaan. Dit is vreeslik, sulke goed (*Sighs heavily*).

## INTERVIEW 2: POSTDIAGNOSTIC ADJUSTMENT AND COPING

R: Ons het reeds oor sekere aspekte van die tweede onderhoud gesels, maar ek wil graag in meer detail oor sekere dinge praat. Spesifiek gaan dit oor julle aanpassing na die diagnose, en ook hoe julle geleer het om dit te hanteer. Eerstens wil ek meer weet oor die algemene roetine in die huis. Jy het spesifiek genoem dat etes 'n probleem is.

F: Ja, toe hy opgehou het om so op te gooi, het dinge verander. Hy het ontsettende voor- en afkeure in kos. Hy kon nie regtig tot op 5 of 6 vaste, growwe kos soos happies vleis en goed eet nie. Dit het baie moeilik gegaan. Hy is grootgemaak op Purity en spaghetti. Spaghetti en tamaties, dit is al wat hy kon inhou. Hy het maar baie beperk geëet. Ek dink wat die nadeel van dit is, is ons sit nie regtig as 'n gesin om 'n tafel en eet nie. Ons probeer dit een keer per week doen, dan braai ons almal buite. En ons probeer dan hier sit en eet. Ons probeer die kos so gewoon as moontlik maak. Jy weet, ons verwag nie van J nie... ons druk hom nie verskriklik nie. So, as hy net lus het vir tamaties, dan maak ons tamatieslaai. As hy net kaas op 'n broodjie kan eet, dan sit ons die broodjie buite op die braai net met kaas op. Nou nog, met elke stukkie kos wat in sy mond ingaan en elke slukkie kos, sê ons: 'Pragtig, J! Daarsy. Kom, volgende.' My ander kind eet net so swak, maar hy kan sy eie ding doen. Hy sal nooit 'n ding nie eet nie omdat J dit nie hoef te eet nie. Hy verstaan; hy is soos 'n ou mensie. Hy weet hy eet wat ons eet, J eet ander goed. Ek sal baie keer vir C sê: 'Luister, ek kan nie meer nie. Gaan kry net vir ons 'n McDonald's burger of Kentucky.' Dan eet J soms heeltemal anders as die res van die gesin. As daar maaltye is met wors in... Ag man, enige ding soos lasagne of spaghetti bolognese, daar bestaan nie so iets vir J nie. Ons eet dit; hy eet sy eie kos. Ons "nanny" maak nou vir my kos, 5 maal 'n week. So ek is baie rustig. Ek ontspan met my kinders; ek geniet my kinders. Sy weet nou al, dit is gewoonlik hoender en opgekookte aartappels en wortels. Ons eet nou al almal so, want dit is wat J kan eet. So, dit is 'n aanpassing in die begin, maar dit voel nie meer vir my soos 'n aanpassing nie, want ek ken dit nie anders nie. As ek na my vriende gaan, en ek sien hulle gee vir hulle kinders pasta en beetslaai en nog iets, dan val my mond oop, want ek kan nie net so nie. Ek kan ook nie net iewers gaan stap en vir my kinders "spring rolls" of samoosas koop nie. Daar is geen manier nie. My kind kan nie. Hy kan nie 'n boereworsrol eet nie. Ja, hy eet nie normaal nie. So ons is maar net gewoond daaraan. Hy is mal oor vrugte. Hy het nou, voor jy gekom het, 4

nartjies en ‘n piesang opgeëet. Hy kry sulke blou kringe onder sy oë in die aande en ek dink hy het ‘n ystertekort. Ek is nie verbaas nie. Ek het nou vir hom Spirulina vir kinders gaan koop, en hy het sowaar vanmiddag die 3 pilletjies gekou. Ek is so bly. Ons maak van niks meer ‘n “issue” nie. Soms val ons emosioneel uitmekaar omdat ons so moet sukkel met elke ete. Hy sit net ingedagte hier (*dining room table*) en hy kyk uit by die venster. Hy kyk vir die water en hy vergeet om te eet. Sy kossies raak yskoud. Ons warm dit soms tot 3 keer op. En dan kom daar tye wat ek net alles weggooi of vir die hond gee en dan moet hy seker maar honger lei, maar ek kan nie so aangaan nie. As ons vir mense gaan kuier, moet ons sommer Kentucky koop op pad soontoe, of hulle sê: ‘Luister, wat eet J nou weer?’ en dan maak hulle dit. Gelukkig is daar ‘n paar standaard goed wat hy inkry. Hy is baie lief vir opgebreekte spaghetti met kaas op gerasper. J (*another parent of an autistic child at Quest*) sê niks wat J eet is reg nie. Sy sê ek voer my kind alles wat verkeerd is. Maar ons verstaan mekaar baie mooi. Ek kannie myself so verwoes as wat sy haarself verwoes nie. En haar kind het reageer op al daai kos. My kind reageer glad nie. Ek het hom afgehaal van sjokolade en kaas en rooiworsies op ‘n stadium. Al wat verander het is dat die “rash” op sy wange weggegaan het. Die blou kringe onder sy oë het minder geword, maar hy het niks verbeter nie. Vir my is verbetering in autisme: leer hy makliker in die klas; konsentreer hy beter; maak hy minder snaakse geluide. Jy weet, ek “worry” nie oor of J “rashes” het op sy wange of kringe het onder sy oë nie. Toe het ek nou maar weer opgehou. Hy eet te min, hy sal doodgaan as ek hom van al daai goed afhaal. J het nou die dag ‘n fantastiese praatjie vir ons gegee oor “good food” en “bad food”. Kyk, ons is basies almal op diëte vir die res van ons lewens. Jy weet nou al dit is beter om eerder ‘n stukkie brood te eet as ‘n pak chips. Ek soek dieselfde, ek wil hê dit moet in my agterkop kom as ek vir J inkopies gaan doen. Dat ek net weet, van die slegte kos is dit dan nou beter om tamaties te koop as nartjies, want J lyk vir my het ‘n tipe van ‘n geel vrug allergie. Hy is so lief vir sy lemoene en nartjies. Blykbaar is piesangs ook nie goed vir hulle nie, maar dit is al wat hy inkry! Maar ek kan nie die “gluten free” en goed doen nie, hoor. Want hy is gesond en hy het nie daardie geweldige maagprobleme wat baie van die kinders het nie. En die dogtertjies het baie meer van die “yeast” probleme, waarmee hy glad nie sukkel nie. Ek wil net hê dat my kind... hy het sy skool en sy spraak terapie en almal werk hard met hom by my huis... Ek aanvaar hom vir wie hy is. Ek is ontsettend lief vir hom. En hier kan hy maar ‘n bietjie wieg op sy stoel en ‘n ding voor sy oë swaai... by sy huis kan hy maar ‘n bietjie ontspan. Ek voel jou huis moet ‘n plek wees waar jy met jou voete op die tafel kan sit en ‘n blik kondensmelk kan uiteet as jy wil. My kinders moet rustig wees en ontspanne. Ek dink ook ek is ‘n te gespanne mens diep binne. Ek dink ek is nogal van nature baie gespanne. Ek streef om perfek te wees, en as ek gaan probeer met J, gaan ek heeltemal uit mekaar uit val. Ek het myself net heeltemal geherprogrammeer.

