Exploring the Value of a Facebook Support Group for Parents of Children with Autism

by

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DECLARATION

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ABSTRACT

The worldwide increase in the diagnosis of autism, the immense pressure parents experience in raising a child with autism, as well as the accessibility of internet-based support, provided a unique opportunity to research parents' experiences in such an online community. Knowledge about their experiences, the value and meaning of an online support group in their daily lives, as well as which parents access online support, could shed light on how online communities could possibly be better utilised to provide instant and low-cost information and support to parents who are otherwise excluded from face-to-face support groups due to various constraints. Additionally, research about online support groups for autism in South Africa seems to be non-existent. This research could contribute significantly to the gap in knowledge about South African parents' experiences.

The aim of the study was to engage with South African parents participating in a Facebook support group in finding out what value (positive or negative) it adds to their lives and determining the meaning they ascribe to their participation in this group. This was a qualitative study based on a social constructionist theoretical framework as it is concerned with how every person's reality is shaped through social interaction with others, as well as through the historical and cultural influences in that person's life. Participants for this study were purposively selected and data was collected through observations of their exchanges within the Facebook support group, as well as through an electronic interview questionnaire. These interactions and correspondence were analysed using thematic analysis.

The research findings indicated the multifaceted role that the Facebook support group plays in the lives of each parent who participated. The amount of support they derived from the group and the value of the group depended on each parent's unique needs and experiences, as well as their unique interpretations of the interactions within the group. Their interactions within the group showed, however, that the group provided a platform where they were able to construct their own identities as autism parents as the experts of their children's lives, as well as advocates in the realm of autism. Their experiences were in line with international literature on online support groups.

Key words: autism; parents; Facebook; support groups; online support; social constructionism; discourse; advocacy; meaning-making

OPSOMMING

Die wêreldwye toename in die diagnose van outisme, die geweldige druk wat ouers ervaar om ŉ kind met outisme groot te maak, asook die toeganklikheid van internet-gebaseerde ondersteuning, het ŉ unieke geleentheid geskep om navorsing te doen oor ouers se ervarings in sodanige aanlyn gemeenskap. Kennis rakende hulle ervarings, die waarde en betekenis van ŉ aanlyn ondersteuningsgroep in hulle daaglikse lewens, asook watter tipe ouers aanlyn raad soek, sou lig kon werp op die onderwerp van hoe sulke aanlyn gemeenskappe moontlik beter aangewend kan word ten einde onmiddelike en goedkoop inligting en ondersteuning te bied aan ouers wat andersins uitgesluit word van kontak-ondersteuningsgroepe as gevolg van verskeie beperkings. Hierdie navorsing kan ŉ belangrike bydrae lewer tot die verbetering van die gebrekkige kennis oor aanlyn ondersteuningsgroepe vir outisme in Suid-Afrika. Hierdie navorsing kan grootliks bydra tot die gebrekkige kennis oor Suid-Afrikaanse ouers se ervarings.

Die doel van hierdie studie was om betrokke te raak by ouers wat deelneem aan ŉ Facebook ondersteuningsgroep ten einde vas te stel watter waarde (positief of negatief) dit toevoeg tot hulle lewens, asook om te bepaal watter betekenis hulle heg aan hul eie deelname aan die groep. Hierdie was ŉ kwalitatiewe studie gebaseer op ŉ sosiaal-konstruksionistiese teoretiese raamwerk, aangesien dit gemoeid was met hoe elke persoon se realiteit beïnvloed word deur sosiale interaksie met ander, asook die historiese en kulturele invloede in daardie persoon se lewe. Deelnemers aan hierdie studie was doelgerig gekies en data is deur waarneming van hul interaksie binne die Facebook ondersteuningsgroep versamel, asook deur ‘n elektroniese onderhoudsvraelys. Hierdie interaksies en korrespondensie is deur tematiese analise ontleed.

Die navorsingsbevindings het die veelkantige rol wat die Facebook ondersteuningsgroep in die lewens van elke deelnemer gespeel het, aangetoon. Die mate van ondersteuning wat elkeen uit die groep ontvang het, asook die waarde van die groep, was afhanklik van elkeen se unieke behoeftes en ervarings en elkeen se unieke vertolking van die interaksie binne die groep. Die ouers se interaksie binne die groep het egter aangedui dat die ondersteuningsgroep ’n platform daargestel het waar hulle hulle eie identiteite as outisme ouers, en kundiges oor hul kinders se lewens, kon konstrueer. Benewens dit was hulle ook kampvegters op die terrein van outisme. Hulle ervarings stem ooreen met internasionale literatuur rakende aanlyn ondersteuningsgroepe.

Sleutelwoorde: outisme; ouers; Facebook; ondersteuningsgroepe; aanlyn ondersteuning; sosiale konstruksionisme; diskoers; voorspraak; betekenis-making

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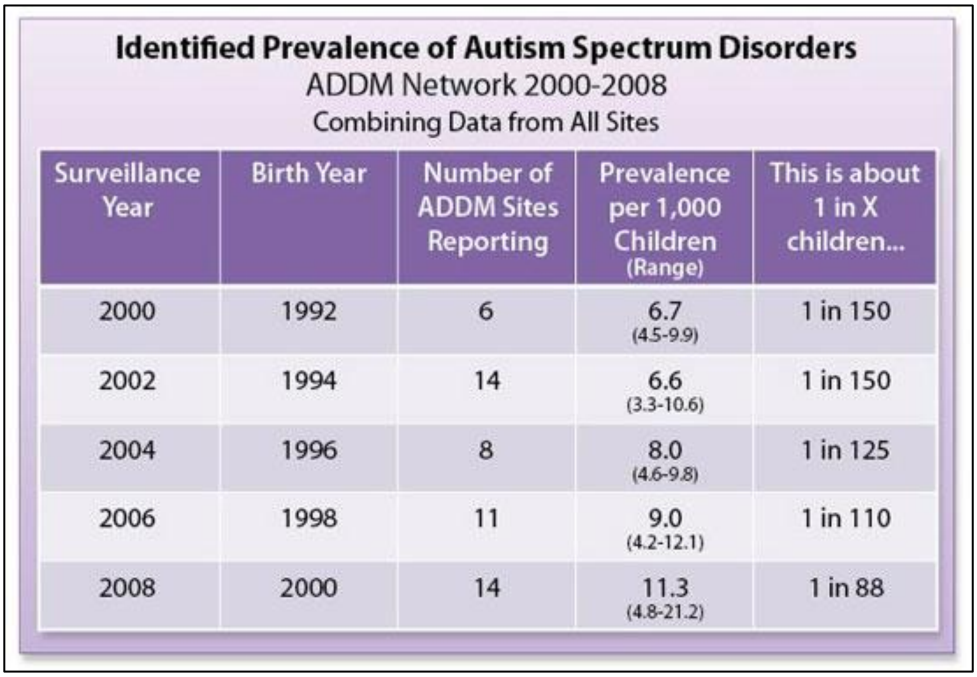
CONTEXT AND RATIONALE OF THE STUDY

1.1. INTRODUCTION

Autism is a complex disorder with currently no known cause. It does not distinguish between social class, race or religion. It is a disorder that can be diagnosed in any family, and the prevalence of autism is rising sharply, with the latest statistics from the *Centre for Disease Control and Prevention* (CDC) indicating that 1 in 88 children is diagnosed with autism (USA Government, 2012). Table 1 shows the rapid increase of the number of children in the USA, diagnosed from 2000 up till 2008.



Identified Prevalence of Autism Spectrum Disorders
ADDM Network 2000-2008
Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88

Table 1.1: Prevalence of autism (USA Government, 2012)

There are no official statistics available regarding the prevalence of autism in South Africa; however, two local authorities on autism have both indicated that South African statistics will be based on international statistics. The Association for Autism (2013) stated that “South Africa is presently making use of the international rate of prevalence as there are no known accurate local statistics in our own country.” In an email from Autism South Africa (personal communication, September 14, 2012), it was suggested that South African professionals in the field of autism also refer to the figures released by the CDC, as to minimise confusion regarding the prevalence of autism and to streamline South African statistics with international figures.

Autism is referred to as a pervasive developmental disorder. Pervasive comes from the Latin word *pervadere*, which means wide spread (De Clercq, 2006). Therefore, autism is a disorder that can affect all areas of a child or person's functioning. It is also a lifelong disorder, meaning it can never be outgrown or cured. Koudstaal (2011) defines autism as a "complex, variable, neurologically based […] disorder that influences both the development and the functioning of the brain." It is very important that this definition includes "variable", as autism presents differently in each person (Bishop, 2012; Welton, 2004; Williams, 1996).

Lorna Wing (Jordaan, 2006, in Koudstaal, 2011; Wing & Gould, 1979, in Seach, 1998) was the person who coined the term *triad of impairments*, referring to three distinct areas of functioning in which people with ASD experience difficulties. These are *communication and language*, *social interaction*, and *restricted interests and imagination*. It is often depicted as a triangle, such as in Figure 1.1. These three areas do not stand in isolation from each other. There is a definite reciprocal influence between all three areas, and thus the pervasiveness of ASD becomes quite clear: impairment in one of these areas will necessarily cause a degree of impairment in the other areas.

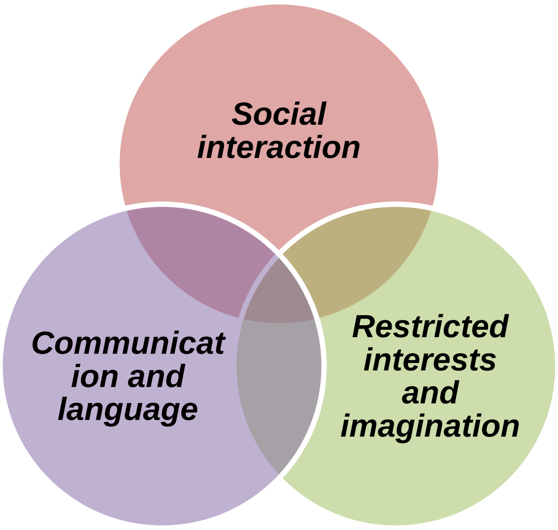


Figure 1.1: Triad of impairments

The characteristics of autism may vary in intensity and nature, from one end of a spectrum, being less severe in influence, to the other end of the spectrum where it has a much more severe impact on the person's life and functioning. Therefore it is classified according to the fourth and fifth editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a spectrum disorder (American Psychiatric Association, 2000; American Psychiatric Association, 2013). Some people with autism may present with many characteristics of autism, whereas others will present with fewer (Twoy, Connolly & Novak, 2007).

Autism has not only a profound impact on the person diagnosed, but also on his/her family (Welton, 2004; Williams, 1996). In an online blog, a parent straight-forwardly titled the blog-post "Autism sucks!", and goes on to describe what is perceived as normality:

> *No person that I know of has ever on hearing that they or their partner was pregnant, has wished for a special needs child. No father to be looks at his wife fondly and whispers, "I so hope it is a cerebral palsy child." No expectant mother caresses her bump and expresses the hope that the child growing there will be on the autistic spectrum. No, the hopes parents have are based on normality. The ten fingers and ten toes hope, embeds a hope, though often unstated, for typical cognitive development as well. The diagnosis comes as a blow. In the years following the birth, a suspicion may have been held, but a hope is maintained. And then the confirmation. Few people rail at the child – the diagnosis, which sucks, is not their fault, and the child itself does not suck.*
> (Woodcock-Reynolds, 2012)

Despite the drastic increase in the diagnosis of autism (Luther, Canham, & Young Cureton, 2005; USA Government, 2012), it remains "poorly understood" by the general public, possibly because of the seemingly normal appearance of a person with autism (Gray, 1993). Autism is often accompanied by behaviour that is frowned upon in public, such as tantrums, self-mutilation or inappropriate comments (Bishop, 2012; Higgins, Bailey & Pearce, 2005; Koudstaal, 2011; Twoy, Connolly & Novak, 2007). Gray (1993, p. 103) states that due to the seemingly normal appearance of a person with autism "parents of autistic children frequently encounter hostile or insensitive reactions from the public when their children behave inappropriately." Woodgate, Ateah and Secco (2008) published a paper on the experiences of parents of children with autism, with the main theme emerging as parents feeling as though they too are living in a world of their own, similar to their children: isolated from society and sometimes even their own families.

Interestingly, research indicates that symptoms of stress and depression are elevated in parents of children with autism compared to parents of children with other disabilities (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005, in Neely-Barnes, Hall, Roberts & Graff, 2011; Montes & Halterman, 2007; Olsson & Hwang, 2001; Sanders & Morgan, 1997, in Boyd, 2002; Sounders, DePaul, Freeman & Levy, 2002; Tunali & Power, 2002). Additionally, Sharpley, Bitsika and Efremidis (1997, in Boyd 2002) indicated that parents' levels of stress and depression concerning their child's autism are affected by the permanency of the disorder, negative perceptions from others about their child's behaviour and receiving little social support. South Africa is unfortunately faced with the reality of great poverty, with 52.3% of the population living on less than R577 per month (Statistics South Africa, 2012, p.5), which creates a gap in parents' access to specialised (and often costly) services necessary for early intervention, such as speech therapy and occupational therapy, as well as the extreme lack of appropriate school placement for children with autism. Personal correspondence with the psychologist at Vera School for Learners with Autism (which is responsible for managing the central waiting list database for all children with autism in the Western Cape) confirmed that the waiting list for placement of children with autism at various special schools in the Western Cape is approximately two years long (Goodwin, personal communication, February 25, 2013).

However, despite parents' perceptions about poor social support and understanding from family and the public, research has indicated that social support from other parents of children with autism has a positive impact on parents' coping abilities and levels of stress and depression (Luther, Canham & Young Cureton, 2005; Twoy, Connolly & Novak, 2007). McCabe (2008, p. 303) reported her findings on caregivers of children with autism that participated in a support group in China and stated in her article that "caregivers in this study discussed the value of being with other parents who share similar experiences. Two reasons were given for the importance of parent-to-parent support: to learn from each other, and to gain moral support and encouragement in a relationship that is more equal and less discriminatory than was experienced from others in society." However, access to support groups in the South African context is not available to all parents. The reality of poverty and rural communities, where services are limited, is faced by many. For parents with financial constraints, or living in rural areas, transport to attend support groups could become a problem (Huws, Jones, & Ingledew, 2001). Other issues to consider are single-parent households and the degree of the child's difficulties that can impact a parent's ability to find a willing person to look after the child while attending a support group meeting (Brady & Guerin, 2010; Huws, Jones, & Ingledew, 2001; Lamberg, 1996).

With technology advancing at a phenomenal rate, people are increasingly able to access alternative methods of support through social media networks on their phones and computers (Brady & Guerin, 2010; Huws, Jones, & Ingledew, 2001; Lamberg, 1996). Social media networks on the internet offer the immediacy of obtaining information either from professionals or people experiencing the same difficulties, as well as sharing experiences (Ahmed, Sullivan, Schneiders & McCrory, 2010; Aho, Paavilainen & Kaunonen, 2012; Baum, 2004; Bender, Jimenez-Marroquin & Jadad, 2011; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones & Ingledew, 2001; Gary & Remolino, 2000; Greene, Choudhry, Klabuk & Shrank, 2010; Lamberg, 1996; Meier, 1998). However, access to internet services in South Africa remains poor among the majority of citizens, as the results of Census 2011 indicate that 64.8% of households in the country have no access to internet, with only 16.3% of the population having access to the internet on their phones (Statistics South Africa, 2011, p. 12), thus excluding a large proportion of South African parents with children with autism from accessing online support communities.

1.2. MOTIVATION FOR THE STUDY

Judgement. Assumptions. Perceptions.

These three words have often come to mind when speaking to people about autism. It is a disorder misunderstood by many, which inevitably leads to judgement, assumptions and (mis)perceptions about the child with autism and his or her family (Gray, 1993; Gray, 2002; Neely-Barnes, Hall, Roberts & Graff, 2011; Woodgate, Ateah & Secco, 2008; Worcester, Nesman & Mendez, 2008). In most cases, however, the parents suffer the brunt of onlookers in public not understanding the reason for a child's excessive behavioural outbursts, such as screaming, crying, aggression to others or the self (often referred to as a melt-down) or otherwise strange behaviour, such as staring, hand-flapping, copying what other people are saying, making vocal sounds, asking inappropriate questions etcetera. Parents report to often being *judged* as unable to control their children, being the recipients of *assumptions* about their lack of instilling discipline, and ultimately witnessing *perceptions* being formed about them and their children without being granted the opportunity to explain the situation. The reason for such judgements, assumptions and perceptions is simply that the child with autism shows no outward signs of having any disorder, and thus no sympathy is granted from the public for socially unacceptable behaviour (Gray, 1993).

Being a teacher at a school for children with autism, dealing with parents and their daily experiences surrounding their child is part of my reality. However, not being a parent myself, and consequently also not a parent of a child with autism, I have often wondered where parents find support and how it helps them to cope with *their* realities. As such, I came upon a support group for parents of children with autism in South Africa on Facebook, an online social media network. With curiosity, I observed the information parents shared among themselves. It ranged from asking for advice about a myriad of topics on their children's behaviour and needs, or sharing positive and not-so-positive daily experiences with each other. It appeared as though they had created a safe space where judgment, perceptions and assumptions from the uninformed public did not have power over them; and more so, they created a support group that is accessible day and night with almost immediate and constant feedback.

This online support group intrigued me, and I wanted to know more about how they experienced their participation within this group, as well as the value or meaning that it added to their lives. Parents of children with autism experience much stress, depression, anxiety and isolation due to their child's condition (Boyd, 2002; Gray, 1993; Gray, 2002; Luther, Canham, & Young Cureton, 2005; McCabe, 2008; Montes & Halterman, 2007; Neely-Barnes, Hall, Roberts & Graff, 2011; Olsson & Hwang, 2001). Support groups have played a big role in providing a space/platform for parents to share their experiences with other parents in safe and understanding environments (Ahmed, Sullivan, Schneiders & McCrory, 2010; Aho, Paavilainen & Kaunonen, 2012; Baum, 2004; Bender, Jimenez-Marroquin & Jadad, 2011; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones & Ingledew, 2001; Gary & Remolino, 2000; Greene, Choudhry, Klabuk & Shrank, 2010; Lamberg, 1996; Meier, 1998), as well as learning coping strategies for themselves or behavioural interventions for their children (Luther, Canham & Young Cureton, 2005; McCabe, 2008; Twoy, Connolly & Novak, 2007). These support groups are usually held at specific intervals, for instance once a month, at a specified location. To attend such support groups holds some concerns and may pose a difficulty to parents of children with autism, as transport or baby-sitting services might not always be available to make it possible for the parents to attend (Brady & Guerin, 2010; Huws, Jones & Ingledew, 2001; Lamberg, 1996).

However, with the increasing accessibility of online social media platforms (Brady & Guerin, 2010; Huws, Jones & Ingledew, 2001; Lamberg, 1996), such as Facebook, I wanted to venture a tentative assumption that in future virtual support groups might be preferred over traditional support groups. Such groups are used by parents in a similar fashion as traditional support groups: sharing information, successes, struggles and experiences (Aho, Paavilainen & Kaunonen, 2012; Baum, 2004; Skinner & Latchford, 2006; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones, & Ingledew, 2001; Mandell & Salzer, 2007; Meier, 1998; Perkins & LaMartin, 2012; Sarkadi & Bremberg, 2005), but without the difficulty of arranging care for their children or the expense and logistical challenges around transport (Brady & Guerin, 2010; Huws, Jones & Ingledew, 2001; Lamberg, 1996). Internet support groups provide instant and immediate access to information or advice (Huws, Jones, & Ingledew, 2001; Meier, 1998), yet it has to be considered what type of parent accesses support services. The literature indicates that it is most often mothers who seek out support services (Baum, 2004; Mandel & Salzer, 2007; Sarkadi & Bremberg, 2005). However, there is a discrepancy in reported findings of the level of education and socio-economic status of such mothers. Mandel and Salzer (2007) and Baum (2004) indicate that higher levels of education as well as middle to higher socio-economic backgrounds correlate with support seeking behaviour, whereas Sarkadi and Bremberg (2005) found in their study based in Sweden that parents from lower socio-economic backgrounds accessed online support more often, and the level of education of the participants was not significantly lower than that of the general population.

1.3. PROBLEM STATEMENT: NEED FOR THIS RESEARCH

The worldwide increase in the diagnosis of autism (Luther, Canham & Young Cureton, 2005), the immense pressure parents experience in raising a child with autism (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005 cited in Neely-Barnes, Hall, Roberts & Graff, 2011; Boyd, 2002; Sanders & Morgan, 1997 cited in Boyd, 2002; Montes & Halterman, 2007; Olsson & Hwang, 2001; Sounders, DePaul, Freeman & Levy, 2002; Tunali & Power, 2002), as well as the accessibility of internet-based support groups (Aho, Paavilainen & Kaunonen, 2012; Baum, 2004; Skinner & Latchford, 2006; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones, & Ingledew, 2001; Mandell & Salzer, 2007; Meier, 1998; Perkins & LaMartin, 2012; Sarkadi & Bremberg, 2005), all create a unique opportunity to research parents' experiences in such an online community. Knowledge about their experiences, the value and meaning of an online support group in their daily lives, as well as which parents access online support, could shed light on how online communities could possibly be better utilised in providing instant and low-cost information and support to parents who are otherwise excluded from face-to-face support groups due to various constraints. Additionally, research about online support groups for autism in South Africa seems to be non-existent. This research could contribute significantly to the gap in knowledge about South African parents' experiences.

1.3.1. Aims of the study

The aim of the study was to engage with South African parents participating in a Facebook support group to find out what value (positive or negative) it adds to their lives and to determine the meaning they ascribe to their participation in this group.

My objective was to explore the reasons for their participation, their reasons for sharing information with the group, and the nature of their engagement with the group. An additional aim was to analyse the demographic composition of the participants in order to understand their motivation for joining an internet support group, and to gain some understanding of the accessibility of this mode of support. Demographic information might also be useful in determining which parents access online support as a means of comparing it to international findings, as well as opening up possibilities for future research on how parents who are excluded from online support communities can be reached.

1.3.2. Research questions

In order to achieve the aims stated above, the following questions were intended to guide my inquiry:

> *What value do parents of children with autism who participate in an online social media support group, attach to their participation in the group?*

The following sub-questions were aimed at adding to my understanding of the parents' experiences:

> *What were their reasons for joining this online source of support?*
>
> *How does their participation contribute to their meaning-making of their daily experiences regarding their child's diagnosis?*
>
> *What is the nature of the information shared among parents in this group?*
>
> *How does their participation contribute to their coping skills and their identities as parents?*

1.4. THEORETICAL FRAMEWORK

In order to conduct research, the researcher needs a foundation from which to build, otherwise the research could come across as ungrounded or unsupported. Critics might question its authenticity and argue that it is not scientific if the researcher has no basis for conducting research. The theoretical framework of a study serves as its foundation by grounding it in a specific theory, and giving direction and meaning to the research process (Merriam, 2009, in Megaw, 2011).

Social constructionism is the foundation upon which my research was based as it is concerned about how every person's reality is shaped through social interaction with others, as well as through the historical and cultural influences in that person's life. Terre Blanche and Durrheim (1999, in Adams, Collair, Oswald & Perold, 2004, p. 356) define research from the social constructionist viewpoint as being "about interpreting the social world as a kind of language, as a system of meanings and practices that construct reality. The way in which people interact with the world is structured by the ruling discourses of the time and context." Within the context of the Facebook support group, social constructionism relates to how these parents' interactions in the group give meaning to their lives in a way that society might not necessarily allow them, thus adding some kind of value to their daily experiences and possibly contributing to the creation of identities as parents of children with autism.

Social constructionism as the theoretical framework for this research is discussed in greater depth in Chapter Two.

1.5. RESEARCH PARADIGM

Whereas the theoretical framework serves as the foundation informing the research questions and making sense of the findings, the research paradigm informs the researcher's understanding of the nature of knowledge, how it can be accessed and how the research questions can be answered (Terreblanche & Durrheim, 2006). Merriam (1998, p. 5) states that one's paradigm is synonymous with the way one views the world, and that a research project should start "with examining your own orientation to basic tenets about the nature of reality [and] the purpose of doing research." I have found that an interpretive constructivist paradigm underpins my worldview, as it supports my belief that people make meaning from their own experiences in unique ways (Adams, Collair, Oswald & Perold, 2004; Terreblanche & Durrheim, 2006). Their experiences cannot be objectively quantified; thus a qualitative approach is best suited where the researcher engages with the research-participants to gain insight into their meaning-making processes. Krauss (2005, p. 759-760) states that "for many qualitative researchers, the best way to understand what is going on is to become immersed in it and to move into the culture or organisation being studied and experience what it is like to be a part of it."

1.6. RESEARCH PROCESS

The process of conducting research links to the researcher's theoretical framework, as well as the research paradigm. These two cornerstones of research determine what is to be researched, how it will be researched, as well as the way the data will be analysed and interpreted (Megaw, 2011). Below is a description of the research process.

1.6.1. Methodology

A qualitative study was conducted from an interpretative constructivist paradigm to attempt to answer the research questions stipulated. According to Adams et al. (2004, p.365) "qualitative methodology aims at providing a comprehensive description of a specific phenomenon rather than the testing of hypotheses common to experimental research methods. An effort is made to understand situations in their uniqueness as part of a particular context and the interactions within the context under study."

1.6.2. Research design

The research which I conducted was designed on the model of a case study, stipulated by Merriam (2009) as focussing on a bounded system where a specific phenomenon is of interest to the researcher. The experiences of parents (phenomenon) participating in a particular support group on Facebook (bounded system) was the focus of the study. Due to ethical considerations of anonymity the name of the group cannot be revealed, and will hereafter be referred to as the Facebook support group. During the time that the research was conducted, there were more than a 100 members in the group, consisting mostly of parents and caregivers of children with autism. Even though most of the members in the group are parents and caregivers of children with autism, there are other members, such as myself and a variety of therapists, who do not have children with autism, but participate in the group by sharing information pertaining to therapeutic strategies. The majority of the members are female.

1.6.3. Participant selection

Seeing that my goal was to explore the value of a Facebook support group for parents of children with autism, participant selection was purposeful, meaning that this group was selected with a specific purpose in mind: “to discover, understand, and gain insight” (Merriam, 2009, p. 77) into their experiences. For the intent of this study, only parents of children with autism participating in this support group who were willing to partake in the study were included in the research population. Thus participant selection can also be viewed as voluntary.

1.6.4. Methods

The members of this group ascribe their own meanings and values to their participation in this support group, and through the means of open-ended electronic questionnaires as well as non-participant observations of the “posts” in this group, my hope was to gain understanding into their motivation to participate and the value that it entails for them. Furthermore, the members of this support group are located around the country, thus electronic interviews were conducted via e-mail correspondence. Participants were able to answer the initial open-ended questionnaire, which was later followed up by giving them an opportunity to provide feedback about the interpretations of the research data. Participants were also informed that their participation in the Facebook group was observed and recorded to confirm and substantiate the data they supplied; however, only with their informed consent. All members of the group were informed that information shared by members of the group who did not wish to participate in the study was not included in the research.

1.6.5. Data analysis

The participants' answers from the electronic interviews, as well as their interactions within the Facebook support group comprised my research data. The method of data analysis that was used, in order to answer my research questions, was thematic analysis, which resonates with my view of how knowledge is produced or constructed and thus seemed to be a good match to this research. Thematic analysis takes into account that the researcher plays an active role in thinking and reflecting about the data that is captured throughout the research, and thus has an impact on which themes are chosen for analysis, as well as how these themes are interpreted (Braun & Clarke, 2006).

A statement made by Maykut and Morehouse (1994, from QDATRAINING Admin, 2012) underpins my theoretical framework and supports the chosen data analysis:

> *Words are the way that most people come to understand their situations; we create our world with words; we explain ourselves with words; we defend and hide ourselves with words […] The task of the researcher is to find patterns within those words and to present those patterns for others to inspect while at the same time staying as close to the construction of the world as the participants originally experienced it.*

In other words, my interpretation of the data was also shared with the participants to get their feedback about the accuracy of my interpretations, and thus added more depth to the quality of the research.

1.6.6. Trustworthiness

Two constructs that are synonymous with scientific research are reliability and validity. A study is *reliable* if it can be repeated in a similar setting and yields the same results, whereas a study is *valid* if the results reflect what was intended to be measured (Andersen & Taylor, 2004; Merriam, 2009). However, this seems to be a contentious issue in qualitative research, seeing that quantitative and qualitative paradigms have differing opinions about what constitutes reality (Merriam, 2009), and ultimately affecting what will be studied, how it will be studied and what conclusions will be drawn from the results of the study. Consequently, qualitative research necessitates a shift in how reliability and validity can be ensured. Guba and Lincoln (1985, in Merriam, 2009; Babbie & Mouton, 2001; Trochim, 2006) proposed alternative criteria to ensure the trustworthiness (Babbie & Mouton, 2001) of a qualitative study, namely *credibility*, *transferability*, *dependability* and *confirmability.*

Credibility refers to the extent that the results of a study reflect the realities of its participants (Trochim, 2006), in other words, how true are the findings of a study to them (Babbie & Mouton, 2001). *Transferability* looks at the possibility of generalising the results of a study to other contexts, however, I caution against this notion as I am worried readers might interpret *transferability* in the same sense as *reliability* from a quantitative perspective. The aim of this study was not to recommend a repeat of exactly the same process, hoping for the same results (as it would be in a quantitative approach), but instead giving such a rich description of the context of the research and the results of the study (Babbie & Mouton, 2001; Merriam, 2009) that readers are able to judge for themselves if a similar study could be conducted elsewhere. *Dependability* refers to how accurately the results of a study match the data that was collected (Merriam, 2009), and it is up to the researcher to ensure that "given the data collected, the results make sense" (Merriam, 2009, p. 221). Lastly, *confirmability* refers to how closely the results of a study link to the initial purpose of the research (Merriam, 2009). This can be achieved through leaving an "audit trail", such as raw data, reduced data, process notes and interview schedules (Babbie & Mouton, 2001; Merriam, 2009; Trochim, 2006) for others to check and confirm whether or not researcher biases (Merriam, 2009) have influenced the research process.

I would like to add an additional criterion to ensure trustworthiness, namely *crystallisation.* Richardson (2000, in Merriam 2009 and Ellingson, 2009) states that qualitative research assumes as a basis that there are multiple ways of viewing the world, not just on the part of its participants, but also on the part of the researcher. In effect it will thus determine how research is conducted. Just as a crystal consists of many angles, so should a qualitative researcher view the world from various angles to ensure the trustworthiness of the data (Richardson, 2000, in Ellingson, 2009, p. 3). Cohen and Crabtree (2006) clarify this by explaining that the qualitative researcher should immerse him/herself in the data analysis process, but also alternate this with a reflective phase (referred to as crystallisation) by "temporarily suspending the process of examining or reading data (immersion) in order to reflect on the analysis experience and attempt to identify and articulate patterns or themes noticed during the immersion process."

1.6.7. Ethical considerations

I view ethics as a researcher's moral and professional responsibility towards participants in a study, by ensuring that certain measures are put in place to respect and protect their wellbeing and human rights. Patton (2002, in Merriam, 2009, p. 233) provides a checklist that qualitative researchers can consider to ensure ethical conduct:

1. *Explaining the purpose of the inquiry and the methods to be used*, thus ensuring that the participants know exactly what will happen;
2. *Promises and reciprocity*, by doing what one promises to do and giving feedback about the research;
3. *Risk assessment*, which determines the level of risk the research poses to the participants;
4. *Confidentiality*, to protect the participant's identity by using pseudonyms and ensuring that no other identifying information is present in the published research;
5. *Informed consent* is obtained through being transparent about the purpose and goal of the research, as well as ensuring voluntary participation;
6. *Data access and ownership* is the researcher's ethical responsibility by ensuring that any research data is safely protected to safeguard against unauthorised access, as well as clarifying to the participants who has ownership of the data;
7. *Advice* throughout the research process is ensured through regular supervision with an experienced researcher.

Doing research in online communities, such as Facebook, is relatively new and as such, regulations around ethical conduct are not as clear as with traditional research methods (Brownlow & O'Dell, 2002). Sharf (1999, in Brownlow & O'Dell, 2002, p. 690-691) proposed five guidelines that pertain specifically to confidentiality and privacy when doing research in online communities:

> 1. *Before starting an investigation and throughout the duration of the study, the researcher should contemplate whether or not the purposes of the research are in conflict with or harmful to the purpose of the group. Conversely, the researcher should consider whether the research will benefit the group in some way, e.g. helping to legitimise the group's function.*
> 2. *The researcher should clearly introduce himself or herself as to identity, role, purpose and intention to the on-line group or individuals who are the desired focus of the study.*
> 3. *The researcher should make a concerted effort to contact directly the individual who has posted a message that he or she wishes to quote in order to seek consent.*
> 4. *The researcher should seek ways to maintain openness to feedback from the e-mail participants who are being studied.*
> 5. *The researcher should strive to maintain and demonstrate a respectful sensitivity toward the psychological boundaries, purposes, vulnerabilities and privacy of the individual members of a self-defined virtual community, even though its disclosure is publicly available.*

The ethical considerations as it pertained to this study will be discussed in greater depth in Chapter Three.

1.7. DECLARING MYSELF AS RESEARCHER

Merriam (2009) points out an additional measure to ensure *credibility* in qualitative research, which is declaring one's position as a researcher. Guba and Lincoln (2000, in Merriam 1998, p. 219) call it "reflexivity" and Merriam (2009, p. 219) clarifies this with the following statement:

> *Investigators need to explain their biases, dispositions, and assumptions regarding the research to be undertaken. Even in journal articles authors are being called upon to articulate and clarify their assumptions, experiences, worldview, and theoretical orientation to the study at hand. Such a clarification allows the reader to better understand how the individual researcher might have arrived at the particular interpretation of the data.*

As explained in sections 1.4 and 1.5 my theoretical framework (social constructionism) and worldview (constructivist interpretivist paradigm) guided my inquiry and streamlined the research process. However, I felt it necessary to declare who I am as a researcher, seeing that my own experiences, history and background shaped me in a different way to any other person, thus relating back to social constructionism of differing realities. My reality and who I am as a researcher necessarily had an influence on the way the data collected from this study was interpreted.

I am a female in my late twenties with a qualification and experience in special needs education. I grew up in a middleclass household where computer technology was very much part of my daily life, and I view myself as being part of a generation where social media, such as Facebook, forms part of our daily experiences. It is a technological mechanism of sharing these experiences to a virtual audience, often with instant feedback as a consequence. It is very much a social community where one's behaviour is kept in check by the reactions of others: positive feedback from others creates in me a sense of well-being or accomplishment, and encourages me to continue sharing similar experiences, but negative feedback has an opposite effect because I am then inclined to avoid sharing information for fear of being embarrassed or ridiculed. A more detailed description of Facebook follows in section 1.8. Being familiar and comfortable with using Facebook, as well as having the financial means to access the internet, I accept it as part of my reality. My reality as a person, however, shapes my view as a researcher and sparked a curiosity in me to discover how a medium such as Facebook is utilised as a support structure, seeing that sensitive (and sometimes not so positive information) is shared within a support group, how this is dealt with by individual members of this support group and who is able to access such support.

1.8. EXPLANATION OF THE USAGE OF CERTAIN TERMS

This section serves to clarify certain terms that will be used throughout this thesis.

1.8.1. Autism

The term *autism* used throughout this thesis will refer to Autism Spectrum Disorder to take into consideration the broad spectrum that autism presents as discussed in section 1.1. In the introduction, I use the term “people with autism” to refer to all people (children and adults) diagnosed with the disorder, as the introduction serves to highlight the disorder and its characteristics, instead of age. However, the research will focus on parents with children with autism, and as such, the term child or children with autism will be used. Furthermore, I will use the term “person with autism” or “child with autism” where it is my own writing, unless a source that I quote from directly refers to “autistic child” or “autistic person.”

1.8.2. Parent

“Parent/s” in this context, unless otherwise specified, will refer to a parent or parents (whether biological or adoptive) or guardian of a child with autism.

1.8.3. Support group

In this thesis, the term support group will refer to a physical or online gathering of people seeking support from like-minded people for various conditions that they have difficulty with.

1.8.4 Facebook

Facebook is an online social network where users can share information with others in a variety of ways. Firstly, a user has to create a personal profile which includes identifying particulars such as a profile picture, their name, age, gender, relationship status, occupation and education. Each user can then add people to their profile by inviting them as a “friend” and share information through “updating” their status, “posting” photos, “posting” a comment on a friend’s or a group’s “wall”, or commenting on someone else’s “post”.

A *status update* informs your friends what you are thinking, feeling or doing at a particular moment. Your status update can also be accompanied by a photo to illustrate your point, which refers to “*posting a photo*” as stated above.

A person's personal profile or the profile of a group (such as the Facebook support group referred to in this thesis) is known as a *wall*, where others can write public messages, called *posts*. These *posts* are visible to others, and also make it possible for others to *comment* on these posts, in other words, leave their own opinions, thoughts or ideas; however, people can also send *private messages* to one another which are not visible to the public.

Below is a visual depiction of my own personal profile to illustrate the mentioned concepts:

Karin Gerber (Karin Coetsee)

Teacher at Vera School for Learners with Autism

Studies Educational Psychology at Stellenbosch University

Lives in Durbanville

From Pretoria, South Africa

Married to Werner Gerber

What's on your mind?

One week to go girls :D Sien julle AMPER* — with and 4 others.

You and like this.

Write a comment...

Figure 1.2: Facebook profile page

1.9. CONCLUSION

This chapter serves as a broad overview of the research project in its entirety. An introduction was given to the nature of autism, its impact on parents, and the use of a Facebook support group for South African parents of children with autism.

Furthermore, I stated the theoretical framework and research paradigm that provides the foundation for this research, and clarified the research methods as well as a range of ethical considerations that were taken into account. The next chapter will provide a more in-depth discussion of social constructionism, autism, support groups in general, as well as the uniqueness of an online support community, such as the Facebook support group that is the focus of this research.

CHAPTER 2
LITERATURE REVIEW

2.1. INTRODUCTION

The research process comprises of many different facets. One of the first aspects looked at during this process is a review of the literature in order to provide a comprehensive context in which the research is based (Kaniki, 2006; Mertens, 2005).

The literature review will firstly focus on a description of modernism and postmodernism, in order to provide context for the chosen theoretical framework of social constructionism for this research. Thereafter, social constructionism will be discussed in greater depth with regards to the process of meaning-making through interaction with others, as well as the role that dominant discourses play in the construction of problem-saturated identities. This will be followed by a section on the history of autism and the evolution of its diagnostic criteria throughout the various published DSM's, as well as the concept of parenting as a means to clarify why parents of children with autism experience stigmatisation from society. In conclusion, the theories upon which the concept of support groups were based are discussed, which is then linked to the role of social media and online support groups.

2.2. MODERNISM AND POSTMODERNISM

It is often necessary to scrutinise what one takes for granted, in order to understand it fully. To me it is almost unimaginable that human behaviour and meaning-making could be viewed in any other way than from the social constructionist perspective. However, this theoretical perspective evolved over time from various scientific, psychological and philosophical orientations regarding people and what constitutes human behaviour. According to Gergen (1985, p. 269) two opposing philosophical world views shaped scientific and psychological opinions about the source of knowledge, namely the *exogenic* versus *endogenic* perspectives. The *exogenic perspective* poses that knowledge exists outside of people in the real world. Therefore, there is one objective reality shared by everyone (Freedman & Combs, 1996). It can then be concluded that human behaviour is influenced by one shared reality, and can thus be studied objectively. The exogenic perspective could be seen as the foundation upon which modernism was based, as modernism is concerned with rules, structure, facts and objectivity (Greer, 2001; Martin & Sugarman, 2000). In a sense, the expectation of people is thus to fit into one mould of what reality is supposed to be. This supposed reality that everyone experiences similarly is sustained by dominant discourses. One such dominant discourse is the nature of normality, because human behaviour that fits into the dominant discourse (or mould as I referred to above) of what is acceptable in society, is seen as normal (Andersen & Taylor, 2004). Behaviour that does not fit into that mould is dubbed abnormal. As such, the role that the DSM IV-TR (2000) and the current DSM V (2013) play in continuing the discourse around normal and abnormal behaviour, specifically related to autism, is discussed later in this chapter.