- R: Dit is ‘n interessante manier van “cope”... om jouself te herprogrammeer en om die verwagtinge wat jy op jouself plaas aan te pas.
- F: Ons het ‘n fantastiese ondersteuningsstelsel en ek en my man gaan so baie uit. Ons doen dinge saam en gaan op vakansies.
- R: Vertel my van julle vakansies. Hoe werk dit?
- F: Een keer ‘n jaar gaan ek en C alleen... ons was hierdie jaar Franshoek toe. Ons het daar vir ‘n week gaan uitkamp in die pragtigste Bed & Breakfast. Dan vergeet ons net van die stres en die kinders en alles. Ons gaan ook baie naweke weg. Ons gaan kamp. Soms gaan kamp ons met J, soms sonder J. En nou die dag was ons op ‘n kerkkamp sonder J. Net die 3 van ons. Ons gee vir onself daardie tyd.

R: Wie sorg dan vir J?

F: Hy bly dan hier by die huis en die oumas kom haal hom en my sussie kom haal hom en die “nannie” sorg vir hom. En ons het ‘n bietjie vroër teruggekom, en ons het eintlik skuldig gevoel, want hy was so gelukkig. So, ons sorg ook baie mooi vir onself. Ek sou ‘n kluisenaar geword het as ek myself nie gedwing het nie. Ek kom ook uit ‘n gesin waar ons baie gelukkig is met ons eie geselskap. Ek voel nooit meer skuldig oor goed nie. Ek is nie ‘n psigopaat nie (*Laughs*). Ek voel nie skuldig nie... “I never beat myself up about things.” Ek erken ek het ‘n fout gemaak, en ons gaan net aan. Ek dink dit help vir my. Ek sal byvoorbeeld nie as ek êrens vroeg afkom huis toe jaag om by my kinders te wees nie; ek sal gaan fliiek. Of ek sal by ‘n vriendin gaan kuier. Ek forseer nie meer vir J om saam met my te gaan “shopping” doen nie. Ek weet hy is lief vir stap, so ons gaan stap saam, ek en ou J. Ek dwing hom nie om snaakse dinge te doen nie. Ons klim eerder in die kar en gaan koop vir ons ‘n heerlike roomys en gaan sit by die see. Ons doen sulke goed, verstaan jy? Dis hoe ek “cope”. En my man, hy hou van gholf speel. Hy is ook baie kunstig. Alles wat jy hier sien het hy gemaak (*various paintings and sculptures throughout the house*). Elke beeld, elke skildery. Elke koppie wat in my huis is, elke ding wat hier lê, alles is my man. So hy stel belang in kuns. Ons is altwee baie lief vir musiek. Ons luister tot laat in die nag en ons speel altwee kitaar en ons sing. Ons geniet dit. J is ook lief daarvoor.

R: Dit klink asof julle nie julle eie belangstellings laat vaar het om J te akkommodeer nie.

F: Ek het aan die begin, maar toe het ek weer begin.

R: Ek wil graag spesifieke aspekte van J se lewe bespreek, en hoe julle dit ervaar. Die eerste is sy opvoeding en dagsorg.