In contrast, the *endogenic perspective* places the source of knowledge within people. In other words, “humans harbour inherent tendencies, it is said, to think, categorize, or process information, and it is these tendencies (rather than features of the world itself) that are of paramount importance in fashioning knowledge” (Gergen, 1985, p. 269). The endogenic perspective thus recognises people’s abilities to interpret and construct their own realities based on the way they experience the world differently from others, but also in relationship with others, which is synonymous with postmodernism. As a metaphor for postmodernism, I imagine a person boxed up in a container, who then breaks free from the constraints of that structured world, into a world with infinite possibilities. From a postmodern perspective, dominant discourses about normality and abnormality can be deconstructed (Babbie & Mouton, 2001; Burr, 2000; Crowe, 2000; Freedman & Combs, 1996; Gergen, 1985; Kenny & Shevlin, 2001; Krauss, 2005; Solvang, 2000; White, 1990) which opens up countless avenues for constructing alternative realities, alternative meanings, and alternative identities that are separate from what mainstream ideologies could have imposed on people.

This has many implications for parents that utilise support groups and social media, as amongst themselves they are continually making new meanings of various experiences they are faced with: autism; being a parent; being a parent of a child with autism; having a voice in the world or perhaps *not* having a voice in the world. Accordingly, it led to a realisation about the importance of social-constructionist theory when exploring the experiences of parents with children with autism as they participate in an on-line support group.

2.3. SOCIAL CONSTRUCTIONISM

Although Terre Blanche and Durrheim (1999, in Adams, Collair, Oswald & Perold, 2004, p. 356) highlight the social constructionist viewpoint as being "about interpreting the social world as a kind of language, as a system of meanings and practices that construct reality", this conceptualisation also describes the way human beings in general make sense of and understand the world. The way this sense-making occurs, is through "the way in which people interact with the world [which] is structured by the ruling discourses of the time and context" (Terre Blanche & Durrheim, 1999, in Adams, Collair, Oswald, & Perold, 2004, p356). There are many different definitions of the term discourse. One such definition is offered by Hare-Mustin (1994, p. 19) as being "a system of statements, practices, and institutional structures that share common values." Winslade and Monk (2007, p. 29) in turn refer to discourses as "clusters of taken-for-granted assumptions that lie just beneath the surface of many conversations in a particular social context." Yet, another definition is from Burr (2003, p. 64) which states "a discourse refers to a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of reality." It would seem as though discourses can be understood as those linguistically produced statements which people take to be absolute truths. This ensues because of what is suggested through everyday language-based practices such as culture, religion, politics and history. One's context, and as such, one's sense of identity, is shaped through taken for granted truths about where one comes from (one's history), what religious practices one is supposed to adhere to, what one's culture suggests to be normal and abnormal behaviour, as well as the current political climate that impacts on one's life (Assarsson & Aarsand, 2011; Foucault, 1988). Such influences that impact on the way one makes sense of oneself is not often deconstructed, and therefore I refer to it as taken for granted truths. Unfortunately, such taken for granted ideas and conceptualisations about oneself, based on ruling or popular discourses, can cause significant distress when one is faced with a situation or condition that does not fit with one's current sense of identity. As such, parents conceptualise (construct) identities for themselves as parents, based on what the ruling discourses of their context, religion and culture suggest a parent should be (Assarsson & Aarsand, 2011; Caplan, 2009; Harkness & Super, 2002;). With the diagnosis of a disability, such as autism, a conflict may arise between the parents' previously constructed sense of identity and their current experience of being the parent of a child with autism (Avdi, Griffin & Brough, 2000; Farrugia, 2009; O'Brien, 2007). However, such newly constructed meanings are not produced in a vacuum. Instead, it occurs within an interactive environment where parents consult specialists, the internet, books, other parents, and so many other sources, to make sense of their experiences – it is at once an internal and external process, because sense-making occurs on an emotional and cognitive level within one's mind based on external information (Beck, 2011). Participating in a support group can be but one of many ways that contributes to parents' processes of constructing different meanings for themselves which are congruent to their experiences.

Therefore, social constructionism seems to be an explanatory theoretical approach through which to understand the ways that parents of children with autism think about themselves, and how their realities are shaped through social interaction. I refer to *realities* specifically because that is the essence of social constructionism: it disregards the notion of one objective truth or reality for all people, and instead takes a stance of multiple realities being created by people who share their lived experiences with each other (Burr, 2000; Freedman & Combs, 1996; Gergen, 1985; White, 1990), in this case the parents of children with autism participating in a Facebook support group. Social constructionism relates to the phenomenon that these parents' interactions with other parents, professionals and interested parties in the Facebook support group might give meaning to their lives in ways that are different, and maybe preferable, to the identities they develop based on the interactions with the broad society. Thus some kind of value may be added to their daily experiences which may possibly contribute to creating preferred identities as parents of children. Discourses on autism are often based on insufficient information, or even misinformation. Such discourses on autism, as well as on what parenting is, or ought to be, how children ought to behave, etcetera, might lead to parents of children with autism to think of themselves in problem-saturated ways (Gray, 1993; Gray, 2002; Neely-Barnes, Hall, Roberts & Graff, 2011; Woodgate, Ateah & Secco, 2008; Worcester, Nesman & Mendez, 2008;). In a support group, however, they are potentially free from the judgements of people who do not know and understand autism. As all of the participants know intimately what being a parent of a child with autism means, reciprocal understanding and support might be possible. However, social constructionism refers to a reciprocal process of meaning-making (Freedman & Combes, 1996), which could lead to a variety of understandings of reality and meaning, both negative and positive. The specific context of a support group implies a group of like-minded people, striving towards appropriate knowledge and empathic understandings of one another's lived experiences. Literature on support groups as such, will be described in more detail in section 2.4.

Social constructionism can be seen as a discourse in its own right, as it describes and understands the nature of reality differently than some other theories. Seeing that social constructionism views reality as fluid instead of fixed, Freedman and Combs (1996, p. 22) stipulated four ideas that inform social constructionist discourses that are important to keep in mind when viewing the language-based communications of parent participants in this study, namely, the assumption that "realities are socially constructed, that realities are constituted through language, that realities are organised and maintained through narrative, and finally that there are no essential truths" (Freedman & Combes, 1996, p16).

Thus, the way people make meaning of their worlds and what essentially constitutes their realities are based on their frames of reference, which are based on their experiences and language used within society. Each person attributes different meanings to what other people say, with the possibility for multiple realities which may exist. Adding to the above mentioned ideas about reality, Burr (2000) relates social constructionism to another four aspects that I find particularly applicable to the realities of parents of children with autism participating in support groups.

Firstly, every person experiences reality differently, and as such, no one objective truth about life and its meaning exists (Burr, 2000). The reality of each parent participating in a support group might be different, seeing that their children are all unique, and they as parents themselves are all unique. Their individual opinions and their daily experiences differ, and consequently shape the meaning they make of who they are and where they belong in the world. This might be tricky for parents of a child with autism, as these meanings could become problem-saturated versions of who they are, and not their preferred narratives of identity.

Secondly, the ways in which people give meaning to their experiences are linked to culture and history (Burr, 2000; Foucault, 1988). Different discourses around parenting abound in different environments or societies (Assarsson & Aarsand, 2011). The difficulties associated with being a parent of a child with autism could relate to the demands that society may place on parents – they are expected to discipline their children for unruly behaviour, and children in turn are expected to respect their elders. These societal demands have not appeared out of nowhere, but instead have been sculpted over hundreds of years by historical, cultural and religious beliefs about the identities of parents and children. Assarsson and Aarsand (2011, p. 81) refer to this as “discursive practices” which sustain certain ideas of what it means to fulfil specific roles in society, such as being a parent or a child:

> *Discursive practices produce certain positions for subjects to assume, and being part of a discursive practice means speaking as a particular kind of subject. As adults, we participate in several activities and settings every day, like being partner, employee, friend, sister and parent.*

Failing to conform to society’s idea of what a parent should be, can have dire consequences. Parents of children with autism may experience the reality of parenthood considerably differently, seeing that the unusual behaviour of their children is frowned upon in public, resulting in feelings of being isolated and stigmatised (Neely-Barnes, Hall, Roberts & Graff, 2011; Woodgate, Ateah & Secco, 2008; Worcester, Nesman & Mendez, 2008). Even the history about autism, and its diagnosis, have created certain discourses about parenting, as discussed later in section 2.3.1. Characteristics of autism which might attract negative attention to parents and their children with autism will be discussed in section 2.3.3.

Thirdly, knowledge about the world is created and sustained through social interaction, based in language (Burr, 2000). Burr (2000, p. 4) cannot state it any better when she explains that “it is through the daily interactions between people in the course of social life that [their] versions of knowledge become fabricated. […]. The goings-on between people in the course of their everyday lives are seen as the practices during which [their] shared versions of knowledge are constructed.” Utilising digital technology and social media like Facebook, Twitter, as well as blogs, provide platforms where interpersonal communication, and thus social interaction, occurs through mainly linguistic means. Experiences can be shared by posts, comments on other’s posts and other visual signs or means which may form part of the specific digital space’s rules and media. Thus, different kinds of conversations are possible, and therefore provide the potential for the construction of different meanings, identities or realities.

Lastly, the meanings that people make of their experienced realities, through interaction with others, necessitate some form of action (Burr, 2000). People are not passive in the way they make meaning of their daily experiences. Instead, the meanings they derive from daily experiences, motivate their actions and reactions (Beck, 2011; Burr, 2003). Through interacting with parents who have similar experiences of parenting a child with autism, on a social media platform, by posting comments and questions, the parents might gain understanding and knowledge from one another’s experiences.

Freedman & Combes (1996, p. 16) summarise the premise of social constructionist thought as the fact that “the beliefs, values, institutions, customs, labels, laws, division of labour, and the like that make up our social realities are constructed by the members of a culture as they interact with one another from generation to generation and day to day.” These socially constructed realities become the “lenses” through which we view our lives and which provide the “beliefs, practices, words, and experiences” which constitute our identities (Freedman & Combes, 1996, p. 16).

The next section of the chapter will cover the literature on autism regarding its history, the evolution of diagnostic criteria throughout the various publications of the

DSM, specific characteristics of autism, as well as parenting in general and with regards to autism.

2.4. AUTISM

With the dramatic increase worldwide in children being diagnosed with autism (Luther, Canham, & Young Cureton, 2005; USA Government, 2012), and the impact it has on a family that receives the diagnosis (De Clercq, 2006; Gray, 1993; Huws, Jones & Ingledew, 2001; Luther, Canham & Young Cureton, 2005; McCabe, 2008; Montes & Halterman, 2007; Randall & Parker, 1999; Seach, 1998; Wing, 1996; Woodgate, Ateah & Secco, 2008), it is necessary to look at how the understanding of autism has evolved over the last few decades.

2.3.1. History of autism

Paul Eugen Bleuler, a Swiss psychiatrist, first coined the term “autism” in 1910, derived from the Greek word *autos* meaning *self*, in an attempt to describe the symptoms of schizophrenia (Exkorn, 2009; Lyons & Fitzgerald, 2007). Leo Kanner, however, first used the term “autism” as it is currently understood in 1943 when he referred to a group of children he had observed in his practice with similar patterns of behaviour as having “early infantile autism” (Wing, 1996). Yet, many other historical accounts exist of children and adults exhibiting behaviour that could have been autism, possibly with the most known case being that of Victor the “Wild Boy of Aveyron”. He was found in the woods in France in 1800, and was believed to be around 12 years old, having survived in the wild until he was found. In 1801, Dr. Jean-Marc-Gaspard Itard took over the boy’s case. The boy could not speak, and his behaviour was deemed strange, but Dr. Itard believed it was due to his isolation from civilisation for so many years, and thus undertook to educate the boy in society’s normal ways (Cattell, 1933; Lieberman, 1982; Wing, 1996).

As mentioned, Leo Kanner carefully documented specific patterns of behaviour in the children he had seen in his practice, and developed a list of diagnostic criteria for early infantile autism (Kanner, 1943; Wing, 1996, p. 19-20):

1. *Profound lack of affective (emotional) contact with other people*
2. *Intense insistence on sameness in their self-chosen, often bizarre and elaborate repetitive routines*
3. *Muteness or marked abnormality of speech*
4. *Fascination with and dexterity in manipulating objects*
5. *High levels of visio-spatial skills or rote memory in contrast to learning difficulties in other areas*
6. *An attractive, alert, intelligent appearance*
7. *Condition is present from birth or within the first 30 months of life*

Only a year later in 1944 did Hans Asperger, an Austrian paediatrician, define a different type of autism (currently referred to as Asperger's Syndrome) based on his observations of children and adolescents with marked social impairments, extreme interests in specific topics and with seemingly normal speech development (Lyons & Fitzgerald, 2007; Wing, 1996).

Other descriptions of autism that surfaced during the 20th century included *childhood psychoses*, referring to odd and peculiar behaviour in children, as well as classifying autism as a form of childhood schizophrenia (Wing, 1996). Along with understanding the symptoms of any disorder comes the need to explain its cause, and as such, the first explanation of the cause of autism linked it to intelligent but emotionally absent and cold parents that affected the child's ability to connect with the social world (Kanner, 1943; Mash & Wolfe, 2010; Randall & Parker, 1999; Wing, 1996). From this belief the term "refrigerator parents" originated, laying the blame for their children's conditions in the lap of parents who were believed to be inadequate at establishing a healthy bond with their children (Bettelheim, 1967, and O'Gormon, 1967, in Randall & Parker, 1999, p.80; Mash & Wolfe, 2010; Wing, 1996). It is only towards the beginning of the 1970's that new studies indicated autism as being a developmental disorder with a neurological cause, rather than the fault of poor parent-child attachment (Bishop, 2012; Dodd, 2005), as well as being part of a spectrum of autistic disorders (Greydanus & Toledo-Pereyra, 2012; Grinker, 2007). As knowledge and awareness of autism increased among professionals, the diagnostic criteria for autism evolved in each publication of the *Diagnostic and Statistical Manual for Mental Disorders* (DSM), as outlined in the sections below.

2.3.1.1. DSM 1

The first edition of the DSM was released in 1952. Autism was not included as a separate diagnostic category, but instead children with autistic-like features were labelled under the *Schizophrenic Reaction, Childhood Type* diagnostic category (Greydanus & Toledo-Pereyra, 2012; Grinker, 2007; Hincha-Ownby, 2013).

2.3.1.2. DSM II

The second DSM was released in 1968. Once again autism was only mentioned as being part of the diagnostic category of *Schizophrenia, Childhood Type* (Greydanus & Toledo-Pereyra, 2012; Grinker, 2007; Hincha-Ownby, 2013). The release of the third DSM signified major changes in the understanding and identification of autism.

2.3.1.3. DSM III

Released in 1980, a separate diagnostic category was included, namely *Infantile Autism* with the following diagnostic criteria (American Psychiatric Association, 1980, p. 89-90; Greydanus & Toledo-Pereyra, 2012; Grinker, 2007; Hincha-Ownby, 2013):

A) Onset before 30 months of age.
B) Pervasive lack of responsiveness to other people (autism).
C) Gross deficits in language development.
D) If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal.
E) Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects.
F) *Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia.*

A reference to schizophrenia seemed to linger in this edition of the DSM, however, the triad of impairments with regards to autism was clearly recognised as a distinguishing factor in the diagnosis of autism.

2.3.1.4. DSM III Revised

Released in 1987, the diagnostic category changed to *Autistic Disorder* with the following diagnostic criteria (American Psychiatric Association, 1987, p38-39; Grinker, 2007; Hincha-Ownby, 2013):

> At least eight of the following sixteen items are present, these to include at least two items from A, one from B, and one from C.
>
> A) *Qualitative impairment in reciprocal social interaction (the examples within parentheses are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:*
>
> 1. Marked lack of awareness of the existence or feelings of others (for example, treats a person as if that person were a piece of furniture; does not notice another person's distress; apparently has no concept of the need of others for privacy);
> 2. No or abnormal seeking of comfort at times of distress (for example, does not come for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, for example, says "cheese, cheese, cheese" whenever hurt);
> 3. No or impaired imitation (for example, does not wave bye-bye; does not copy parent's domestic activities; mechanical imitation of others' actions out of context);
> 4. No or abnormal social play (for example, does not actively participate in simple games; prefers solitary play activities; involves other children in play only as mechanical aids);
> 5. Gross impairment in ability to make peer friendships (for example, no interest in making peer friendships despite interest in making friends, demonstrates lack of understanding of conventions of social interaction, for example, reads phone book to uninterested peer.
>
> B) *Qualitative impairment in verbal and nonverbal communication and in imaginative activity, (the numbered items are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:*
>
> 1. No mode of communication, such as: communicative babbling, facial expression, gesture, mime, or spoken language;
> 2. Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (for example, does not anticipate being held, stiffens when held, does not look at the person or smile when

making a social approach, does not greet parents or visitors, has a fixed stare in social situations);

3. Absence of imaginative activity, such as play-acting of adult roles, fantasy character or animals; lack of interest in stories about imaginary events;
4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (for example, monotonous tone, question-like melody, or high pitch);
5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (for example, immediate echolalia or mechanical repetition of a television commercial); use of "you" when "I" is meant (for example, using "You want cookie?" to mean "I want a cookie"); idiosyncratic use of words or phrases (for example, "Go on green riding" to mean "I want to go on the swing"); or frequent irrelevant remarks (for example, starts talking about train schedules during a conversation about ports);
6. Marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech (for example, indulging in lengthy monologues on one subject regardless of interjections from others).

C) *Markedly restricted repertoire of activities and interests as manifested by the following:*

1. Stereotyped body movements (for example, hand flicking or twisting, spinning, head-banging, complex whole-body movements);
2. Persistent preoccupation with parts of objects (for example, sniffing or smelling objects, repetitive feeling of texture of materials, spinning wheels of toy cars) or attachment to unusual objects (for example, insists on carrying around a piece of string);
3. Marked distress over changes in trivial aspects of environment (for example, when a vase is moved from usual position);
4. Unreasonable insistence on following routines in precise detail (for example, insisting that exactly the same route always be followed when shopping);
5. Markedly restricted range of interests and a preoccupation with one narrow interest, e.g., interested only in lining up objects, in amassing facts about meteorology, or in pretending to be a fantasy character.

D) *Onset during infancy or early childhood.*
(Specify if childhood onset, after 36 months of age)

Evidently, with each release of the DSM, the understanding of autism increased, as it is reflected in the ever-extending diagnostic criteria. The DSM III was the first edition to expand on each of the aspects of the triad of impairments of autism, by including specific diagnostic criteria for each category.

2.3.1.5. DSM IV and DSM IV TR (Text Revised)

The DSM IV was released in 1994, and the Text Revised edition in 2000. The diagnostic category changed to *Pervasive Developmental Disorders*, which served as the umbrella to the following disorders, each with its own diagnostic criteria:

- *Autistic Disoder*
- *Asperger's Disorder*
- *Rett's Disorder*
- *Childhood Disintegrative Disorder*
- *Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)*

For the purposes of this research, only the diagnostic criteria for Autistic Disorder, Asperger's Disorder and PDD-NOS will be discussed. The diagnostic criteria for Autistic Disorder according to the DSM IV-TR are as follows (American Psychiatric Association, 2000, p. 75; Greydanus & Toledo-Pereyra, 2012; Hincha-Ownby, 2013; Grinker, 2007):

A) *A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):*
   1. Qualitative impairment in social interaction, as manifested by at least two of the following:
      a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
      b) Failure to develop peer relationships appropriate to developmental level;
      c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest);
      d) Lack of social or emotional reciprocity.

   2. Qualitative impairments in communication as manifested by at least one of the following:

   a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);
   b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
   c) Stereotyped and repetitive use of language or idiosyncratic language;
   d) Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level.

3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least of one of the following:
   a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
   b) Apparently inflexible adherence to specific, nonfunctional routines or rituals;
   c) Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements);
   d) Persistent preoccupation with parts of objects.

B) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
(1) social interaction,
(2) language as used in social communication, or
(3) symbolic or imaginative play.

C) The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

The diagnostic criteria for Autistic Disorder remained largely unchanged from the previous edition of the DSM, except for the addition of the criterium regarding Rett’s disorder and childhood disintegrative disorder. Both are genetic disorders which present with similar behavioural patterns as autism, and were therefore included to rule out the possibility of genetic causes before diagnosing autism (Neul & Zoghbi, 2004; Tsai, 1992)

The diagnostic criteria for Asperger’s Disorder in the DSM IV-TR are largely similar to that of Autistic Disorder, except with regards to language development, as the development of language and speech in children with Asperger’s Disorder is on par with typically developing children (American Psychiatric Association, 2000, p. 84; Grinker, 2007; Hincha-Ownby, 2013):

A) *Qualitative impairment in social interaction, as manifested by at least two of the following:*
   1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction;
   2. Failure to develop peer relationships appropriate to developmental level;
   3. A lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g.. by a lack of showing, bringing, or pointing out objects of interest to other people);
   4. Lack of social or emotional reciprocity.

B) *Restricted repetitive & stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:*
   1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
   2. Apparently inflexible adherence to specific, nonfunctional routines or rituals;
   3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements);
   4. Persistent preoccupation with parts of objects.

C) *The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.*

D) *There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years).*

E) *There is no clinically significant delay in cognitive development or in the development of age-appropriate self help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood.*

F) *Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.*

When many features of autism are present, but it is not sufficient to meet the diagnostic criteria of the DSM IV TR, a person might be diagnosed with PDD-NOS

(American Psychiatric Association, 2000, p. 84). The DSM IV TR was in use for thirteen years before the newest publication was released, with major changes issued for the diagnostic category of pervasive developmental disorders.

2.3.1.6. DSM V

The DSM V was released in May 2013 and caused great controversy within the international autism community, as the diagnostic category of *Asperger's Disorder* completely fell away (Buxbaum & Baron-Cohen, 2013). A new diagnostic category of *Autism Spectrum Disorder* replaced *Pervasive Developmental Disorder*, with Rett's Disorder, Childhood Disintegrative Disorder and PDD-NOS falling away. To accommodate the spectrum of autism, the diagnostic criteria include a specifier for the level of severity of autism, with level 1 indicating a need for support, level 2 indicating a need for substantial support, and level 3 indicating a need for very substantial support. The diagnostic criteria for *Autism Spectrum Disorder* state the person must meet criteria A, B, C, D and E (American Psychiatric Association, 2013, p. 50-51; Hincha-Ownby, 2013):

A) *Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:*
   1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction;
   2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures;
   3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.

B) *Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:*

1. Stereotyped or repetitive speech, motor movements, or use of objects (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases);
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes);
3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests);
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C) Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).

D) Symptoms together limit and impair everyday functioning.

E) These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

For the first time, the DSM recognised the sensory aspects of autism as a diagnostic feature; however, the triad of impairments was replaced rather by a dyad of impairments, as deficits in communication and language would necessarily have an impact on and impair social interaction (Kaufmann, 2012). These two aspects of the triad were thus collapsed into one diagnostic category of social interaction and communication.

2.3.2. Reflections on autism

It is quite clear that the diagnostic criteria have expanded and changed significantly as the awareness and understanding of autism evolved within the professional community, but many debates have arised surrounding the diagnositc criteria. One such debate is the drastic increase in autism diagnoses and whether it is an increase in awareness and more thorough criteria which are resulting in more children being diagnosed, or whether there is actually just an alarming increase in children being diagnosed with autism (Matson & Kozlowski, 2011; Newschaffer, Falb, & Gurney, 2005; Prior, 2003). Another heated debate surrounded the release of the DSM V, specifically with regards to the diagnostic category of Asperger's Disorder being subsumed within the ASD umbrella. Professionals, parents and diagnosed persons alike were outraged at this decision from the American Psychiatric Association, as they felt it potentially had the consequence of people diagnosed with Asperger's Disorder not fitting any diagnostic category anymore and thus will not qualify for the support services needed, such as unemployment grants, medical aid benefits or special school placement (Autism Research Institute, 2012; Buxbaum & Baron-Cohen, 2013; DiScalfani, 2012; Smith, 2012; Wing, Gould & Gillberg, 2011). For people diagnosed with Asperger's, this change threatened their very identities as being people who are different to people diagnosed with autism (Autism Research Institute, 2012; Buxbaum & Baron-Cohen, 2013; Smith, 2012). Buxbaum and Baron-Cohen (2013) agree that the deletion of the entire diagnostic category from the DSM V might have been too drastic, and that the possibility of people not meeting the criteria for autism spectrum disorder anymore could have other clinical disorders as a result, especially depression and potential suicide. On the surface, however, the DSM V seems to account better for the spectrum of abilities that is apparent in people with autism, but the applicability of the diagnostic criteria and the impact it will have in "the real world", as Buxbaum and Baron-Cohen (2013, p. 12) put it, remains to be seen as psychologists and other professionals start using the new manual.

2.3.3. Characteristics of autism

> *Jane got hooked on an old blanket. It was an extra large one and she kept tripping over it. It had to be carried everywhere, otherwise she'd just scream and kick – people used to get exasperated in shops because we were so slow moving around with the damned blanket. People keep looking at us. They think we made her the way she is. [She also] got really frightened of car tyres crunching on our gravel drive. She would cry*

> *and cry – once started it was so difficult to control.* (Randall & Parker, 1999, p. 110-111)

This is one parent's experience of her child with autism, giving a description of some of the unique behaviours that accompany autism, and the consequent reactions of people in public. The way autism presents, however, varies significantly from one person to another (Bishop, 2012), and as such the characteristics described in this section give only a broad overview of autistic behaviours in accordance with the DSM V diagnostic categories.

2.3.3.1. Social interaction and communication

According to Wall (2004, in Bishop, 2012), the development of social interaction starts in infancy, as babies are naturally interested in and inclined to explore their environments and the people in it, and consequently learn to react to the social environment. This entails the recognition of familiar people, as well as the facial expressions and body language of others (Bishop, 2012; Wall, 2004). As children develop, they integrate the social associations of facial expressions and body language of others. Consequently, they are able to interpret the meanings thereof, and adapt social behaviour accordingly (Wall, 2004). However, the development of these skills appears to be impaired in children with autism, and they therefore find it difficult to interpret social situations and relate to other people (Bishop, 2012; Carr, 2006; De Clercq, 2006; Koudstaal, 2011; Mash & Wolfe, 2010). Inextricably linked to social interaction is communication (Kaufmann, 2012), which includes both verbal and non-verbal modes of interacting with others, such as eye-contact and body language. These modes of communication are aimed at regulating social interaction between people. For instance, if two people are talking, and one of them keeps looking at their watch, it could possibly indicate that the person is perhaps bored with the conversation and wishes it to be over, or the person might be late for an appointment. The other person in the conversation would most likely pick up on these non-verbal cues, and possibly hurry up and end the conversation. However, as the DSM V indicates, people with autism have difficulties with understanding the reciprocity of social interactions and communication, as well as the role of non-verbal cues in communication (American Psychiatric Association, 2013). In the scenario described, the person with autism might carry on talking without picking up the body language of the other person.

Another subtlety underlying social interaction is the ability to distinguish when someone is being serious or not, for instance when making a joke or being sarcastic. Jokes and sarcasm often rely on abstract language, but people with autism find abstract language confusing, as they tend to interpret language very literally (Bishop, 2012; Carr, 2006; Welton, 2004; Williams, 1996; Wing, 1996; Van Roekel, Scholte & Didden, 2010). Therefore, everyday sayings like “it is raining cats and dogs” would seem bizarre to a person with autism, because cats and dogs are not actually falling out of the sky.

Furthermore, relating to other people is linked to a concept called Theory of Mind, which Attwood (2007, p. 112) defines as follows:

> *The psychological term Theory of Mind (ToM) means an ability to recognize and understand thoughts, beliefs, desires and intentions of other people in order to make sense of their behaviour and predict what they are going to do next.*

Being impaired in understanding social situations and interacting accordingly creates great difficulties for people with autism, because they find it difficult to understand the intentions of others, and also have difficulty with understanding that their own actions might have an effect on others (Attwood, 2007; Bishop, 2012; Koudstaal, 2011). This often results in odd or inappropriate behaviour, for instance, interrupting others’ conversations, struggling to take turns during conversations, tending to only want to talk about their own topics of interest without being interested in what others want to talk about, and making comments that could be perceived as rude or hurtful to others (Robinson, 2007; Wall, 2004) – not because it is intentional, but rather because they are purely stating a fact, without understanding the emotional effect it might have on the person the comment is directed at. An example would be commenting on the way someone looks or talks.

Delays in the development of speech in some people with autism are also a contributing factor to frustration, and possible outbursts, due to not being understood and having certain needs met (Bishop, 2012; Welton, 2004; Williams, 1996; Wing, 1996; Wing & Gould, 1979).

In children with autism, their interactions can vary from being aloof and avoiding social contact with others, to wanting to interact with others, but often doing it inappropriately (Bishop, 2012; Carr, 2006; Koudstaal, 2011; Mash & Wolfe, 2010; Wing, 1996), for instance hugging strangers or interrupting their peers' games without understanding that there are social rules at play.

2.3.3.2. Restricted patterns of interest and behaviour

The second aspect of autism, according to the DSM V, is ritualistic and unusual types of behaviour (American Psychiatric Association, 2013). These include behaviour such as asking repetitive questions, copying the exact phrases that other people say (referred to as echolalia), strange body movements like hand flapping or finger wriggling, strange vocalisations, an extreme need for routine and sameness, and a seemingly excessive reaction to sensory stimuli, such as sounds, textures, or light (American Psychiatric Association, 2013; Barlow & Durand, 2009; Bishop, 2012; Carr, 2006; Mash & Wolfe, 2010).

As Bishop (2012, p. 27) stated, "undesirable and challenging behaviour often is a secondary consequence rather than a feature of [autism]. Thus, socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming, running away and self-injury are often associated with [autism] but these behaviours in actual fact are reactions to the environment or a desperate attempt to communicate." To the general public, these behaviours of a seemingly normal looking child is incomprehensible, and hence parents feel they are judged and stigmatised (Gray, 1993; Gray, 2002; Huws, Jones & Ingledew, 2001; McCabe, 2008; Neely-Barnes, Hall, Roberts & Graff, 2011; Randall & Parker, 1999; Twoy, Connolly & Novak, 2007).

2.3.4. Parenting

A part of understanding why parents of children with autism experience stigmatisation from society, and why society accepts autism differently to other disabilities (where the physical nature of the disability is evident to the public), is by looking at social conventions, norms and discourses regarding parenting and disabilities in the Western context.

Greynadus and Toledo-Pereyra (2012, p.2) give an account of historical conventions regarding children with disabilities:

> *Prejudice and avoidance were common for countless thousands of years in many cultures toward those with defects such as mental retardation and epilepsy […], both of which were traditionally blamed on demon possession in Western cultures. One scholar in ancient China notes that mentally retarded children during the Zhou Dynasty (841 BC–221 BC) were identified as being 'stupid, a child born stupid and fearful.' Babies deemed defective after careful inspection in ancient Sparta (700 BC–300 BC) were thrown into a chiasm at a cliff […]. Plato (424 BC–347 BC) concluded that disabilities interfered with a world of perfection and wrote, 'The offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should.' The Old Testament did not allow those with blindness or lameness to enter the house of believers, whereas the New Testament taught that those with mental illnesses were possessed by demons […]. A long-held belief in some religions was that birth defects and disabilities were the result of God's punishment due to the sins of the parents.*

From the beginning of civilisation it seems as if there had been social constructions related to what is normal and abnormal, as well as an attempt to blame something or someone for the cause of abnormality, ranging from demon possession to God's punishment (Greydanus & Toledo-Pereyra, 2012; Ramsden, 2013). These tendencies are deeply ingrained in society and form part of our collective thinking about parenting and disabilities, or more specifically regarding normal and abnormal behaviour. However, the question arises about who decides what is normal and what is abnormal, and as such, Ramsden (2013, p. 2) argues that definitions around normality arise from the society we live in. We therefore need to understand what *society* means:

> *A society is a collective of individuals who are defined by the language that is spoken, religious practices and ethnic diversity. Societies are fluid and constantly changing. What was the norm for a society one hundred years ago may not be the norm of the same society today. How an individual behaves within a group is defined by the constraints of the society. Rules and norms govern what are deemed to be normal parameters. […] When an individual lives within a group, the definition of normal behaviour is usually classified by a consensus of what is considered to be normal for that group. […]. Many normal behaviours are classified by age ranges. […]. The norms that govern behaviour at different age categories have unwritten rules that guide behaviour […] of what is considered age-appropriate […] and anyone acting outside these boundaries would probably be classified as behaving in an abnormal way.*

Therefore, the expectation that society has of seemingly "normal looking" children of specific ages, is to "act their age" so to speak. However, children with autism who seem "normal" may exhibit odd, unusual, and often disruptive behaviour, which seems to spark a need in people to find the cause of the problem – often ending up in blaming the parents. In a study conducted by Neely-Barnes et al. (2011) regarding public perceptions of parents of children with autism, it emerged that the parent-participants often felt they were seen as bad parents by the public, due to the unseen nature of autism. According to Neely-Barnes et al. (2011, p. 213) "parents explained that it is difficult for people in public to 'see' autism. All the public sees is a child acting out. Because they do not see a physical manifestation of the disability, they assume the behavior (sic) is a result of bad parenting." One of the parent-participants explained the unseen nature of autism further: "If there was something that could show that he was different instead of just being bad, it would be easier, – but he appears normal so therefore he should be normal. He should act normal" (Neely-Barnes, Hall, Roberts & Graff, 2011, p. 213).

As mentioned earlier, our ideas and conceptualisations around normality (and therefore abnormality), are founded and sustained within the society we grow up in through the process of socialisation. Andersen and Taylor (2004, p. 88) refer to socialisation as "the process by which people learn the expectations of society."

Everyone in society communicates these expectations on one level or another, by "doing what they consider 'normal'" and in turn enforcing on others to also do things in a normal manner" (Andersen & Taylor, 2004, p. 88). Conforming to what society expects can lead to feelings of pressure (Andersen & Taylor, 2004), which substantiates the feelings parents of children with autism experience in public when their children act outside of what is expected.

As humans, we are also driven by social expectations. If we conform to social expectations, we assume a feeling of success. However, if we do not conform to social expectations, we experience feelings of pressure. Rubin (1998, in Harkness & Super, 2002, p. 275) states:

> *The psychological 'meaning' attributed to any given social behavior (sic) is, in large part, a function of the ecological niche within which it is produced. If a given behavior (sic) is viewed as acceptable, then parents (and significant others) will attempt to encourage its development; if the behavior (sic) is perceived as maladaptive or abnormal, then parents (and significant others) will attempt to discourage its growth and development.*

This statement refers to child development, but in essence also refers to the positive and negative social experiences of parents: if a child behaves acceptably, it is a positive reflection on parenting and is socially encouraged by others; if a child behaves unacceptably, it is a negative reflection on parenting, and is actively discouraged by others through, for example, negative comments or negative body language.

2.4. SUPPORT GROUPS

Due to the nature of the pressure that parents of children with autism experience from society about their children's behaviour, support groups play a role in mediating these pressures and providing an environment where the difficulties experienced by parents are socially acceptable. Seeing that my main research focus was on the value of an online support group, it was necessary to explore the literature regarding the theoretical assumptions that traditional support groups are based on, the value of support groups in the lives of people that utilise it, as well as the rise of online support groups and their value.

2.4.1. Theories and function of support groups

The foundation of support groups is based on several sociological theories, of which the *Social Comparison Theory*, the *Stress and Coping Perspective* and the *Helper Therapy Principle* will be discussed briefly.

The *Social Comparison Theory* was developed by Leon Festinger, an American psychologist. He published a paper in 1954, *A Theory of Social Comparison Processes*, where he described how people form ideas and opinions about themselves in comparison to others' ideas and opinions (Festinger, 1954; Buunk & Gibbons, 2007). Festinger (1954, in Buunk & Gibbons, 2007, p. 4) posited that "individuals are driven by a desire for self-evaluation, a motivation to establish that one's opinions are correct" and that people will do this by seeking "out the company of others similar to themselves" where their opinions are validated as correct. This theory is quite applicable to support groups, where people in need of support seek out groups that address their specific needs and thus create a space where they may share their experiences with people who will potentially be affirming of their opinions and experiences.

The *Stress and Coping Perspective* is part of a broader framework of social support theories, and suggests that "support reduces the effects of stressful life events […] through either the supportive actions of others […] or the belief that support is available" (Lakey & Cohen, 2000, p. 30). This theory, therefore, proposes that people experiencing difficulties in their lives may benefit from the social support received from others, as in a support group, and that even the notion of potentially gaining access to support, can reduce stress. Many parents, upon receiving the diagnosis of autism in their child, receive information about support groups either from doctors or therapists, or seek out support groups themselves via the internet or other means. As the *Stress and Coping Perspective* states, just the knowledge that support is available already may aid in lessening experienced stress (Lakey & Cohen, 2000).

The *Helper Principle* is based on the belief that "a sufferer of a certain malady is particularly adept and impassioned in assisting fellow sufferers" (White, 2000, in Pagano, Post & Johnson, 2011, p. 27), and in turn "gains a sense of meaning, self-worth, [and] a social role" (Schwartz & Sendor, 1999, in Pagano, Post, & Johnson, 2011, p. 27). Within the context of support groups, people experiencing the same difficulties come together in the hope to gain support from their peers due to their shared understanding and empathy, which seems to promote a positive sense of self for members in the group as role-players in someone else's healing process.

The literature provides ample examples of how the above mentioned principles are applied in practice within the context of support groups, and how it translates into benefits for its members (Luther, Canham & Young Cureton, 2005; Mandell & Salzer, 2007; McCabe, 2008; Twoy, Connolly & Novak, 2007; Boyd, 2002). Themes that have emerged from the literature of support groups revolve around peer support, social support, diminished levels of stress and depression, and coping. Research has indicated that parents who are faced with a child with a disability find the support from other families who have gone through similar experiences as extremely beneficial (Boyd, 2002; Luther, Canham & Young Cureton, 2005; Mandell & Salzer, 2007; McCabe, 2008; Twoy, Connolly & Novak, 2007). In a study by McCabe (2008, p. 303) that examined the experiences of care-givers of children with autism after attending an intervention programme, it became apparent that the participants found parent-to-parent support most beneficial as a means of "learn[ing] from each other, and to gain moral support and encouragement in a relationship that is more equal and less discriminatory than was experienced from others in society." The social support from families facing similar challenges has been shown to have an impact on diminished stress levels in parents of children with autism and other disabilities by giving them a sense of agency and guidance (Boyd, 2002; Mandel & Salzer, 2007). Mandell and Salzer (2007, p. 112) stated that "studies have found that parents of children with developmental disabilities are highly satisfied with the sense of agency and belonging they achieve from participating in groups, and report that their parenting skills improve as a result of participation, their sense of isolation is reduced, they obtain important information about services, and they feel a greater sense of emotional support." Similarly, a study by Luther et al. (2005, p. 45) found that "support groups benefit parents by giving them a place to discuss their difficulties, to share coping strategies and accomplishments, and to meet other parents in a similar situation."

With regards to the levels of stress and depression in parents of children with autism, a study conducted by Wolf, Noh, Fisman and Speechley (1989, in Boyd, 2002, p. 209) found that parents of children with autism showed significantly higher levels of stress and were more prone to depression than parents of children with other disabilities, but "symptoms of depression in mothers who believed that social support was readily available were suppressed." Gill and Harris (1991, in Boyd, 2002, p. 210) found that mothers of children with autism that had access to social support showed fewer signs of symptoms related to depression and stress. Yet another study indicated that parents of children with autism "who received more social support scored lower on measures of depression, anxiety, and anger" (Gray & Holden, 1992, in Boyd, 2002, p. 211).