F: Elke ouer begin mos maar by ‘n gewone speelskooltjie. En ek het net gister met ouers gepraat wat van Graaff Reinet af kom. Hulle seuntjie... ons vermoed hy is autisties... hulle kom sien vir my by die skool... maar dit is ‘n privaat deel... en ek het hulle so jammer gekry. Hulle seuntjie is nou in daardie krisis stadium. Hy is 5 jaar oud en daar is niks vir hom nêrens in Graaff Reinet nie, en hulle kry so swaar. Nou probeer hulle oorplasings kry met hulle werke, want hulle voel PE is beter. PE is dalk beter, maar J het ook maar begin met Pickwicks, waar die dierbare mense hulle bes probeer het. Hulle het hom nooit uitgeskop nie. Ek moet vir jou sê, ek was gelukkig. Ek het hom maar orals uitgehaal, want ek het besef dit is nie geskik vir hom nie. As ouer gaan jy ook deur ‘n rouproses en ‘n ontkeningsproses. En ‘n krisistyd is nou net daar waar jy begin met die skole. In die gewone skool kom jy gou agter iets is nie lekker nie. Die ou verslaggies is altyd so... jy weet, as ek na I se verslae kyk, wat ‘n vreugde... en J se ou goedjies is so tragies. Toe haal ek hom uit by Pickwicks, toe sit ek hom by Joan Jorritsma se skooltjie. Ek onthou ek het in die gang gaan staan by hierdie groot, lang vrou, en ek het vir haar gesê: ‘Daar is groot fout met my kind.’ En ek het my oë uitgehuil in haar kantoor vir ‘n uur lank en sy was bereid om my te help, om na hierdie snaakse seuntjie te kyk. En hy was by daai skooltjie vir omtrent ‘n jaar en ‘n half. Toe het ek die hoof by Cape Receive gaan spreek. Jy sien, gelukkig ken ek al die arbeidsterapeute en ek was baie betrokke by die skool. Toe gaan ek en my man met hom gesels en sê: ‘Wil jy nie hierdie arme kind help nie. Ons vermoed hy is autisties. Hy is nog nie finaal gediagnoseer nie, maar ons weet net hy het spesiale onderrig nodig. Is dit moontlik?’ Hy sê toe ja, en toe is J daar vir 3 en ‘n half jaar by ‘n fantastiese vrou. Maar, omdat hulle nie die regte manier van skoolhou het vir autistiese kinders nie, het hy hulle totaal gemanipuleer. En hy het later net met ‘n bal gestaan en hy het net met die bal gespeel. Hy het net ge-êêêê as hy moet sit by die tafel. En hy was absoluut so slim, hy manipuleer hulle links en regs. Toe het ek hom uitgehaal en hom in Quest in Uitenhage gesit. Weet jy,

wat 'n ommekeer. Daar was hulp vir my in die sin van, toe ek moes Quest toe gaan toe hy nog by Joan was, by die dowe skooltjie, toe het Quest my geleer hoe om met hom te werk. Hulle was fantasties. Ek moes R25.00 gee, dan het hulle 'n uur lank met my gesit, een keer per week, saam 'n programmetjie uitgewerk met graderingsbeginsels. Dan moes ek nou werk en afmerk wat het ek nou al alles gedoen en reggekry. En elke week het ons saam gesit, dan het sy my die volgende goedjies geleer. Toe het ek, toe hy by Cape Receive was, het ek daardie spraakterapeut en OT gaan leer hoe om met hom te werk. Toe het hulle fantasties met hom gewerk in die terapië. My vriendin, wat hom hier kom sien het, ek het haar geleer. En sy het dit net so gedoen. En op 'n stadium het ek 'n sielkunde meestersstudent gehad, en ek het haar geleer. En as ekstra inkomste het sy een maal per week ingekom. En dit was heerlik. Hy is mal daaroor. Hy is vreeslik lief vir mense, en "one-on-one" is J op sy beste. En toe hy nou by Quest beland, het ek gevoel dit is fantasties. Toe was ek ook minder "geworry", ek moet jou sê. Hy is daar, en tot twee uur in die middag word hy besig gehou. Sy klas voel ek net... toe ons by Junika (School for Autism in Pretoria) was in Pretoria, het ek gesien die kinders sit elkeen amper in 'n afskorting. Jy is deel van 'n klas, maar autiste is mos nie eintlik met mekaar gepla nie. Maar hulle sal mekaar seermaak en mekaar pla. J maak die hele tyd daai geluide. Dink net hoe moet hy die ander kinders pla. Hulle pla hom, want hulle skree af en toe en hulle pla hom en raak aan hom en hy kan dit nie verdra as iemand aan hom vat nie. Hy is vreeslik "tactile defensive". Dit is by die skool amper soos afskortings en jy moet amper so maak (*bends over backwards*) om die ou langs jou te sien. Nou weet ek nie... al sy goed is op die tafel en dit is oop en daar is die volgende tafel. Ek voel hulle moet hom amper laat sit soos by die outydse bibliotekies wat die Sub A juffrouens altyd gehad het... Daai houtstellasetjies wat die kinders afskort. Ek voel hulle kan hom 'n bietjie meer afskort om sy aandag meer te fokus. Die aandag wat hy kry by die spraakterapeut voel ek is genoegsaam. Sy is ontsettend betrokke. Sy het 'n hele nuwe stelsel uitgewerk wat daai kind gaan leer praat, ek is seker. Ek werk saam met haar, die juffrou werk saam... daardie spraaktassie gaan die hele tyd skool toe, so daar is 'n totale veralgemening en integrasie tussen sy spraakterapie en by die juffrou en by my. Dit werk baie goed. Die ondersteuningsstelsel vir ouers is baie, baie swak in PE. As dit nie was vir 'n paar van ons ouers wat so af en toe by mekaar kom nie, sou ons nooit nie. Gelukkig het 'n paar van ons soort van mekaar ontmoet, maar ons sien mekaar min. Maar ek het net gister besef wat dit is toe ek nou vir daardie ouers van Graaff Reiniet 'n bietjie ondersteuning gee. Hulle het my ook ondersteun. Ons het almal later gehuil; die pa, ek en die ma het in trane uitgebars gister. Net omdat hulle so sukkel. Ek kry hulle so jammer. Ek het die man so jammer gekry, want ek besef... hy sê daar is niemand wat hom verstaan nie. Hy sê sy base weet nie eers wat dit is nie. Hulle het hom aan 'n lyntjie gehou oor sy afspraak by my. Hulle moes van Graaff Reiniet af ry. Tot Maandagaand het hulle nie geweet of hulle Dinsdagoggend by my kan wees nie. So, daar is net nie begrip nie. Daar is geen begrip by dokters nie. Dr. W (paediatrician) en ek het 'n goeie verstandhouding, maar ook nie regtig nie. Ek weet daar is geweldig navorsing aan die gang, maar daar is niks uitkomst nie. Ek sien niks nie. Daar is geen pil wat vir my kind help of werk nie. Daar is geen diët wat my kind verbeter of verander nie. Daar is nie genoegsame ondersteuning nie, maar dat Quest fantasties is, is seker. Hulle vergelyk net so goed met enige van die ander skole. Ek voel net hulle moet die afskortings kry, soos ek reeds gesê het... soos by die skool in Pretoria.

R: Hoe lank was J daar?

F: Nee, ons was net vir die dag daar... net vir die finale diagnose. Daar is pragtige, wonderlike boeke wat nou geskryf word... meer realistiese boeke wat ook uit die oog van die ouers geskryf word. Daai boeke help baie. En dan was daar nou die dag in 'n tydskrif 'n fantastiese, nugter artikel oor autisme. Ek probeer daai goed lees. En dan is daar J (one of the parents at Quest)... 'n mens kan altyd vir J bel en vra wat is die nuutste!

- R: Die volgende area waaroor ek meer wil vra is gedragsbeheer en dissipline. Party ouers het dit meer nodig as ander, afhangend van die graad van aggressie en destruktiwiteit in die kind. Wat is julle ervaring met J?
- F: J is aan die ander kant van die spektrum. Hy is meer stil en rustig. Hy is op die oomblik of daar gom aan hom is; hy kry nie beweeg nie. Hy is so vas; hy kom nie deur 'n deur nie en hy kry nie sy arms by 'n bord kos nie. Hy kry nie geloop van een kamer na 'n ander kamer nie. Hy is 'n meer "passive" kind. Maar hy raak obsternaat oor sekere goed. Sekere dinge moet gebeur. Ongelukkig, al is hy soos 'n "alien" hier op aarde, is daar sekere reëls en regulasies en hier is sekere dinge wat moet gebeur en sekere dinge wat nie mag gebeur nie. So ons is ferm, maar ons het nog nooit in ons lewens ons hande gelig of 'n houtlepel gebruik of iets nie... daai kind weet nie wat dit is nie. Hy skrik hom dood net as jou oë begin kwaai raak. Of as jy begin skerper praat, as jou stemtoon 'n bietjie begin lig. Dit is hoe ons hom beheer. Hy is baie sensitief. Ek kan hom met belonings sover kry om sy kos te eet. As ek 'n lekkertjie daar sit en ek het hom nog nie oopgemaak nie, dan weet hy dis die einddoel (*Laughs*). En as ek hom dryg (*Raises her voice*): 'J, wil jy pak hê?' Hy ken daai woord baie goed! En ek werk maar net deur dit... ek werk maar net dwarsdeur hom. As hy nie wil nie, dan vat ek net sy hand en ek werk dwarsdeur hom. Ek staan agter sy lyf en ek loop agter sy bene en ek loop met sy bene vir hom en ons gaan nou maar net waarheen ons moet gaan. 'Ja, jy moet nou uitklim,' en ja, ons klim in stadions uit 'n kar uit. 'Sit jou voetjies uit,' dan sit hy sy voete uit. 'Sit dit op die grond,' dan sit hy sy voete op die grond. 'Goed, gee vir Mamma jou hand,' dan gee hy my sy hand. 'Kom,' en dan moet jy hom nogsteeds trek, verstaan jy. So ons gebruik fisiese manipulasie. Ons werk deur hom; werk deur sy handjies. Hand-oor-hand word dinge nou maar gedoen. En as hy nou op my meubels begin spring, wat hy doen, sê ek (*Talks in a firm voice*): 'Nee, J, nee!' En as hy stop: 'Dankie, Skat.' Alles is nee an dankie. So kom ons aan, en ek weet dit werk nie vir almal nie.
- R: Jy is gelukkig dat hy nie aggressief of self-destruktief is nie...
- F: Hy is self-destruktief in die sin dat hy sy vingernaels afkou, vreeslik erg. Die bloed kom soms uit, maar hy maak nie homself op ander maniere seer nie. Hy kry lekker seer as hy seerkry, maar hy sal byvoorbeeld, as hy sy toon stamp, sal hy nou te kere gaan oor die toon. Maar dan sal hy hom brand by die Weber wanneer ons dit nie sien nie, dan maak hy nie 'n geluid nie. In die aand, as hy in die bad klim, dan sien jy maar sy vinger is heeltemal gebrand. Eienaardige goed.
- R: En teenoor sy boetie?
- F: Nooit nie. Nooit klapperig of stamperig nie. Nee. As hy weet ons gaan sy boetie by die skool haal, is hy opgewonde. As ek gou-gou ry... sê nou ek het iets by die kafee vergeet en hulle is nou in pajamas en Pappa is nog nie by die huis nie, dan sluit ek al die deure en ek kan vir hom sê: 'Bly net gou by boetie. Mamma het iets vergeet by die winkel.' Baie gelukkig so. As sy boetie TV kyk en hy kan hier saam met sy boetie sit en kyk, dan kry ek die gevoel hy voel baie tevrede. Jy weet, hy het sy gesin en sekuriteit.
- R: Die laaste area het ons reeds bespreek, naamlik die invloed van die autistiese lid op ander gesinslede. Buite die kerngesin het jy vir my genoem dat jou man se ouers reeds taamlik bejaard is, en dit is vir hulle moeilik.
- F: Ek kry die idee hulle is bang hy gaan iets doen en dit gaan vir hulle moeilik wees om hom te hanteer. Maar hulle kyk na hom, en een keer in 'n maand doen hulle 'n oorslaap. Maar kyk, I is baie verantwoordelik, so hy doen die meeste van die goed vir J. Hy sal onthou om vir J