2.4.3. Social media and online support groups

The rise of social media as an alternative platform for support groups has been the focus of recent research (Aho, Paavilainen & Kaunonen, 2012; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones & Ingledew, 2001; Lamberg, 1996; Sarkadi & Bremberg, 2005). Although the benefits of face-to-face support groups, as discussed in the previous section, are significant to its participants, there can be limitations for participants to always attend meetings, such as "lack of available time, travel difficulties and childcare constraints" (Huws, Jones, & Ingledew, 2001, p. 570). The internet has created opportunities to overcome these barriers in seeking and obtaining social support through the means of online support communities and information websites that offer immediate access to its participants (Aho, Paavilainen & Kaunonen, 2012; Huws, Jones & Ingledew, 2001; Lamberg, 1996). However, it seems that the effects of participating in online support groups are very similar to face-to-face support group meetings. A study by Jones and Lewis (2000, in Huws, Jones & Ingledew, 2001, p. 571) about parents of children with Down Syndrome who participated in an Internet discussion group found that "the group was used by the parents to communicate a sense of celebration, to advocate seeing the child rather than the handicap, to share hope and optimism, for becoming the agents for change, and to provide a validating and supportive environment.” Another study examined the experiences of parents of children with autism participating in an email discussion thread, and the results indicated that the discussions centered around the parents’ meaning-making regarding their children’s diagnoses, as well as lending support to each other by “validating and reciprocating [each other’s] concerns” (Huws, Jones & Ingledew, 2001, p. 581). Research by Aho, Paavilainen and Kaunonen (2012) about an online support group for mothers facing the loss of a child indicated that exchanging stories of loss and hope, celebrating birthdays and providing information on professional services were topics that were covered, but that the mothers were also enabled “to share their experiences and feelings and to receive compassion and support for their coping. The mothers also had a sense of belonging to a peer community which accepted them for who they are” (Aho, Paavilainen & Kaunonen, 2012, p. 424).

In the medical field, research regarding online support groups has focussed on the internet being used as a source of information and support for patients with a variety of medical conditions, especially cancer, as well as disabilities, with similar themes emerging such as emotional support, coping with the condition or disability, receiving information, sharing experiences with people who understand, feeling empowered and less isolated, and being able to help others (Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Lamberg, 1996). Research regarding groups on Facebook, specifically such as groups about concussion, diabetes and cancer groups, conveyed how these groups are largely utilised to share experiences and information (Ahmed, Sullivan, Schneiders & McCrory, 2010; Bender, Jimenez-Marroquin & Jadad, 2011; Greene, Choudhry, Klabuk & Shrank, 2010; Perkins & LaMartin, 2012).

There are drawbacks, however, to participation in online support groups. Various studies have indicated that information shared by group participants can be misinterpreted due to the lack of face-to-face contact where non-verbal cues can mediate a situation, and that negative comments and criticisms by group participants affect the cohesion and supportive nature of online support groups (Aho, Paavilainen & Kaunonen, 2012; Baum, 2004; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones & Ingledew, 2001; Perkins & LaMartin, 2012). In addition, computer technology (and more specifically internet access) seems to be limited to higher socio-economic groups and a younger population that are familiar with the use of computer technology (Braithwaite, Waldron & Finn, 1999; Perkins & LaMartin, 2012; Sarkadi & Bremberg, 2005). In South Africa, access to internet services seems to be limited, as the results of Census 2011 indicate that 64.8% of households in the country have no access to internet, with only 16.3% of the population having access to the internet on their phones (Statistics South Africa, 2011, p. 12), thus excluding a large proportion of South African parents of children with autism from accessing online support communities.

2.5. CONCLUSION

This chapter provided a foundation for the research based in the literature. Firstly, the theoretical framework of social constructionism upon which the research was based was explained with regards to its origin in modernist and postmodernist thinking. Thereafter, an in-depth discussion followed regarding the premises of social constructionism and how it linked with this research. Seeing that the research focus was on parents with children with autism participating in a Facebook support group, the history of autism was depicted, along with social ideologies about parenting. This chapter was concluded by providing descriptions of some of the theories upon which support groups are based, and how it relates to the support provided by online support groups. The drawbacks of online support groups were also discussed, as it excludes a large population in South Africa due to lack of access to the internet, as well as misinterpretations that can occur without the physical communication cues that are present in face to face communication. The next chapter provides an in-depth description of the complete research process.

CHAPTER 3
RESEARCH DESIGN AND IMPLEMENTATION

3.1. INTRODUCTION

Before embarking on any research project, the researcher has to experience a curiosity regarding a specific topic, which activates the researcher's need to explore further. In Chapter One I gave an overview of my curiosity regarding the experiences of parents of children with autism participating in a Facebook support group. This online support group intrigued me, and I wanted to know more about how the parents experience their participation within this group, as well as the value or meaning that it added to their lives. Parents of children with autism experience much stress, depression, anxiety and isolation due to their child's condition (Boyd, 2002; Gray, 1993; Luther et al., 2005; McCabe, 2008; Montes & Halterman, 2007; Neely-Barnes et al., 2011; Olsson & Hwang, 2001). Support groups have played a big role in providing a platform for parents to share their experiences with other parents in safe and understanding environments, as well as learning coping strategies for themselves or behavioural interventions for their children (Baum, 2004; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Gary & Remolino, 2000; Greene, Choudhry, Klabuk & Shrank, 2010; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Hurley, Sullivan & McCarthy, 2007; Huws, Jones & Ingledew, 2001; Lamberg, 1996; McCabe, 2008; Sarkadi & Bremberg, 2005). However, with the increasing accessibility of online social media platforms (Aho, Paavilainen & Kaunonen, 2012; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Huws, Jones & Ingledew, 2001; Lamberg, 1996; Sarkadi & Bremberg, 2005), such as Facebook, parents can share information, successes, struggles and experiences at any time of the day (Baum, 2004; Brady & Guerin, 2010; Braithwaite, Waldron & Finn, 1999; Gary & Remolino, 2000; Greene, Choudhry, Klabuk & Shrank, 2010; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Hurley, Sullivan & McCarthy, 2007; Huws, Jones & Ingledew, 2001; Lamberg, 1996; McCabe, 2008; Meier, 1998; Sarkadi & Bremberg, 2005). The accessibility of internet-based support groups creates a unique opportunity to research parents' experiences in such an online community. Knowledge about their experiences, the value and meaning of an online support group in their daily lives, as well as which parents access online support, could shed light on how online communities could possibly be better utilised in providing instant and low-cost information and support to parents who are otherwise excluded from face-to-face support groups due to various constraints. Additionally, research about online support groups for autism in South Africa seems to be non-existent. This research could contribute significantly to the gap in knowledge about South African parents' experiences.

In order to achieve the aims stated above, the following questions were intended to guide my inquiry:

> *What value do parents of children with autism, who participate in an online social media support group, attach to their participation in the group?*

The following sub-questions further guided my enquiry in an understanding of the parents' experiences:

> *What were their reasons for joining this online source of support?*
>
> *How does their participation contribute to their meaning-making of their daily experiences regarding their child's diagnosis?*
>
> *What is the nature of the information shared among parents in this group?*
>
> *How does their participation contribute to their coping skills and their identities as parents?*

This chapter sets out the entire research process, from the research design, paradigm and participant selection, to collecting and analysing the data, and ensuring trustworthiness. Ethical considerations as an intricate part of the research process will also be discussed, along with my reflections as a researcher.

3.2. RESEARCH PROCESS

The research process is sparked by the researcher's curiosity regarding a certain topic, as previously mentioned. In order to progress in a logical fashion through the research process, and ultimately to ensure scientific rigour, the researcher sets out a framework according to which to conduct the research. This framework would include the research design chosen for the research, as well as the paradigm from which the researcher will depart. The research paradigm further informs the researcher about the ontology, epistemology and methodology of the research (Denzin & Lincoln, 2005; King & Horrocks, 2010; Kincheloe and McLaren, 2005; Mertens, Holms & Harris, 2009; Nilsen, 2008; Zajicek, 2005). The selection of participants, the data collection and analysis procedure also need to be elucidated. The chart below indicates the broad framework of the research process chosen for this study:

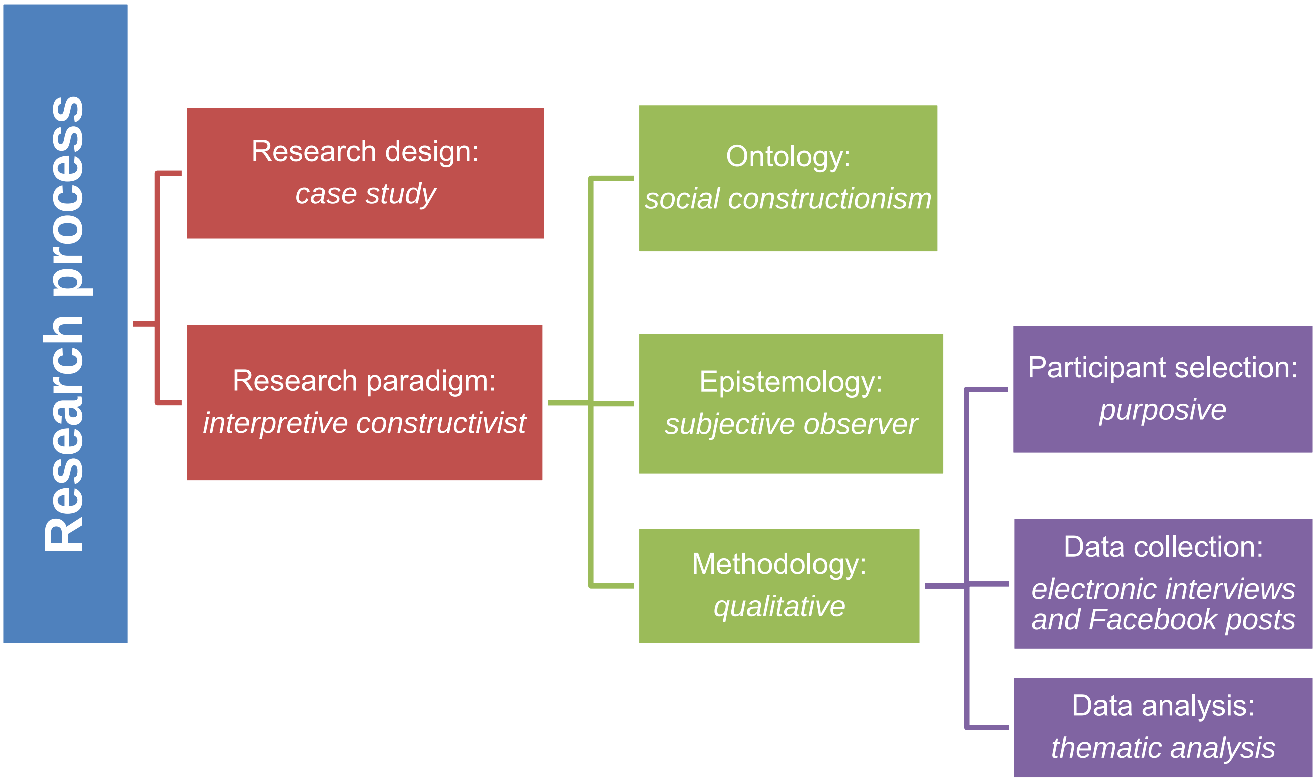


Figure 3.1. Framework of the research process

3.2.1. Research design

For the purpose of this research, I deemed it necessary to firstly determine the research design, as I felt that knowing the boundaries of the study would enable me to conduct my research accordingly. The research I conducted was designed on the model of a case study. Various definitions are given for case studies. Merriam (2009) describes it as focussing on a bounded system where a specific phenomenon is of interest to the researcher. Anthony and Jack (2009, p. 1172) state that “case study as a research methodology [is] grounded in an interpretive, constructivist paradigm, which guides an empirical inquiry of contemporary phenomena within inseparable real-life contexts." Kenny and Grotelueschen (1984, in Ghesquière, Maes & Vandenberghe, 2004, p. 172) also state that case studies aim "to identify and describe phenomena" but they go further to explain that case studies are unique in the sense that they require participation, or interaction, from the researcher as an integral part of the research process:

> *In a case study the data are collected in a communicative interaction between the researcher and the research participant. Therefore, qualitative data are the product of an encounter in which the subjectivity of all partners plays a part. The data cannot be situated in a research context that exists independently of the researcher. They result from the social construction of the research process itself. The quality of the data therefore depends on the quality of the relationship the researcher has built with the research participants. The researcher's subjectivity is an important methodological theme in such a context.*
> (Ghesquière, Maes & Vandenberghe, 2004, p. 174)

Thus researcher reflexivity is an important part of the research process and adds value as one of the multiple sources of data required from qualitative case study research, which will be discussed later in this chapter. The ultimate aim of case study research is to understand real life situations in an in-depth way, as they occur in the social world and the meanings that are constructed by each participant as they are living it (Anthony & Jack, 2009; Hodgetts & Stolte, 2012; Macpherson, Brooker & Ainsworth, 2000). Therefore, in order to report on case study research, the researcher is required to "provide a rich, detailed, in-depth, and holistic description of the phenomenon that has been studied" (Kenny and Grotelueschen, 1984, in Ghesquière, Maes & Vandenberghe, 2004, p. 172), which can be achieved by ensuring that the research participants are actively part of the construction of the data:

> *Researchers need to build closer relationships with participants and to facilitate dialogue, so that participants can add to the compilation of the story of the research in ways that are meaningful for them. From this point of view, a successful case study is one which provides a well-crafted and*

> *researched narrative that 'allows the reader to imagine himself [sic] in the social world of the case being studied' (Kemmis, 1980)*
> (Ghesquière, Maes, & Vandenberghe, 2004, p. 174).

Another important quality of case study research is the focus on particular, or specific, phenomena instead of aiming towards generalising the research findings (Anthony & Jack, 2009; Macpherson, Brooker & Ainsworth, 2000). Stake (1998, in Macpherson, Brooker & Ainsworth, 2000, p. 52) states that "damage occurs when the commitment to generalize (sic) or create theory runs so strong that the researcher's attention is drawn away from features important for understanding the case itself." It is, therefore, imperative to employ multiple methods of data collection to gain in-depth understanding of the particularity of a specific case, and thus ensuring rich descriptions, instead of generalisations, on the researched case. Denzin and Lincoln (1998, in Macpherson, Brooker, & Ainsworth, 2000, p. 53) state:

> *Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.*

The case study design was chosen for this research as the experiences of parents (phenomenon) participating in a particular support group on Facebook (bounded system) was the focus of the study, and that this particular design was deemed the best suited to answer the research questions. The next section discusses the research paradigm as an adjunct to the research design, to give a full overview of the theoretical basis upon which this study was conducted.

3.2.2. Research paradigm

The research paradigm informs the researcher's understanding of the nature of knowledge (*ontology*), how it can be accessed (*epistemology*) and how the research questions can be answered (*methodology*) (Denzin & Lincoln, 2005; King & Horrocks, 2010; Kincheloe and McLaren, 2005; Mertens, Holms & Harris, 2009; Nilsen, 2008; Terreblanche & Durrheim, 2006; Zajicek, 2005). Merriam (1998, p. 5) states that one's paradigm is synonymous with the way one views the world, and that a research project should start "with examining your own orientation to basic tenets about the nature of reality [and] the purpose of doing research." I have found that an interpretive constructivist paradigm underpins my worldview, as it supports my belief that people make meaning from their own experiences in unique ways (Adams, Collair, Oswald, & Perold, 2004; Terreblanche & Durrheim, 2006). Schwandt (2000, in Walters, 2009) affirms this statement in saying that researchers operating from within an interpretive constructivist paradigm aim to understand the experiences of people as they live it. Their experiences cannot be objectively quantified, and the aim of the research is also not to arrive at one single conclusion or truth; thus a qualitative approach is best suited where the researcher engages with the research-participants to gain insight into their meaning-making processes. Krauss (2005, p. 759-760) states that "for many qualitative researchers, the best way to understand what is going on is to become immersed in it and to move into the culture or organisation being studied and experience what it is like to be a part of it." In order to immerse myself as researcher into the natural setting of the case in focus in this study, I joined the particular Facebook support group myself, and became part of the community participating in it. However, I realise, not being a parent myself, and even though I became part of the community, my experiences would still be limited and not exactly the same as the particpating parents, like Krause (2005) claimed.

The interpretive constructivist research paradigm, within a social constructionist framework, as it pertains to this study will be further clarified in the following sections regarding its ontology, epistemology and methodology.

3.2.2.1. Ontology and epistemology

Terreblanche and Durrheim (2006) refer to ontology as the nature of reality and epistemology as the researcher's interaction with this said reality. In other words, the researcher's beliefs in what reality is will necessarily influence how the researcher will interpret reality. Interpretive constructivist research is based on social constructionist principles of reality, therefore stating that reality is not fixed, it cannot be objectively studied, and there is no one single truth to reality (Burr, 2000;

Freedman & Combs, 1996; Gergen, 1985; White, 1990). Conversely, social constructionism accepts that people construct and interpret their own realities through social interaction with others, meaning that each person's construction and interpretation of their experiences might differ (Burr, 2000; Freedman & Combs, 1996; Gergen, 1985; White, 1990). Almost as a paradox, the epistemology of research conducted from an interpretive constructivist paradigm has to take into account that the researcher herself is busy with a social construction of the research process as she engages with participants, and as such, the nature of reality and the way it is interpreted by the researcher is inextricably linked (Kincheloe & McLaren, 2005; Megaw, 2011). Therefore, it is imperative that the researcher acknowledges the part that she plays in the construction of knowledge throughout the research process, which will be discussed later in section 3.4 regarding researcher reflexivity.

3.2.2.2. Methodology

The theoretical and philosophical frameworks, namely social constructionism and interpretive constructivism, have been discussed in depth throughout the preceding chapter, which leads to the discussion on the research methodology chosen for this study. Megaw (2011) states that the methodology of a study aims at linking the researcher's view on reality (*ontology*) and how knowledge is created (*epistemology*) through establishing what the best means will be of conducting the research, based on the mentioned ontological and epistemological assumptions. As stated before, I have employed a qualitative methodology from an interpretative constructivist paradigm, attempting to answer the research questions stipulated. According to Adams et al. (2004, p.365) "qualitative methodology aims at providing a comprehensive description of a specific phenomenon rather than the testing of hypotheses common to experimental research methods. An effort is made to understand situations in their uniqueness as part of a particular context and the interactions within the context under study." Therefore, the aim of this research was to gain insight into the meanings that participants of a Facebook support group constructed for themselves through their participation in the group, and to give rich descriptions of their unique experiences as they lived it. Krauss (2005, p. 764) gives an apt description of the researcher's role in qualitative interpretive constructivist inquiries:

> *The goal of qualitative investigation is to understand the complex world of human experience and behavior (sic) from the point-of-view of those involved in a situation of interest. Therefore, the investigator is expected not to have an a priori, well, delineated conceptualization (sic) of the phenomenon; rather, this conceptualization (sic) is to emerge from the interaction between participants and investigator.*

Seeing that a specific context is of interest to the researcher from within this paradigm, specific methods are chosen to conduct the research, as will be discussed below.

3.2.2.2.1. Participant selection

Seeing that my aim was to explore the value of a Facebook support group for parents of children with autism, participant selection was purposeful, meaning that this group was selected with a specific purpose in mind: “to discover, understand, and gain insight” (Merriam, 2009, p. 77) into their experiences. Megaw (2011, p. 77) points out that purposive sampling “allows the qualitative researcher to seek out a setting and individuals where the processes being studied are most likely to occur” and where the setting provides the researcher with the opportunity to gain in-depth knowledge of the specific issue or topic of interest.

Having been a teacher at a school for children with autism, dealing with parents and their daily experiences surrounding their child was part of my reality. However, not being a parent myself, and also not a parent of a child with autism, I have often wondered where parents find support and how it helps them to cope with their realities. Being part of the digital age where online platforms, such as Facebook, are used to share daily experiences is also a part of my reality. As such, I came upon a support group for parents of children with autism in South Africa on Facebook in 2012, and have been a member of that group ever since, by being invited into this closed group by one of its principal members after discussing my potential research and asking for consent to be an observer within the group. With curiosity, I observed the information parents shared among themselves. It ranged from asking for advice about a myriad of topics on their children's behaviour and needs, or sharing positive and not-so-positive daily experiences with each other. My impression was that they created a safe space where judgment, perceptions and assumptions from the uninformed public did not have power over them; and more so, they created a support group that is accessible day and night with almost immediate and constant feedback. This online support group intrigued me, and I wanted to know more about how the parents as members of this group experienced their participation within the group, as well as the value or meaning that it added to their lives. This curiosity prompted this study.

At the time of the study, there were more than a hundred members in the group, consisting mostly of parents and caregivers of children with autism. Even though most of the members in the group are parents and caregivers of children with autism, there are other members, such as myself and a variety of therapists, who do not have children with autism, but participate in the group by sharing information pertaining to therapeutic or educational strategies. The majority of the members are female.