te sê: ‘Eet, boetie, eet! Sit in jou mond.’ Maar hulle kom nogal reg... hulle is ontsettend dierbaar. Dit was vir hulle ‘n geweldige skok toe ons uitgevind het J het autisme. C, my man, het ‘n autistiese niggie waarvan ons nie geweet het nie, en blykbaar is die kind sommer in ‘n inrigting gedruk. So dit is vir hulle net wonderlik dat die kind by ons is. Sy sê... hulle is Engels: ‘What can old people do, my love? We can look after your children, we can help you, we can be a support for you.’ So ek het daardie ondersteuning. My ma was al die jare daar. Dit is verskriklik traumaties vir ons, want sy is gek oor hom. En dan my suster en ek is beste vriende. Hulle kan naweke daar oorbly. Hulle is ook uitstekend, J is vreeslik lief vir hulle. En sy het 3 kinders, wat hom op die hande dra. Maar dit is vir my broer baie moeilik. Hy is in Gordonsbaai in die Kaap en hy sien J min. Ek het ‘n tweeling broer en suster; hulle is 8 jaar ouer as ek. Dit is vir hom moeilik en hy kry my altyd verskriklik jammer. Ek kan dit nie verdra dat iemand my jammer kry nie. Dit is okay as jy my jammer kry op die regte manier, maar moet my net nie bejammer nie. My lewe gaan aan. Dit is nou maar wat na my kant toe gekom het. Ek sal wens daar was nog meer ondersteuning, veral in die formele sektor.

### **INTERVIEW 3: PRIMARY NEEDS, CONCERNS AND SUPPORT SYSTEMS**

- R: Basies het jy grotendeels al oor die ondersteuningsbronne gepraat. As ek jou vra om terug te dink oor alles waardeur julle as gesin nou al is met J, watter dele van die proses voel jy het jy die meeste ondersteuning nodig gehad of het jy miskien verskriklik alleen gevoel?
- F: Ek dink toe J omtrent so 3 jaar oud was. Toe raak dit vir my baie erg. Toe was hy nog nie gediagnoseer nie. Ek het baie min ondersteuning gekry. Selfs my familie het daardie tyd nog gedink hy makeer niks nie. Hy het nie ingepas nie. Hy het nie maatjies gemaak nie. As ons genooi is na partytjies, was dit altyd ‘n krisis. Ek het altyd rondgehardloop en gespartel met hierdie kind. Ek het sosiaal geweldig ‘n “knock” gehad. Jy weet, almal se kinders raak nou groter en oulik en begin praat en jou kind... jy weet daar is iets groot fout met jou kind. Almal kan saam kuier en gesels en weggaan, en jy kan nie saamgaan nie, want jou kind is so tragies. As almal in ‘n “tea garden” gaan sit, hardloop jy net agter jou kind aan, want hy hardloop onder die swaai en goed deur, want hy sien dit nie. Dit was traumaties... hy kom nie agter as iets gevaarlik is nie. Nee, dit was aaklig. Om uit te vind wat hom makeer... en al die snaakse goed wat hy doen. En hy kan nie reg speel nie, en hy leer nie om self dingetjies te doen nie. Hy is so ontsettend afhanklik van jou, en ook gladnie. Dit was aaklig.
- R: Ja, jou 2 kinders is nogal na aan mekaar, ouderdomsgewys. Dit is seker moeilik as jy die verskille in ontwikkeling by jou eie kinders waarneem.
- F: Ja, dit is nogal moeilik as jou gestremde kind jou oudste kind is, in die sin van jy weet nie wat om te verwag nie. Jy is dalk ‘n bietjie meer positief, want jy weet nie wat moes eintlik gewees het nie. As ek hom na I moes gehad het, sou ek my doodgeskrik het, vinniger dalk. Al wat sleg was, is dat ek I ook nooit kon geniet nie, want ek het so “geworry” oor J. I se eerste verjaarsdag het ons in Bloemfontein gesit met daai trauma, en ‘n vriendin van my het vir hom sy eerste verjaarsdag gehou. Weet jy hoe getraumatiseer was ek deur dit? Gelukkig hou ek nie skuldgevoelens oor nie, maar dit het my gegooi. Want hier sit ek en sukkel met hierdie kind en my babatjie, wat niks makeer nie, my vriendin moet sy partytjie vir hom hou. Ek kan niks van I onthou nie... dit is net ‘n deurmekaarspul van dokters en sukkel en opgooi en hy kan nie van die doeke afkom nie. En hy is so anders as my vriende se kinders, en ons kan nêrens meer saamgaan nie, want ons is so anders. Dit is ‘n warboel. Dit is soos swart en grys kryt deurmekaar gekrap op ‘n blaaie. Ek weet nie wat daar aangaan nie.
- R: Tog het jy anderkant uitgekom.

- F: Een ding is, of jy vlieg, of jy is dood. Daar is nie ‘n tussenin nie (*Laughs*). Dit is ‘n kondisie van uiterstes.
- R: As ek luister na die manier waarop jy praat, klink dit vir my asof jou man ook ‘n sterk bron van ondersteuning was, tesame met sy eie kommer.
- F: Ja, hy het my ook gedra, want ek het meer uit mekaar geval as hy. Ek het op ‘n stadium agter J in die tuin aangehardloop en as ek hom gekry het, het ek hom doodgemaak, so verskriklik soos dit klink. Ek weet nie wat daai dag gebeur het nie, maar ek het net “gesnap”. Hierdie kinders het “guardian angels”... as ons een het, het hulle 10. En hy het net geweet hy moet vinnig uit my pad uit kom. Ek dink dit was weer oor kos; hy het weer opgegooi. Ek was net klaar met die een lot en die babatjie was ook daar. Ek het net gehardloop. Ek hardloop, en hy hardloop, en my dierbare “nannie” hardloop agter my aan. En die 3 van ons hardloop, en sy gil op my, en ek gil op hom, en hy is soos ‘n weerligstraal in daai boom op. En ek staan onder daai boom, en sy vat my aan my arm en sy sê vir my: ‘Madam, don’t you worry. I will look after J, you just go and lie down.’ En ek is hier in, snot en trane hier in my huis ingeloopt, en probeer kalmeer en bedaar. Ja, so daar kom ook sulke tye (*Laughs*). J was al 2 keer feitlik dood, wat ek net weet daar is ‘n rede waarom hierdie kind leef. Dit was 2 keer in hierdie huis. Die een keer het hy per ongeluk... hy was 18 maande... en iemand het hierdie voorste hekke oopgemaak en ek weet nie daarvan nie... toe sit ek hoog swanger... ek was 7 maande swanger en ek en my ma het sit en gesels... en ek hoor net skielik die karre “hoot”. Dit is ‘n baie besige straat... ek was op kraamverlof... toe is daai ou seuntjie in die pad uit op sy skopfietsie. Heen en weer oor die pad in daardie verkeer. Ek hardloop met hierdie groot maag; die karre stop. Die een man stop en tel die kind op. Wat dink hulle nou? Ek is nou ‘n slegte ma. Maar jy kan nie altyd met hierdie kinders, veral as hulle jonk is... hulle is dol... hulle is heeltemal hiperaktief. Die ander keer... hy raak nooit weg nie, hy loop nie weg nie... maar die keer weet ek nie wat het gebeur nie, maar sy ou balletjie het uit sy hand uit geval en, soos die duiwel dit wil hê, is al 2 hekke nie op knip nie. En ek en my man staan hier en sukkel met iets met die klavier en die kitaar. Genade, die volgende oomblik kom daar ‘n vrou in hierdie “driveway” afgestap en sy druk haar neus teen my neus en sê (*raises her voice*): ‘Jou kind moes nou dood gewees het!’ En J bons en huppel en lag langs haar. Toe het hy oor die pad gehardloop agter sy bal aan. Sy het gestop, toe raak sy klere aan haar kar. So, daar is ‘n rede vir hom en ons sien dit so as dinge baie erg raak. As ons regtig nie meer kan nie.
- R: Jy het reeds vir my gesê van die hulpbronne in PE en omgewing; of liever die gebrek aan hulpbronne. Kom ons gaan dus verby die hulpbronne, en kyk na die behoeftes van ouers. As ouer, wat sal jy sê is die primêre behoeftes van ouers met autistiese kinders, en hoe kan professionele persone die ouers beter ondersteun?
- F: Die eerste punt is dat daar nie ‘n “support group” is nie. Die skool het nou so ‘n rukkie terug ‘n heerlike dag gehad, wat die ouers bymekaar gekom het en gepraat het oor diëte en die “adult client”, want hulle wil nou begin huise koop, soos in Amerika, waar die kinders kan bly as hulle klaar is met skool. Kaapstad het een en Pretoria het die ander een. Maar, daar is ook maar “teething problems”, maar dit gaan maar daar wees. Ek wens net dat daar ‘n groter groep was en meer dinamiese ouers wat tyd gehad het, dan kon ‘n mens ‘n interessante groep begin het. Jy kan ‘n ondersteuningsgroep hê, maar ‘n lekker een waar ons sommer by mekaar se huise gaan braai. Waar die kinders welkom is, en as daai een byvoorbeeld alles breek, pak jy net alles weg. Hierdie kind skryf in al die boeke, so jy sit net al die boeke weg. Soos die ouers gister, hulle weet hulle kan net op ‘n sekere plek ontspan. Hulle kan nêrens gaan met hulle seuntjie nie, maar hulle weet hulle kan na my kom. Dit was so lekker vir hulle om ook net ‘n bietjie te kan sit en te ontspan. Daar moet so ‘n “set-up” wees, waar ons