Participants for this study were specifically selected based on the criterion of being parents (whether biological or adopted) of a child or children with autism, participating in this Facebook support group. Another selection criterion was that the participants had to be South African. Participant selection was also voluntary, as only members of the group who were willing to partake in the research were included in the research population. Obtaining informed consent will be discussed in detail in section 3.5.

As mentioned, one of the principal members of the group invited me to be a member after I explained my proposed research. Subsequent to obtaining ethical clearance from my university's Research Ethics Committee (REC), I was able to introduce my research to the Facebook support group by means of a post on the group's wall, which included the aims of the study, as well as a downloadable document stating what the requirements were of participants choosing to partake. Unfortunately, there were no responses to the post, and I decided to approach the most actively participating members in the group by sending each of them a private message on

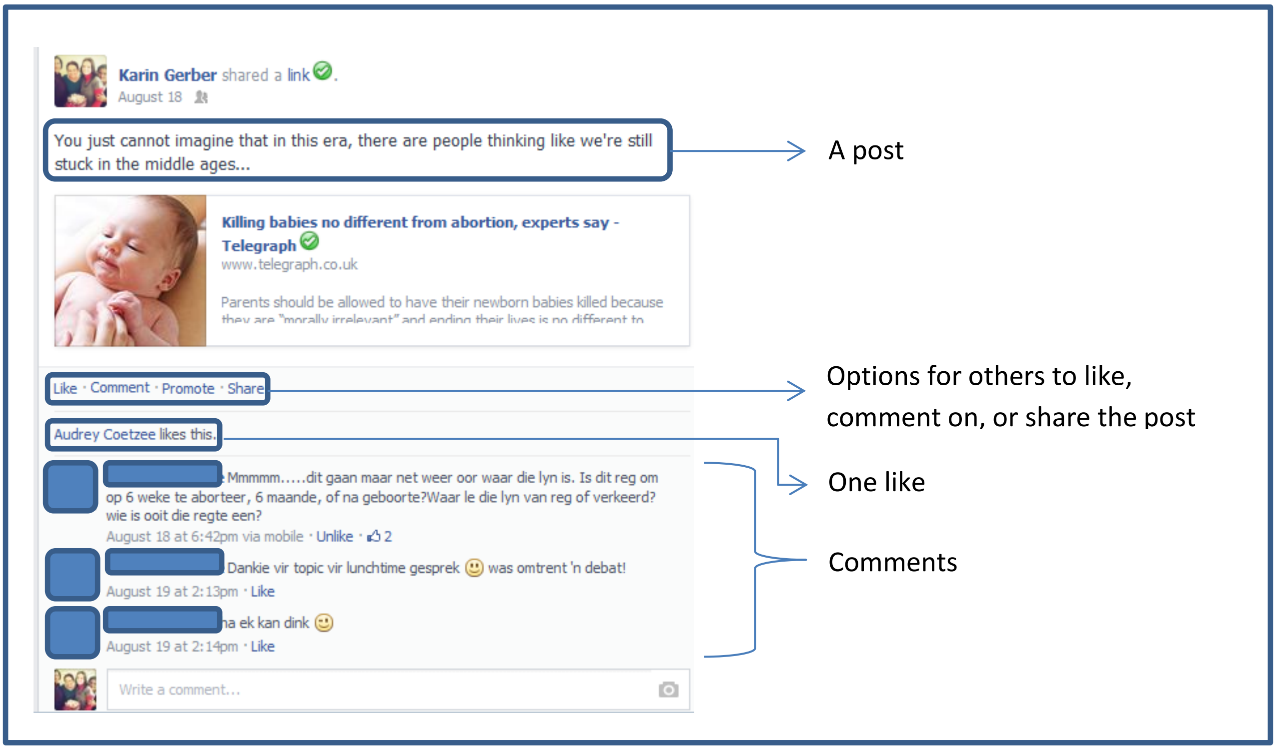
Facebook. The response was positive, and ten members indicated a willingness to participate.

3.2.2.2.2. Data collection

As discussed in section 1.6.4, the participants' posts in the Facebook support group, as well as open-ended research questionnaires were used as data for this study. I contacted each participant individually via email with the attached electronic questionnaire, as well as the consent form. The electronic questionnaire can be found in Addendum D, and the consent form in Addendum B.

The members of this group are located all around South Africa, and as such, an alternative method to face-to-face data collection was necessary. Most often, focus group discussions are held as a means of collecting qualitative data, however, this was not possible for the study. Therefore, I decided to simulate an interview by creating an electronic interview questionnaire that was emailed individually to each of the consenting participants, along with the consent form that had to be completed by each participant. The questions were formulated based on an extensive literature review, and were structured in an open-ended format to elicit rich information about each participant's experiences and to add to the rich description of the data as it pertains to qualitative research (Kvale, 2010; Roulston, 2008). The reason for sending individual emails was to protect the identity of the participants from each other, as confidentiality was non-negotiable. Other ethical considerations will be discussed in section 3.5. The consent forms were returned to me by each parent via email, along with the completed questionnaires. Although only eight parents completed the questionnaires, two of the initial ten parents who were willing to participate are the spouses of other parents who consented to participate, and indicated that they would complete the questionnaire together.

After obtaining consent from each participant, I was able to start collecting data of each participant's activity within the group (whether it was their own posts or commenting on other members' posts). This process was two-fold, as retrospective posts and comments from the participants during the months of May and June were gathered, which was then followed up by real-time observation of the participants' interactions within the group during the month of July. Porter (2011) and Peräkylä (2011) refer to this as naturally occurring data, where the researcher observes the interaction between people in a naturalistic setting or context, which is what the Facebook support group is. Although it is an online context, it is nevertheless a space where parents share their experiences as they live it, with feedback from other members in the group through the means of “comments” or “likes”. *Comments* refer to a person’s written response to someone else’s post, whereas “*likes*” refer to a person’s response to someone else’s post by clicking the “like” button underneath the post, as demonstrated in figure 3.2 below:



Karin Gerber shared a link.
August 18

You just cannot imagine that in this era, there are people thinking like we're still stuck in the middle ages...

Killing babies no different from abortion, experts say - Telegraph
www.telegraph.co.uk

Parents should be allowed to have their newborn babies killed because they are "morally irrelevant" and ending their lives is no different to

Like · Comment · Promote · Share

Audrey Coetzee likes this.

[redacted] [redacted] Mmmmm.....dit gaan maar net weer oor waar die lyn is. Is dit reg om op 6 weke te aborteer, 6 maande, of na geboorte?Waar le die lyn van reg of verkeerd? wie is ooit die regte een?
August 18 at 6:42pm via mobile · Unlike · 👍 2

[redacted] [redacted] Dankie vir topic vir lunchtime gesprek 🙂 was omtrent 'n debat!
August 19 at 2:13pm · Like

[redacted] [redacted] ha ek kan dink 🙂
August 19 at 2:14pm · Like

Write a comment...

A post

Options for others to like, comment on, or share the post

One like

Comments

Figure 3.2: Depiction of posts, comments and likes on Facebook

The data collection phase of research was followed up by the process of analysing all of the information.

3.2.2.2.3. Data analysis

Boeije (2010) states that the research process starts with defining a specific topic to be researched and formulating research questions, which are followed up by an extensive literature review, selecting a research population and sample according to relevant ethical principles, and gathering research data. Only then can data analysis occur, whereby all the information gathered from various sources is collated in order to present the research findings in a structured manner, such as a thesis (Boeije, 2010; Gibbs, 2007).

The participants’ responses to the electronic interview questionnaire, as well as their activity in the Facebook support group, were analysed using thematic analysis, which resonates with my view of how knowledge is produced or constructed and thus seemed a good match to this research. Thematic analysis is used to categorise data into units of meaning (Corbin & Strauss, 2008). It also takes into account that the researcher plays an active role in thinking and reflecting about the data that is captured throughout the research, and thus has an impact on which themes are chosen for analysis, as well as how these themes are interpreted (Braun & Clarke, 2006). Seeing that no verbal interviews were conducted during this research, no transcribing of information was necessary, as all of the interactions within the Facebook support group, as well as in the electronic interviews, were already written by the participants in their own words. The process of open coding was then used to code all the data, as this process relies on identifying themes directly from the text as it is, instead of coding the data according to preconceived themes based on the literature review (Bishop, 2012; Charmaz, 2011; Corbin & Strauss, 2008).

The coding process was two-fold. The first phase of the coding process began with an initial reading of all of the data collected from the participants’ interactions within the Facebook support group in order to become familiar with it, and to start identifying possible themes. A second, more in-depth reading followed, whereby the actual coding started. The interactions of the participants were given codes that consisted of words or phrases, conveying the units of meaning (Corbin and Strauss, 2008). The second phase of the coding process was similar to the first, whereby the participants’ responses to the electronic questionnaire were also read, and reread, before codes were allocated to their responses. The codes generated from both sets of data were then firstly assessed to determine the occurrence of and relevance of each code. Codes that appeared infrequently were not included as research findings. Secondly, the codes that remained were then merged into overarching categories, with themes and subthemes that matched each category. An excerpt from both phases of the coding process can be found in Addendum F and Addendum G, which indicate the identification of the various categories, themes and subthemes.

Furthermore, a statement made by Maykut and Morehouse (1994, from QDATRAINING Admin, 2012) underpins my theoretical framework and supports the chosen data analysis:

> *Words are the way that most people come to understand their situations; we create our world with words; we explain ourselves with words; we defend and hide ourselves with words […] The task of the researcher is to find patterns within those words and to present those patterns for others to inspect while at the same time staying as close to the construction of the world as the participants originally experienced it.*

Therefore, as a means of checking the data, and ensuring that I stay as close to the experiences of the participants as they would want, my interpretation of the data was also shared with the participants to get their feedback about the accuracy of my interpretations. This is further discussed in section 3.3 regarding the quality and trustworthiness of the data.

The research findings are discussed in detail in Chapter Four, according to the identified categories, themes and subthemes. Additionally, the research findings were further used to draw conclusions from it based on the relevant literature, which is also addressed in Chapter Four.

The data analysis process, however, goes hand in hand with ensuring the accuracy, quality and trustworthiness thereof (Rubin & Babbie, 2007), which is discussed next.

3.3. QUALITY AND TRUSTWORTHINESS OF DATA

Two constructs that are synonymous with scientific research are reliability and validity (Foxcroft & Roodt, 2007). A study is reliable if it can be repeated in a similar setting and yields the same results, whereas a study is valid if the results reflect what was intended to be measured (Andersen & Taylor, 2004; Merriam, 2009). However, this seems to be a contentious issue in qualitative research, seeing that quantitative and qualitative paradigms have differing opinions about what constitutes reality (Merriam, 2009), thus affecting what will be studied, how it will be studied and what conclusions will be drawn from the results of the study. Consequently, qualitative research necessitates a shift in how reliability and validity can be ensured. Various scholars proposed alternative criteria to ensure the trustworthiness of a qualitative study, namely credibility, transferability, dependability and confirmability (Babbie & Mouton, 2001; Ballinger, 2008; Guba & Lincoln, 1985, in Merriam, 2009; Mertens, 1998; Mertens, 2005; Trochim, 2006)

3.3.1. Credibility

Credibility refers to the extent that the results of a study reflect the realities of its participants (Trochim, 2006), in other words, how true are the findings of a study to them (Babbie & Mouton, 2001; Mertens, 2005). According to Denzin (1978, in Merriam, 2009) and Flick (2007), one way of ensuring credibility is triangulation, by using multiple methods and multiple sources of data, to check the accuracy and consistency of the data (Merriam, 2009; Mertens, 2005; Taylor & Bogdan, 1998). Denzin and Lincoln (1998, in Macpherson, Brooker, & Ainsworth, 2000, p. 53) state:

> *Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspective, life story, interview, observational, historical, interactional and visual texts—that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand.*

In order to immerse myself as researcher into the natural setting of the case in focus in this study, I joined the particular Facebook support group myself, and became part of the community participating in it. To further ensure credibility in this research, I used electronic interviews, observations of the participants' interactions in the Facebook support group, as well as documents in the form of a literature review. An additional measure was put in place to ensure credibility by employing member checks (Babbie & Mouton, 2001; Merriam, 2009), whereby my interpretations of the data were sent to the participants for their feedback, which was then incorporated as part of the data analysis as well.

3.3.2. Transferability

Transferability looks at the possibility of generalising the results of a study to other contexts (Boeije, 2010; Merriam, 2009). However, I caution against this notion as I am concerned that readers might interpret transferability in the same sense as reliability from a quantitative perspective. The aim of this study was not to recommend a repeat of exactly the same process, hoping for the same results (as it would be in a quantitative approach), but instead giving such a rich description of the context of the research and the results of the study (Babbie & Mouton, 2001; Merriam, 2009) that readers are able to judge for themselves if a similar study could be conducted elsewhere (Jensen, 2008). Additionally, the population chosen for this study was done so particularly to learn about their uniqueness, and thus some elements of the study might be applied in other research contexts to gain insight into other populations' uniqueness. As Wolcott (2005, in Merriam, 2009, p. 228) states: "every case is, in certain aspects, like all other cases, like some other cases, and like no other case."

3.3.3. Dependability

Dependability refers to how accurately the findings of a study match the data that was collected (Merriam, 2009), and it is up to the researcher to ensure that "given the data collected, the results make sense" (Merriam, 2009, p. 221). This is ensured by keeping accurate records of the data collection and analysis process (which can be found in Addendum F and Addendum G), as well as describing the research process as a whole, as done in section 3.2. According to Trochim (2006) dependability "emphasizes (sic) the need for the researcher to account for the ever-changing context within which research occurs. The research[er] is responsible for describing the changes that occur in the setting and how these changes affected the way the research[er] approached the study." Only then can the research be called dependable. Chapter Four gives an indication of how the context of the Facebook support group was affected by certain events, and consequently impacted on the research process.

3.3.4. Confirmability

Confirmability refers to how closely the results of a study link to the initial purpose of the research (Merriam, 2009). This can be achieved through leaving an audit trail, such as raw data, reduced data, process notes and interview schedules (Babbie & Mouton, 2001; Merriam, 2009; Trochim, 2006) for others to check and confirm whether or not researcher biases (Merriam, 2009) have influenced the research process. In my case, the confirmability of my research was checked by my thesis supervisor, and a sample of the audit trail of this research is included in Addendums D, F and G.

3.3.5. Crystallisation

I would like to add an additional criterion to ensure trustworthiness, namely *crystallisation*. Richardson (2000, in Merriam 2009 and Ellingson, 2009) states that qualitative research assumes as a basis that there are multiple ways of viewing the world, not just on the part of its participants, but also on the part of the researcher. In effect it will thus determine how research is conducted. Just as a crystal consists of many angles, so should a qualitative researcher view the world from various angles to ensure the trustworthiness of the data (Richardson, 2000, in Ellingson, 2009, p. 3). Cohen and Crabtree (2006) clarify this by explaining that the qualitative researcher should immerse herself in the data analysis process, but also alternate this with a reflective phase (referred to as crystallisation) by “temporarily suspending the process of examining or reading data (immersion) in order to reflect on the analysis experience and attempt to identify and articulate patterns or themes noticed during the immersion process.” The following section is a discussion on my own reflections as a researcher being engaged and immersed in the Facebook support group, the participants in this study, as well as the data analysis procedure.

3.4. RESEARCHER REFLEXIVITY

Merriam (2009) points out an additional measure to ensure *credibility* in qualitative research, which is declaring one's position as a researcher. Guba and Lincoln (2000, in Merriam 2009, p. 219) call it "reflexivity" and Merriam (2009, p. 219) clarifies this with the following statement:

> *Investigators need to explain their biases, dispositions, and assumptions regarding the research to be undertaken. Even in journal articles authors are being called upon to articulate and clarify their assumptions, experiences, worldview, and theoretical orientation to the study at hand. Such a clarification allows the reader to better understand how the individual researcher might have arrived at the particular interpretation of the data.*

Additionally, Mauthner (1998, in Walters, 2009, p. 311) states that "qualitative research celebrates the reflexive role of the researcher, who becomes a major part of the research context" due to the fact that this type of research specifically relies on the relationship between the researcher and participants to gain the required in-depth and rich descriptions of qualitative research, and the active role that the researcher plays in constructing her own ideas about the research as it is conducted. As explained in Chapter One, my theoretical framework (social constructionism) and worldview (constructivist interpretivist paradigm) guided my inquiry and streamlined what I intended to research. In Chapter One I also stated that my own experiences, history and background shaped me in a different way to any other person, thus relating back to social constructionism of differing realities, and as such, who I am as a researcher would have had an influence on the way the data collected from this study was interpreted. Therefore, I feel compelled to emphatically pronounce my own voice as critical to this study, as it is clear that this thesis is written from a first-person perspective: my perspective. Writing this thesis was as much my process, as it was the process of each participant, because I was intricately involved in the story-telling process. My reflections regarding the research process is incorporated throughout Chapter Four as an inseparable part of the presentation of the research findings, meaning that without the construction of my own ideas regarding the data I collected, an analysis and the presentation thereof would not have been possible.

3.5. ETHICAL CONSIDERATIONS

I view ethics as a researcher's moral and professional responsibility towards participants in a study, by ensuring that certain measures are put in place to respect and protect their wellbeing and human rights (O'Leary, 2010). The first part of this process entailed submitting my research proposal for ethical clearance to the Research Ethics Committee (REC) of Stellenbosch University. Ethical clearance was granted on 21 June 2013. The clearance document can be found in Addendum A.

Subsequent to obtaining ethical clearance, I adhered to a checklist of Patton (2002, in Merriam, 2009, p. 233) which guides qualitative researchers in conducting ethical research. The first point states that the researcher should explain *"the purpose of the inquiry and the methods to be used"*, thus ensuring that the participants know exactly what will happen. Firstly, the consent form that was sent to all participants contained detailed information regarding the purpose of the research, the manner in which data were to be collected, the role they were to play in the research process, as well as detailing what the expectations of their participation would be. This document can be found in Addendum B.

Secondly, it is important that the researcher adheres to what was agreed upon between her and the participants and engages in a reciprocal process of giving feedback about the research. The consent form served as the agreement between myself and the participants, stipulating the roles and responsibilities of each party clearly, including that feedback regarding the analysis of the data would be required of each participant. Additionally, upon completion of this thesis, the full document will be sent to each participant as another measure of providing feedback to the participants about the entire research project based within the literature.

Thirdly, qualitative research involves people, which requires of the researcher to conduct a "*risk assessment"* (Merriam, 2009, p. 233), which determines the level of risk the research poses to the participants. Once again, the consent form stated all foreseeable risks, and possible feelings of discomfort, that might arise from participating in the research. Additionally, the website details of MedPages were included in the consent form, where the participants could look up the contact details of their nearest psychologists if they felt at any time that their participation in this research could cause them psychological harm.

Fourthly, it is the researcher's ethical responsibility to maintain "*confidentiality"*, in order to protect the participants' identities (Merriam, 2009, p. 233). This was ensured in multiple ways. None of the participants' names or other identifying information was used in the writing up of this thesis. The data collected was only viewed and interpreted by myself and my supervisor. Furthermore, the protection of data was ensured by storing it on a password protected laptop, as well as using email encryption software to protect the information sent via email between myself and the participants. The encryption certificate can be found in Addendum C.

Fifthly, "*informed consent" (*Merriam, 2009, p. 233) has to be obtained through being transparent about the purpose and goal of the research, as well as ensuring voluntary participation. As previously mentioned, the purpose of the research was explained fully in the consent form. This document also contained a section explaining to the participants that they had a choice whether they wished to be in this study or not. It was further explained that they may withdraw at any time from the research without consequences of any kind, and that they also have the right to refuse to answer any questions if they did not want to and still remain in the study. To protect the participants in the unlikely event of harm, they were informed that I may withdraw them from this research if circumstances arose which warranted doing so.

The sixth point stipulated that "*data access"* (Merriam, 2009, p. 233) is the researcher's ethical responsibility and should be addressed by ensuring that any research data is safely protected to safeguard against unauthorised access. As mentioned, the data was stored on a password protected laptop, and emails between myself and the participants were encrypted.

Lastly, the researcher should receive "*advice*" (Merriam, 2009, p. 233) and guidance throughout the research process through regular supervision with an experienced researcher. Mrs. Perold from the Department of Educational Psychology at the

University of Stellenbosch was my supervisor, and was available for regular consultation to ensure the credibility and ethical soundness of this research project.

Doing research in online communities, such as Facebook, is a relatively new practice, and as such, regulations around ethical conduct are not as clear as with traditional research methods (Brownlow & O'Dell, 2002). Sharf (1999, in Brownlow & O'Dell, 2002, p. 690-691) proposed 5 guidelines that pertain specifically to respect, confidentiality and privacy when doing research in online communities.

Firstly, *"before starting an investigation and throughout the duration of the study, the researcher should contemplate whether or not the purposes of the research are in conflict with or harmful to the purpose of the group"* (Sharf, 1999, in Brownlow & O'Dell, 2002, p. 690-691). To address this, I posted an invitation to participate in the research on the Facebook support group's wall. This invitation stated the proposed research, as well as indicating that if any member of the group (whether as a participant or non-participant of this research) experienced aspects of this research as having a negative impact, they were welcome to contact me, and if I felt convinced that aspects of this research had a negative impact, such aspects of the research would have been discontinued. No one contacted me to express their concern about the research.

Secondly, *"the researcher should clearly introduce himself or herself as to identity, role, purpose and intention to the on-line group or individuals who are the desired focus of the study"* (Sharf, 1999, in Brownlow & O'Dell, 2002, p. 690-691). The consent form stipulated that I am a Master's student in Educational Psychology at the University of Stellenbosch, completing a research project in fulfilment of the requirements of the degree. This document also included the purpose of the research, as well as the role and responsibilities of the researcher and the participants.

Thirdly, *"the researcher should make a concerted effort to contact directly the individual who has posted a message that he or she wishes to quote in order to seek consent"* (Sharf, 1999, in Brownlow & O'Dell, 2002, p. 690-691). The consent form indicated that participants who agreed to this research consent to their exchanges within the Facebook support group, as well as their responses from the electronic questionnaires, being used in this thesis. All participants signed and returned their consent forms.

Fourthly, *"the researcher should seek ways to maintain openness to feedback from the […] participants who are being studied"* (Sharf, 1999, in Brownlow & O'Dell, 2002, p. 690-691). The consent form stated that I would provide each participant with feedback about my interpretations of their responses to the electronic questionnaires, as well as my observations from their activity in the Facebook support group. The participants were in turn invited to give honest feedback regarding these interpretations to ensure that accurate descriptions of their own words and experiences were guaranteed.

Lastly, *"the researcher should strive to maintain and demonstrate a respectful sensitivity toward the psychological boundaries, purposes, vulnerabilities and privacy of the individual members of a self-defined virtual community, even though its disclosure is publicly available"* (Sharf, 1999, in Brownlow & O'Dell, 2002, p. 690-691). All members of the group were informed by means of a post on the Facebook support group's wall that information shared by members of the group who did not wish to participate in the study was not to be included in the research.

3.6. CONCLUSION

This chapter served as a thorough overview of the complete research process. Firstly, the research design was discussed based on the model of a case study. The reasons for choosing this design were stated, as it seemed to fit the purpose of the research as a whole. Secondly, the research paradigm was depicted according to three crucial aspects of research, namely ontology, epistemology and methodology. Adding to this, the methodology of this research study was further clarified through providing in-depth descriptions of the purposive nature of participant selection, the data collection process, as well as the process of reducing and analysing the data. Another crucial aspect of qualitative research is explaining how validity and reliability throughout the research process is ensured and maintained. This was discussed based on five features of qualitative research, namely credibility, transferability, dependability, confirmability and crystallisation. This chapter was concluded with a section dedicated to the importance of researcher reflexivity, as well as the ethical considerations that were taken into account to ensure sound ethical research practices. By giving a thorough overview of the complete research process, the researcher is enabled to portray the research findings in a structured manner, followed by a discussion of these findings. Chapter Four will therefore attend to the presentation of the research findings, as well as the discussion thereof based on the literature.

CHAPTER 4

RESEARCH FINDINGS AND DISCUSSION

4.1. INTRODUCTION

This chapter serves the purpose of outlining the categories and themes that emerged from the research process, followed by a discussion thereof as it relates to answering the main research question, which is:

> *What value do parents of children with autism who participate in an online social media support group, attach to their participation in the group?*

The following sub-questions were aimed at adding to my understanding of the parents' experiences:

> *What were their reasons for joining this online source of support?*
>
> *How does their participation contribute to their meaning-making of their daily experiences regarding their child's diagnosis?*
>
> *What is the nature of the information shared among parents in this group?*
>
> *How does their participation contribute to their coping skills and their identities as parents?*

Figure 4.1 is a diagram of the three main categories of findings that emerged during the research, each with its own themes and subthemes. This serves as a broad overview for the presentation of the findings, as well as the discussion thereof to follow in the rest of the chapter.

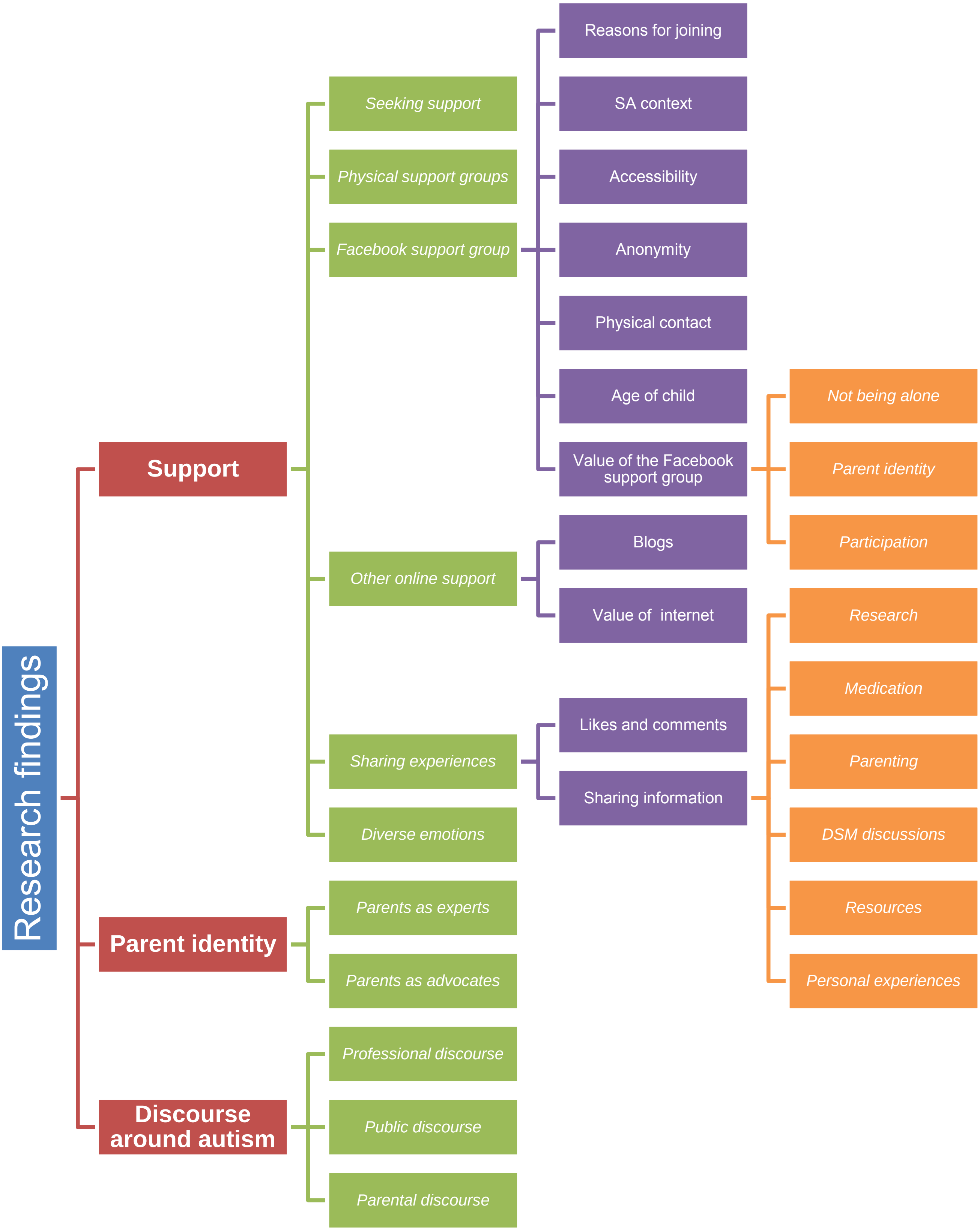


Figure 4.1: Diagram of thematic content of research findings

4.2. CONTEXT OF THE RESEARCH

It is perhaps necessary at this point to introduce the participants, the context of the support group, and an event that might have impacted on the interactions within the Facebook support group, before presenting the categories and themes that emerged, in order to provide background to these themes.

Seeing that most of the members of the Facebook support group were female, the participants that responded reflected this occurrence. Eight of the participants were female, and two were male. The ages of the participants ranged between early forties and early fifties, with almost all of the participants having obtained tertiary education, as well as being married or in a partnership. The ages of the participants' children with autism differed from early childhood to adulthood, indicating quite a diverse range of experiences among the parents related to their child's autism.

April is known internationally among the autism community as World Autism Awareness Month. Each year a variety of organisations around the globe launch campaigns to create more awareness among the general public regarding autism, in an effort to reduce the stigma and perceptions around it, as well as advocating for the rights of people with autism. One such local organisation is Autism South Africa (ASA). On 20 March 2013, ASA sent notice to all its members of a planned campaign named the "*Talk about autism campaign*" that was based on controversial statements regarding autism. This campaign took the stance that these statements will create curiosity among the general public to find out more about autism, and as such, create more awareness. This notice can be found in Addendum E. These statements were:

Autism is for retards
Autism is for whites only
Autism is for blacks only
Autism is for spastics
Autism is for violent people
Autism is for the possessed

However, the actual launch of the campaign, with very graphically illustrated billboards and full-page advertisements in major South African newspapers, had an enormously negative impact on the South African autism community (Chipangura, 2013; SAPA, 2013), which consequently saw the campaign being retracted soon after its launch. The impact of this campaign was reflected in the dynamics within the Facebook support group, as well as participants' reactions to the electronic interview questionnaire, as one parent pointed out:

> *Sadly, divisions in the physical world do impact on the online world. The recent campaign by Autism South Africa, featuring posters stating for example that "Autism is for Possessed People" did cause a great deal of division with the result that some people from both sides in the ensuing fight, have reduced their participation in the [Facebook] Support Group [Parent 4]*

Additionally, from hereon I will refer to the participants as parents, because it was in that capacity that they responded to this research, and I feel that in referring to them as parents, instead of participants, their authentic role is valued.

4.3. THEMATIC CONTENT OF RESEARCH FINDINGS

The next section depicts the three categories of findings that emerged from the research, along with its various corresponding themes and sub-themes.

4.3.1. Support

Support emerged as one of the main categories of the research findings, which was then sub-divided into various themes matching the description of support, as discussed below.

4.3.1.1. Seeking support

It would seem that the impact of receiving a diagnosis of autism for their children played a large part in activating the parents in seeking support, as well as information, from various sources. Educating themselves about autism and where to find relevant services were a commonality among the parents' responses.

The parents described a variety of thoughts and feelings they had upon receiving the diagnosis. A sense of resilience and intuition was described by a few parents:

> *Made me tougher [Parent 1]*
>
> *The final diagnosis just makes explaining easier [Parent 2]*
>
> *By the time the diagnosis was formalised, I had already done a great deal of research into ASD and remediation. For this reason, we were well prepared [Parent 4]*
>
> *It gave clarity to things I already thought was going on [Parent 6]*

Devastation, denial and uncertainty in some of the other parents' responses were prevalent:

> *I was absolutely devastated […]. I knew [my child] had a lot of problems, although in the back of my mind I hoped [my child] would outgrow them [Parent 3]*
>
> *I was not sure what "Autism" meant. I only realised much later on what effect it has on us as a family [Parent 5]*
>
> *Major emotional breakdown as once the diagnosis was received, there was no help or school available immediately [Parent 7]*

However, it appeared as though these parents were spurred into action to educate themselves, as well as finding services and support for their children and for themselves, despite the impact the diagnosis had on them. One parent affirmed this when she said: "*My grief lasted all of 24 hours because I went into survivor-mode and started researching ways to help [my child] be the best [my child] can be*" [Parent 7]. Professionals, such as doctors and therapists, and various autism-related organisations, such as schools and associations for autism, were among the formal support structures that were available. Social support was sought in various ways. Some parents joined support groups as a place to meet other parents with children on the autism spectrum; others felt that support groups weren't as freely available to them, but that family support along with support from friends and other parents with children with special needs were helpful. The internet was also mentioned as a means of seeking information, and a source of support through various Facebook groups.

> *My husband and I joined a support group. Also got support from friends and the therapists who worked with our son [Parent 1]*
>
> *Mostly from my son's paediatrician at the time. His speech therapist was really great, as well as the occupational therapist. My parents do not always understand, but remains (sic) supportive [Parent 2]*
>
> *Autism South Africa was a source of information. I also received support from paid professionals, i.e. [my child's] various therapists [Parent 3]*
>
> *Support, primarily from friends, and his speech therapist [Parent4]*
>
> *International Autism Support Network on the internet. [The Facebook Support Group]. "Ask me I'm autistic" facebook page [Parent 6]*

4.3.1.2. Physical support groups

In seeking support, the majority of the parents belonged to physical support groups in the past; however, only a few of them currently attend support group meetings. Some of the main reasons given for not being able to attend support group meetings any longer were time and transport constraints. Parent 4 said that they weren't able to attend support group meetings "*due to the distance and time of the meeting*" and Parent 7 similarly answered that it is often difficult to attend meetings due to "*other commitments like lectures, child unwell, […], transport cost*." Yet another parent answered:

> *Unfortunately I was not able to attend more due to work constraints. The scheduling was such that I could not attend [Parent 2]*

For the parents that do still attend support group meetings, it seems to depend largely on two factors: relevant topics presented at the formally structured meetings, and the social nature of informal gatherings. To put this into context first, the parents gave a description of the difference, in their opinions, between formal support group meetings and social support gatherings, which consequently influence their decisions regarding attending.

> *The first group who hold monthly meetings target parent training, support, information talks, general family get-togethers, sibling support, aspie support. The second group […] provide[s] an informal and relaxed social outing. There is no agenda and each person is respectful of other members. It is an opportunity to meet up with other parents (generally Mums) who have a child with special needs. We have been known to have some good laughs over the years! [Parent 3]*

> *I only attend [the formal support group meetings] if the topic is relevant. [Social] group I attend if I have time [Parent 1]*

According to the parents, formal support group meetings are usually held at specified intervals, for instance once a month, and are mostly facilitated by either a professional or an involved parent. These meetings typically target a specific topic, and often a guest speaker is invited regarding that topic. Afterward, an opportunity is given for discussion, either in the form of a "Question and Answer" session or small group discussions. Parent 1 said that the formal support group meetings that she attended had "*a guest speaker talking on topics related to ASD*" with a "*Q and A after*". The parents who attend formal support group meetings do so based on the topic of discussion, and whether it is relevant to them or not:

> *I don't attend every meeting of the […] group, as at times the topic for the month is not something that I may be interested in or perhaps I already have enough knowledge in (sic) the subject [Parent 3]*

In contrast, the social support gatherings seem to be much more informal, in the sense that they are organised by parents, for parents, with no facilitation:

> *[Social] support group was general chit chat/ casual discussion about random Autism related topics. […] It is relationship oriented [Parent 1]*
>
> *The [Social] group is a lot less formal and is very relaxed. I prefer the informality of the group and I also really appreciate that we don't just talk about autism the whole time! [Parent 3]*
>
> *This group was more for support and socialising [Parent 2]*

In terms of preference between the formal support group meetings and the social gatherings, there did not seem to be any. Positive qualities of both scenarios were given, with the formal meetings being educational and informative, as well as providing opportunities to network, and the social meetings providing some time for leisure:

> *The first group is informative and very helpful to parents and carers who are new to autism. In fact it is beneficial to all that attend for a variety of reasons. The second group is a lot less formal and is very relaxed. I prefer the informality of the group and I also really appreciate that we don't just talk about autism the whole time! [Parent 3]*

Another positive quality of both types of support meetings was value attached to the interpersonal interactions that it entailed for the parents who attended. Sharing experiences with other parents who understood, and who could shed light on their child's behaviour, was valued, along with meeting new people and being part of a community:

> *Shared experiences, with no judgement on child behaviour [Parent 2]*
>
> *One gets advice from other parents who have gone through or who are currently going through what we are and they share what has worked for them [Parent 5]*
>
> *[It] has enabled me to meet so many different people from all walks of life. It is an equalizer, no matter what race, religion or financial status we may have. We all have that common bond of autism and that makes us a community [Parent 3]*

4.3.1.3. Facebook support group

All of the parents who participated in this research are long-term members of the Facebook support group, with membership of more than a year and a half.

The reasons for joining this specific Facebook support group ranged from being curious about belonging to such a group, to learning from other parents who are in similar situations and also sharing personal experiences or advice in an effort to help others.

> *I believe strongly in the social construction of knowledge and membership of a group such as this would allow me to learn and to help [Parent 4]*
>
> *To get to know and hear of other parents and their concerns. To share with them and to give advice and to receive advice [Parent 5]*
>
> *To gain insight from parents in the same situation [Parent 6]*

It would thus seem as though the participants were looking at receiving support as well as providing support to others.

Another important factor seemed to be that the Facebook support group was aimed at the South African context, which made it different to other Facebook support groups that have international membership:

> *This was the only local group I felt comfortable in [Parent 2]*
>
> *To be part of a South African online group of parents [Parent 3]*

Whereas time and transport constraints limited participation for some parents in physical support group meetings, the accessibility of the Facebook support group was highlighted. The parents did not have to take time out from their days to participate in the Facebook support group, as they could post or comment on other posts at any time of the day. It also provides access to a diverse range of information from many different people:

> *Online support groups are always accessible, even if I lie awake at night with a question; there are not time constraints to posting a question or a comment. I prefer online groups, because it fits in with my schedule. It is also accessible when an issue arise (sic), I don't have to wait for a scheduled meeting to discuss something. I can also withdraw for a time without feeling bad about it. [Parent 2]*

> *The primary difference is accessibility. Barring internet connection issues, the group is available to post to 24/7. There is no schedule as such and no topic at a given date and time [Parent 4]*

> *Online support groups are immediately available, they do not expect you to leave your home or your work or your child to attend the group. Online support groups provide you with a wide variety of people with a wide variety of knowledge and contacts for help [Parent 6]*

Building relationships with members of the group was also not necessary, and in a sense the anonymity of communicating in a virtual space was seen as a benefit, in contrast to physical support group meetings where some members might not be comfortable to share so openly:

> *Some people are more comfortable asking strangers for advice or a supportive ear without the added stress of forming a "relationship" first. Not everyone is comfortable with one-on-one or public sharing. Also, it is helpful to have many different views regarding one issue. The varied responses online and the wealth of information and knowledge online can't be beat (sic)! [Parent 7]*

It was prevalent how the anonymity given by the Facebook support group also removes certain social norms, such as good manners, perhaps based on non-verbal communication cues, which would be seemingly more intact during face-to-face contact:

> *People are quick to take offense, which goes to show that it is impossible to have a conversation when you are actually not in front of that person OR even on a phone call. Words alone are not enough. We need to see facial expression, body language and hear what is being spoken. I find that people are much more polite face to face. The internet tends to be anonymous; therefore people feel they can say whatever they wish without regard to how the words may be perceived. People are far more*

> *respectful face to face. It is possible to have a difference of opinion, however, I have found that it doesn't get out of hand when you are in the physical presence of the person you are talking to. Being able to read the other person's facial expression and body language is of huge importance to me [Parent 3]*

> *One of the problems at times is that words can sometimes be taken out of context as there are no visible clues as to their intent [Parent 4]*

> *The on line group has no accountability. The live group people control their language and are respectful in their expressions if they disagree with something [Parent 1]*

> *It is, however, easier to misunderstand a comment or post, as there is no interpersonal cues to follow on interpreting something [Parent 2]*

A further comparison between support group meetings and the Facebook support group pointed to the physical comfort gained from actual contact that is absent in online support:

> *There are emotions shared in a physical contact group and tears that cannot really be shared online. Nothing can be beat a real, warm HUG! [Parent 7]*

> *Physical support groups helps in that a virtual hug is simply not the same as a real one. The support is more real in physical groups [Parent 2]*

It would also appear as though the age of the child with autism impacted on the parent's participation in and experience of the Facebook support group, seeing that the need for constant, day to day support was not necessary so much when the child is older, as well as having different parental needs with an older child with autism:

> *I am no longer at the place where I need support on a daily basis. My [child] is [an adolescent]. […] Most of the experiences expressed in the group are difficulties we have overcome and are no longer facing [Parent 1]*

> *I am sure that the age of the child and where the parent is in the whole process of coming to terms with having a child with autism makes a huge difference on how they engage with an online support group. I feel that*

> *online groups are very helpful for parents in the early days as they receive the support and can also get a lot of information/feedback [Parent 3]*
>
> *I find that the group is mainly of the younger generation whose Autistic children are still young. One ultimately needs a group for Adult Autistics. I was hoping to be able to share more with parents who have Adult Autistics and who can help with their experiences. At times there's not much help for Adult Autistics in the form of advice and suggestions for parents [Parent 5]*

In conclusion, the parents were asked questions with regard to the value of the Facebook support group, to determine how it contributed to their daily experiences, and what impact it would have on them if they were no longer able to participate in this group.