almal met ons karavane kan weggaan en almal se kinders is snaaks, maar almal kan die tyd saam geniet. En as amper 'n "baby sitting club" kan gestig word, waar ons almal lekker kan gaan fliëk vanaand of gaan uiteet. Dan is dit byvoorbeeld my en C se beurt om na die 8 kinders te kyk, of 6 kinders of 4 kinders. Jy moet realisties wees! En dan weet ek, vir die volgende 4 maande kan ek een keer 'n maand gaan uiteet, en ek weet my kind is veilig by iemand wat hom verstaan. Sulke goed moet daar wees, praktiese hulp. En interessante artikels kan gefotostateer word en in die kinders se sakkies vir die ouers gestuur word. Moet dit nie oplak by die skool nie, want wanneer kom jy nou daar. Ek het nou die dag die oulikste goed teen die muur gesien. Ons sal daarvoor betaal. Rol dit af, sê vir my dit het R2.00 gekos, en ek stuur dit net môre saam met J skool toe. Sulke tipe goed. Ek wens daar kan 'n sentrum begin word waar daai dokter en daai OT en daai sielkundige baie weet van hulle. Hulle sien byvoorbeeld alle leergestremde kinders, maar hulle is byvoorbeeld "ge-gear" vir autisme. Jou "odd" kind, jou snaakse kind met die mannerismes en goed en die "tics". Dat ek weet ek kan vir J ook soontoe vat. Ek wens iemand was daar, soos wat ek nou daar is vir hierdie ouers, ek wens net dit was vir my daar. Ek het swaar gekry. Ons het gesukkel, maar Quest het baie beteken, al was dit ook hulle beginjare. Al is dit professioneel, wil ek ook hê iemand moet sommer kan huil saam met my. Ek wil nie hê jy moet nou so oulik en "grand" wees en jy gaan nou daar uit die hoogte vir my probeer help nie. Dit gaan daaroor; jy is 'n mens en dit is traumaties. Dan kan ek regtig met jou gesels, want ek weet van watter pyn jy praat, hoe jy uitgeskop voel, hoe jy skaam is as jy êrens met jou kind moet gaan. Waar ons nie van bakboord na stuurboord gestuur word nie, maar waar jy gaan en dit is klaar en alles is daar en hulle stuur jou uit met 'n diagnose. Ek is lief vir 'n diagnose. Ek weet hulle sê jy moet nie 'n kind etiketteer nie, maar dit is 'n teken vir ons as ouers, 'n beginpunt. Dit is een van jou tragiëste diagnoses wat gemaak kan word, maar minstens weet ek dit is dit en daar is 'n spektrum en hy is nie die heel ergste nie. Hy is iewers hier in die middel en daar is 'n skooltjie vir hom en daar is 'n ondersteuningsstelsel vir hom en hulle plaas jou in kontak met ander ouers in dieselfde situasie. En dan dink ek die huis vir volwasse kinders is belangrik. Jy kan nog by jou ouers bly tot 18 of 21, maar darem van 21 soek jy 'n plek waar jy ook voel hy het ook sy mense. Dit is my behoefte en dit is bereikbaar. Die ouers en die "support" en die braai saam en die "baby sitting club", dit is almal heeltemal binne bereik.

- R: Jy het nou net iets genoem wat inskakel met die laaste vraag wat ek het, en dit is in verband met J se toekoms. As jy dink aan J se toekoms, waarheen hy op pad is... waarvoor spesifiek is jy as ouer bekommerd en ook, aan die ander kant, wat gee jou hoop vir hom en sy toekoms?
- F: Ek is bekommerd dat, as hy nou nie meer skool toe gaan nie, dat daai doelgerigheid in sy lewe weg is. Ek is bang dat hy nie meer sal weet hoe om homself besig te hou nie. Ek is bang ons het nie die goed om hom mee besig te hou nie. Ek sal graag wil hê dat hy moet inskakel, al is dit nou om 'n eenvoudige werkjie te doen, by Quest. Hulle wil nou so 'n ding by Quest begin. Dat hy weet hy staan in die oggend op en hy loop tot by sy werkjie, en daar is mense wat hom verstaan. En hy kom weer terug. Hy kan vir die res van sy lewe by my bly. Dit is nie vir my 'n "issue" nie. Dit is 'n "issue" in die sin van ek wil ook eendag onafhanklik wees en oorsee gaan en my ding doen en toer. Ek is meer 'n introvert en ek het uitgesien na die dag wat ek weer my huis vir myself het. As die kinders uit die huis uit gaan, maar nou weet jy dit gaan nooit gebeur nie. Ek hoop nog dit kan gebeur. Dit is die motivering waarom ek op die kommitte is om daardie eerste huis te begin. Ek glo dat dit dan vir J fantasties sal wees. Ek gaan ook sy naam by Lake Farm opgee. Ek voel ook dit is 'n oplossing vir J. Ek wil hê hy moet ook 'n lewe hê. Nie net ek en sy pa nie. Ek wil ook nie hê hy moet hom verveel nie. Ek bedoel, die huis gaan vir hom niks beteken nie. Kan jy jou voorstel hoe hy sy naels gaan afbyt of heelyd 'n video kyk of ... Ek hoop en bid elke oggend en aand en deur die dag dat hy net kan leer lees op 'n manier, al is hy ook 16 of 18. As 'n

mens kan lees, het jy ook al die helfte van jou dag om. Ek hoop ook... my positiewe ding is dat hy miskien eendag sal leer praat, om homself beter uit te druk. Ek hoop dat hy eendag sy geluide en geraas in so 'n mate kan hanteer dat hy saam met ons kan fliiek toe gaan en dat hy saam met ons kan kerk toe gaan en dat hy saam met ons kan gaan vakansie hou, sonder om uit mekaar uit te val. Ek sien tog dat daai goed kan gebeur. M, wat nou by Quest werk, is vir my 'n geweldige inspirasie. Hy is 45, en hy was erger as J. Vandag werk hy by Quest. Jy kan nie te veel druk op hom sit nie, maar hy doen al die afrolwerk en hy is verantwoordelik vir die hekke en hy doen die gras. En hy het 'n lewe. Hy bly steeds by sy ouers, maar hy is onafhanklik. Hy kry 'n geldjie. Ek het my vorige selfoon vir hom gegee. Ek betaal vir hom elke 6 maande, dan kry hy ook hierdie "Pay as you go". Hy SMS vir ons. Hy dink hy het vriende, maar hy het nie regtig vriende nie. Dit is hier in sy kop genoeg vir hom. Hy weet hy is anders en snaaks, maar hy kan al gaan vakansie hou alleen. Hy kan al toesprakies gee. Hy het daardie pragtige boek, Raaiselkind... toe het hy gaan praat en hy was deel van die opening, toe die vrou haar boek bekendgestel het. Hy praat fantasties. Ek kyk na hom, en ek weet tot op 21 het daai man 'n stokkie voor sy oë rondgeswaai en hy het begin praat op 16... dan is daar hoop. As daar 'n wonderwerk is, hoop ek my kind is eendag soos wat my ander kind is. As daar nie 'n wonderwerk is nie, dan hoop ek dat hy soos M kan word. Daar is definitief hoop. My lewe staan beslis nie stil nie. My vriende dink ons het 'n swaar lewe. As daar enigiets anders in ons lewe gebeur, dan sê hulle: 'Haai, shame. Hoe kan dit nou ook nog met julle gebeur?' Maar ek weet dat my ouers ook gaan doodgaan en my skoonouers en ek gaan ook by begrafnis moet gaan staan en dinge gaan ook maar met ons gebeur. Dit is die normale loop van die lewe. Die feit dat ek daardie kind gekry het, vrywaar my nie van die res van die dinge van die lewe nie. Ek sit daagliks in onderhoude met ouers van gestremde kindertjies en as hulle hoor dat ek ook maar deur dit gaan, dan is daar meer 'n gemaklikheid. En ek kan ook vir ouers makliker aanvat en sê: 'Luister, jy moet dit nou maar net doen!' Hulle kan nie vir my sê ek verstaan nie. Ek verstaan, maar die lewe is die lewe en jy moet dit nou maar doen. Jy moet jou kind versorg en ja dit is harder werk as die res van die mense, maar so het ek dit ook maar.

R: Baie dankie. Ek wil graag net die spasie daar stel... jy hoef dit nie te gebruik nie... is daar enigiets wat jy nog wil sê of wat jy voel ek het nie aan aandag gegee nie?

F: Nee, ek dink ons het alles "ge-cover".

R: Goed. Baie dankie vir jou bereidwilligheid om aan die navorsing deel te neem. Ek waardeer jou tyd en energie.

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## APPENDIX C: PARTICIPANT INFORMATION LETTER AND CONSENT FORM

### INFORMATION LETTER

#### Dear parent/grandparent/guardian

I am hereby requesting your participation in a research project that aims to explore how the primary caregivers of children with autism experience the diagnostic process, how they adjust and learn to cope after the diagnosis has been made, and what their primary needs and concerns are.

The challenges of raising children with autism have mostly been researched in Europe (predominantly England), North America, and Australia. One finding seems universal to all these studies: Among the childhood pathologies, autism occupies an extreme position in terms of its severity, duration and impact on the family. In South Africa, research in this field is relatively scarce. This study was therefore developed to provide information on the experiences of caregivers of autistic children in the South African context, which is characterised by limited resources and an increased need for home-based care for these special children. It is envisaged that the sharing of your unique experiences may lead to knowledge and understanding which, in turn, could inform helping professionals to develop intervention models and counselling programs that are sensitive to the unique needs of people such as yourself, who are responsible for the day-to-day care of a child with autism.

The study will be conducted under the auspices of the Department of Psychology at Rhodes University in Grahamstown. A postgraduate student in Clinical Psychology will carry out the research, and the research process will be closely monitored and supervised by a qualified Clinical Psychologist and member of staff at Rhodes University.

Your participation will take the form of three interviews (approximately 60 minutes each) with the researcher, who will ask you to share your experiences of:

- **Interview 1:** Raising a child with autism from birth, up to and including the period when your child was first diagnosed with autism.
- **Interview 2:** Adjusting and learning how to cope with the child's special needs after the diagnosis was made. What was helpful, and what hindered adjustment across various areas of functioning, such as the establishment of a daily routine, finding appropriate education, and dealing with the impact on other family members?

- **Interview 3:** The efficacy and shortcomings of available resources, specific needs that are not attended to by these resources, and the concerns that remain for you regarding your child's future.

Depending on your preference, these interviews will be conducted at your home, or on the premises of Quest School for Learners with Autism in Port Elizabeth. With your permission and written consent, the interviews will be audio taped. Your responses to the research questions will be kept strictly confidential, and individual responses will not be shared with the personnel of the school. The transcripts of all audiotapes will be coded, so that your name does not appear and the tapes will be destroyed at the completion of the research study. Identifying information will also be deleted or disguised in any subsequent publication of the research findings. Feedback regarding the major findings and recommendations of the study will be made available to you, on request.

Please note that you have the right to withdraw from the research project at any time, and that your decision to participate or not to participate will not affect your relationship with the school in any manner. Your help in this project will be greatly appreciated and could make a very important difference to other caregivers of autistic children in South Africa, who are in a similar situation as you.

If you are willing to participate in this study, **please complete and sign the attached consent form, and return it to your child's teacher by/before the end of this week.**

Thank you for your assistance.

Yours sincerely

**Yolandi Swanepoel (Researcher)**

**Deidré Matthee (Supervisor)**

**Date:** \_\_\_\_\_

## CONSENT FORM

**Dear Yolandi**

I agree to voluntarily participate in your research study about primary caregivers' experiences of raising children with autism. I understand that my responses will be reported in an anonymous manner, and that I have the right to withdraw from the study at any time, without affecting my relationship with the personnel of Quest School for Learners with Autism in any way.

I prefer that you conduct the interviews at **(Please tick the block of your preference)**:

1. Quest School in South End, Port Elizabeth	<input type="checkbox"/>
2. My private home	<input type="checkbox"/>

Preferred language in which interviews should be conducted **(Please tick the block of your choice)**:

1. English	<input type="checkbox"/>
2. Afrikaans	<input type="checkbox"/>

You may contact me at the following telephone number/s to arrange suitable times for us to meet:

Dialling code: \_\_\_\_\_ Telephone number: \_\_\_\_\_

Relation to learner at Quest School for Autism **(Please tick the appropriate block)**:

MALE		FEMALE	
Father	<input type="checkbox"/>	Mother	<input type="checkbox"/>
Grandfather	<input type="checkbox"/>	Grandmother	<input type="checkbox"/>
Uncle	<input type="checkbox"/>	Aunt	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	Other (please specify)	<input type="checkbox"/>

**Name (PRINT):** \_\_\_\_\_ **Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_