- **Not being alone**

The sub-theme of not being alone was raised, as well as being able to witness other families' successes, share personal experiences, and obtain valuable resources from other members of the group:

> *That I am not alone in the issues I have to deal with. It helps that someone out there found a solution/explanation or coping mechanism [Parent 2]*
>
> *I think we are all in a unique situation in that we all have our ups and downs concerning our children and not all Autistic kids are the same. At times one can relate to others' experiences with their kids and give advice as to how we coped in that same or similar situation [Parent 5]*
>
> *It makes one feel less alone and it gives you methods that worked for other parents that you could try in helping your own child [Parent 6]*
>
> *I have used many references/links to help with speech/OT as we cannot afford weekly OT/speech – it has to be one or the other! I have gained hope from the success of other parents' kids – inspiration from their personal journeys. Learnt techniques/teaching methods from other parents [Parent 7]*

However, to some parents the Facebook support group contributed less to their daily experiences. Parent 1's child is older, and she, therefore, felt that the group does not currently add value to her life; however, she does "*like to see how other families [she knows] are doing*." Another parent stated that their child "*is a high functioning autistic and to some extent this results in a sense of exclusion as I cannot identify as readily with situations as some others might. To this extent the group contributes less to our sense making than it might for others.*" It would appear then that each parent's situation is unique, and that there might be times where the information shared and their own participation in the Facebook support group is of value to them, and at other times not so much.

- **Parent identity**

Other responses that shed more light upon the value of the Facebook support group in the parents' lives revolved around the question of what they as parents believed of themselves currently (their identity), that they might not have believed before joining the group. The responses indicate that the group in actual fact did add some value to their beliefs about themselves as parents, albeit in very different ways:

> *I used to think I was struggling, but when I see what others say I realise I am doing well. I would probably not have realised that in its fullness if I didn't know how difficult other families found being parents of kids with ASD [Parent 1]*
>
> *That I did the right thing at the right times [Parent 2]*
>
> *I want to remain open minded and accept that, although we all have children with autism, we actually are travelling our own journeys. I now feel that it is important to be non judgemental [Parent 3]*
>
> *That I may have got something right after all [Parent 5]*
>
> *I am not alone and my child is not unique in difficult behaviour [Parent 6]*
>
> *That I can actually be of assistance to others irrespective of how long ago their ASD journey started [Parent 7]*

- **Participation in the Facebook support group**

Each parent had different experiences regarding their participation in the Facebook support group, as it varied according to their current situations and needs. Parent 1 stated that she found some shared information on Facebook helpful, as well as notification of upcoming events. However, her own participation online were mostly limited to sharing humorous video clips or jokes, and rarely commenting on others' activities on Facebook. There were other parents too who saw themselves as more inactive within the Facebook support group:

> *I very rarely share any information on the Facebook group [Parent 3]*
>
> *At this stage I am not really sharing at all! I feel guilty because I don't talk much online – but I really do not have time [Parent 6]*

However, in contrast, these parents utilised other online mediums, such as blogs, other Facebook groups, or their personal Facebook profiles, to share their experiences, reflect on them, and to get supportive feedback from others. In Parent 6's case, with not having time to share, it would still appear that the information shared by others online contributed to her sense of belonging to a community and not being alone, because not being able to access the internet any longer would have a very big impact on her as "*the internet brings support and information within seconds*."

The parents were also asked what the impact on them would be if they were no longer able to participate in the Facebook support group. The impact of the ASA campaign was reflected to some extent in some of the parents' responses, as they had negative experiences within the Facebook support group due to the campaign:

> *Since [April], I have refrained from posting or commenting on the Support group. […]. The huge negativity and hate-mail that went around after the Autism South Africa Advertising Campaign was too much for me to deal with [Parent 7]*
>
> *The recent campaign by Autism South Africa […] did cause a great deal of division with the result that some people from both sides in the*

> *ensuing fight, have reduced their participation in the [Facebook] Support Group. Yes, I have had negative experiences […] within the [Facebook] group. Particularly over the recent ASA campaign. If I were asked, I would in fact say that was applicable to most as usage of the page seems to be down since then and I know of people who used to participate actively who now no longer do [Parent 4]*

As such, some parents felt that not being able to participate in this group anymore would not have an impact on them. Other parents indicated that it would create a feeling of loss and isolation:

> *None [Parent 1 – in response to the question about the impact of not being a member of the Facebook support group anymore]*
>
> *I will feel the loss acutely [Parent 2]*
>
> *It wouldn't really make an impact [Parent 3]*
>
> *It would upset me a great deal. I believe that the group benefits me and others and if I were not a member, I would lose the privilege of knowing some wonderful people [Parent 4]*
>
> *I would not be able to share my experiences anymore [Parent 5]*
>
> *I would feel a bit lost and alone [Parent 6]*
>
> *In this case (with regards to ASA campaign), I am happier [Parent 7]*

4.3.1.4. Other online support

Although the focus of this research was primarily on the Facebook support group, I felt it necessary to explore the value of other online support as well, especially in the light of the ASA campaign and the effect it could have had on the parents' participation in and experience of the Facebook support group.

- **Blogs**

All of the parents indicated that they followed a variety of blogs, which can be described as an online journal where the creator of the blog records personal experiences, ideas, opinions and so forth. These blogs are available on the internet for viewing by any person, and blogs usually include an area for comments from others as well. The value of reading other people's stories varied from parent to parent depending on their personal opinions. Some found the subjectivity of blogs, as it is only one person's perspective, of less value, whereas other parents felt the content of the blogs resonated with their own experiences:

> *I do not find them helpful as they are usually one person's opinion about their experiences with their own child, so very subjective […]. I find them interesting at times, but largely unprofessional [Parent 1]*
>
> *I follow their journeys out of interest. It is really more about the connection of being an autism parent and sharing the road with others in the same boat. The impact of the content doesn't really stand out for me, although as mentioned, I do enjoy reading other peoples' journeys [Parent 3]*
>
> *The blogs I do follow tend to mirror my own in that while they are written by parents they deal more with non-parenting issues. Outside the issue of parenting these blogs […] do impact largely on my perceptions of what is happening [Parent 4]*
>
> *I appreciated reading about why my child does certain things and how to handle [my child] when [my child] does. So it does help tremendously to be able to 'get inside [my child's] head' and the only way to do this is for another Autistic [person] to share his or her experiences with us [Parent 5]*
>
> *It actually brings some comic relief at difficult times [Parent 6]*
>
> *I am hugely inspired by various writers and Psychologists (Bill Nason). I have yet to find one thing about autism that he has written on the Autism Discussion Page that I disagree with. I learn everyday from this page! [Parent 7]*

Two of the parents have their own blogs, and another parent indicated that her personal Facebook profile is the platform that she chooses to share her daily experiences. For these three parents, being able to write about their own stories, and receiving feedback from others in the form of comments, seemed to be an important aspect of the way in which they made sense of their daily experiences:

> *I use it as a way of reflecting on my experiences with raising my [child]. Documenting our journey keeps me focused and motivated to keep moving forward. It is lovely to receive positive comments and I have built up a regular readership. I like that there are other people out there who follow my line of thought and who enjoy following our journey [Parent 3]*
>
> *The blog in many ways contributes more to my daily sense-making than the Facebook page as it is more reflective than my Facebook posts. That being said, while it deals with parenting an autistic child, it also deals with other autism related issues [Parent 4]*
>
> *I do not have a blog, but my personal Facebook page is my daily sharing of ASD-related experience. It also helps knowing that I am not alone! [Parent 7]*

- **The value of the internet**

In response to questions regarding the value of the internet in the parents' lives, where I asked what impact it would have on them if they were never able to access the internet again, ambivalence was communicated. The responses varied from no impact, to a feeling of devastation and loss. The interpersonal nature of some of the connections made online would be missed, but it seemed that the initial loss could be overcome:

> *None [Parent 1]*
>
> *Acute loss. I will feel isolated [Parent 2]*
>
> *I think that initially I would miss the contact; however, over time I don't think I would miss the interaction with the other bloggers. Although, saying that, I would remain in email contact with a select few [Parent 3]*
>
> *Lord, my response here jumps between being devastated and saying "so what". […]. I am certain I would miss the relationships and the information, but then there would be more focus on the local community and that is not necessarily bad [Parent 4]*
>
> *I would feel isolated and lonely [Parent 5]*

> *A very big impact, the internet brings support and information within seconds [Parent 6]*
>
> *I will be devastated! It is the internet that has got me to "meet" the people that have helped me help change my child's life from hopeless to "unlimited possibilities". Hundreds of people have had an impact on my personal journey – […] my greatest help came from contacts on the internet – so NO – don't take my facebook/internet away!!! [Parent 7]*

The next section will discuss in more depth the theme of sharing, as it has already been highlighted as one of the most important aspects of online support, within the Facebook support group as well as other online platforms.

4.3.1.5. Sharing experiences

The theme of sharing was one of the most prominent aspects that came about from this research, which was prevalent from an analysis of the parents' interactions within the Facebook support group, as well as from their responses to the electronic interview questionnaire. The theme of sharing is included in the category of support, because the very nature of the multitude of information shared within the Facebook support group is based on the assumption of receiving and providing some measure of support. Even the ASA campaign resulted in sharing among the members of the Facebook support group, which will be discussed in more detail in sections 4.2.1.6 and 4.2.2.

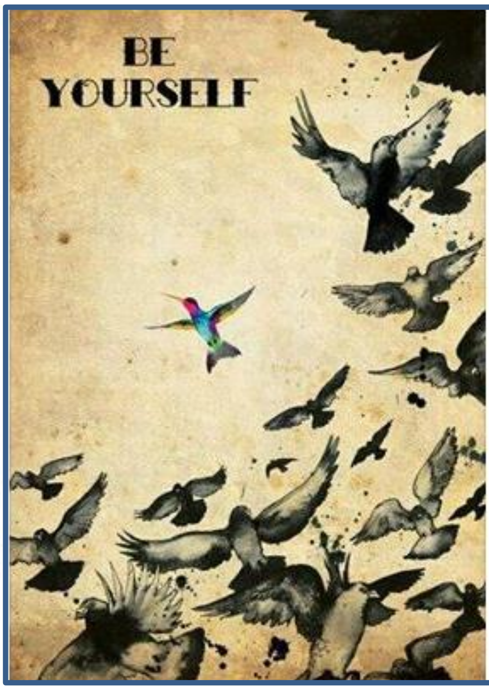
My analysis of the communication exchanges within the Facebook support group over a three month period yielded a variety of topics that were frequently shared among the parents. A simple word search of the coded themes that were generated from the analysis of the participating parents' interactions within the Facebook support group revealed the quantity of each theme's appearance within the three month observation period, as shown in Table 4.1:

CODES	AMOUNT
Likes	397
Comments	106
Information:	95
Research and news	44
Methods (medication, parenting)	13
DSM & ICD discussions	38
Resources	10
Experiences	73

Table 4.1: Appearance of coded themes

- **Likes and comments**

Firstly, at surface level, by just looking at the quantity of “likes” and “comments” on other group members’ posts, it already became quite apparent that interaction was frequent within the Facebook support group, as there were rarely posts that were not liked or commented on by at least another person. By “liking” someone’s post or comment, by definition that person is affirming or supporting what the other person posted. To clarify, people can post written or visual content. Written content refers to words written by individuals themselves, whereas visual content refers to either pictures or video clips. Either way, posting written or visual content conveys certain messages; the person who “likes” that content, therefore, affirms its message. Figure 4.2 below, as an illustration of a combined post with visual and written content, was posted by a parent, with the message of hope conveyed in a quote by Emily Dickinson. This post had 5 “likes”:



Hope is the thing with feathers that perches in the soul and sings the tune without the words, and never stops at all.

~Emily Dickinson

Figure 4.2: Facebook support group post about hope (5 May, 2013)

- **Sharing information**

Secondly, sharing of information among the parents in the Facebook support group covered a wide range of topics. It varied from sharing current research or newsworthy events regarding autism, to sharing with each other various methods that have worked or not, such as various methods of parenting or medication.

○ **Sharing research**

An example of sharing research was when a parent posted a website link to an article regarding brain plasticity:

> ***Parent post:*** *Brain elasticity happens at synapse level (where many think that the problem with the autistic brain lies) - research is indicating that getting out and experiencing life might be a good thing to help dendrites fire.* *http://www.the-scientist.com/?articles.view%2FarticleNo%2F35514%2Ftitle%2FThe-Neurobiology-of-Individuality%2F*

- ### Medication

Conversations about various types of medication also occurred, with some parents asking for others' opinions or experiences regarding medication:

> ***Comment 1:*** *From what I have read their (sic) is one important aspect that must be considered - is the child's inattention due to autism (sensory overload for instance or sensory seeking or avoiding) or is it due to ADHD. Not all fidgety, distracted or inattentive behaviour is ADHD. I am not sure if that is accurate though as I cannot remember the source so I cannot tell you that it was from a reputable source.*
>
> ***Comment 2:*** *Fizz C to the rescue. We found out, by accident, that it calms [my child's] anxiety and meltdowns. Chatted with doc. He says it is quite possible as it helps to neutralise chemicals released into the body due to stress. […]. Also, he said that in many people who are on seizure control meds (and in particular Auties who are picky eaters to start with) should be on a good supplement as one of the side effects of seizure meds is that it depletes the body. Thought I would share just in case I can help someone else.*

- ### Parenting

With regards to parenting methods, one parent asked for others to share their personal approaches in order to give helpful guidelines to a new facilitator, which received 8 comments:

> ***Parent Post:*** *You all have a wealth of expertise that I would be honoured to draw on as I am compiling training notes for the new facilitator. If there is a teaching method tip or a behavioural management tip that has helped you; please post it here or inbox me. (I am thinking those "out-the-box-thinking-stuff-that-you-do-that-is-not-in-the-'schools-of-thought'-that-you-figured-out-through-common-sense-and-necessity").*
>
> ***Comment 1:*** *Increase wait time for processing information (at least 45 seconds). Use experience sharing language (20% imperative, 80 % declarative). Think *out loud* so that the*

*child hears your thoughts. Don't be repetitive. Cut back on the talking! At all times be mindful of giving the child lots of opportunities to *think* for him/herself.*

- **DSM discussions**

Table 4.1 also indicated that a large amount of discussions in the Facebook support group centred on the pending release of the DSM V, and the possible implications it might entail for the autism community, as well as its impact on another international classification system called the International Classification of Diseases (ICD). A parent posted the following in reference to the release of the DSM V, which received 23 comments from other parents in the Facebook support group:

Parent Post: *For those of you whose kids had a diagnosis of Asperger's Syndrome, please remember that as of 18 May, the American Psychiatric Association requires you to consider your kid as the child formerly diagnosed with Asperger's Syndrome.*

Comment 1: *Or you could go with the ICD-10 criteria (ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems, by the World Health Organization) where Asperger's syndrome is still an active diagnosis.*

Comment 3: *Oh, I fully intend going with ICD 10 and where necessary pushing for its use. A number of medical aids though use DSM and that concerns me because based on that they determine what therapies are appropriate to pay for.*

Comment 4: *Actually the DSM is the most commonly used diagnostic manual and I will not be surprised if the WHO (World Health Organization) follows its definition in due course.*

Comment 5: *I am not sure that ICD will move in the same direction because the NIMH (National Institute of Mental Health) have rejected it and acceptance is lukewarm even among the APA (America Psychiatric Association).*

Comment 7: *In addition to that, the DSM at one stage had autism as a psychotic disorder called childhood schizophrenia (or*

> *something like that) and the result of that is that TO THIS DAY the education department of [a South African university] sites autism as an example of a psychotic disorder. These things do matter!*

- **Resources**

Thirdly, the parents shared an extensive amount of resource information based on their own experiences, which covered the contact details and names of various professionals, to asking about others' opinions of specific autism-related therapies, as well as applying for disability grants:

> ***Comment 1:*** *Yes. [Your child] qualifies for what is called a care dependency grant if he is younger than 18. Older is disability grant. Take your ID and [your child's] birth certificate to the nearest SASSA (South African Social Security Agency) office and request to apply for care dependency grant*

> ***Comment 2:*** *There's a very gentle and understanding Dentist in Pretoria Moot - Riviera area - backside of Union Buildings - if you are interested*

> ***Comment 3:*** *I've heard of it; but not sure what the costs are [in response to a query about Tomatis therapy]*

> ***Comment 4:*** *Fanitsa (educational psychologist) is super brilliant! She knows autism and Asperger's so well... Not only does she do a full thorough assessment and 8 page report back, but her suggestions for the next year are brilliant! Highly recommended!*

- **Personal experiences**

Lastly, sharing of personal experiences encompassed an emotional aspect of the interactions between the parents in the Facebook support group, which will be discussed in more depth in section 4.2.1.6. Sharing the joys and accomplishments of their children often received much positive feedback from other parents in the group. It conveyed a sense of pride in their children that was worth sharing with others, as well as knowing that these accomplishments would be understood by the other parents in the Facebook support group. Apart from accomplishments, difficult experiences were also shared, and once more the feedback from other parents in the group was supportive and empathetic, often in the form of giving advice on how to deal with the difficulties, or some verbal encouragement:

Parent Post: *Dear friends, I need assistance with our little [child]... [Our child] is very difficult lately. We have gone through rough changes the past three months (new home, new school, new town, [our child] stopped using nappies AND [our child] gave up the bottle!) - at this stage [our child] is very difficult and seems to be deliberately naughty - e.g. jumping up and down in front of the TV when we are watching, refusing to move; ignoring ALL instructions, throwing tantrums if we do not do what [our child] wants us to do... very aggressive, demanding attention ALL the time... Attacking us and generally being very anxious and frustrated. I have no idea how to relieve the situation or make things easier for [our child]... Please help!*

Various parents responded with advice about routine, as well as encouragement. Another parent shared an experience about an outing they had:

Parent Post: *So today, for all of 20-30 minutes [my child] decided, no, insisted [that my child and a friend] was going to play "skittles" - Ten-Pin-Bowling - at Gateway. They loved it, till the sensory input became too much for [my child] and I stopped it. Part of me is so proud of [my child] for "putting herself out there"; part of me want (sic) to stand up and shout "WHY the hell do you have to put your frigging music so loud?!!!"*

Comment 1: *It is, sadly, the modern, inconsiderate way. But I am so proud of [your child] for coping for so long and so well.*

The sharing of personal experiences can be seen as based on various emotional aspects, in the hope of receiving positive feedback and support from others who witness and understand the parents' successes, struggles and frustrations. The next section delves into the diversity of emotions that were uncovered during the analysis of the interactions between the parents in the Facebook support group.

4.3.1.6. Diverse emotions

The exchanges between the parents in the Facebook support group revealed an emotional aspect which seems to be part of the daily experiences they have to make sense of. The range of emotions underpinning the exchanges in the Facebook support group could be divided into two categories. The first category would refer to emotions related to daily experiences, such as pride, fear, worry, desperation and being thankful. The second category refers to the fierce emotions sparked by the ASA campaign, which include anger, outrage, shock, disbelief and a feeling of betrayal.

Demonstrating exchanges related to the first category of daily experiences, below are posts or comments encompassing all the mentioned emotions:

> *I think in time you develop a thick skin and the realisation that your kid is better than the arrogant types that pass judgement. Hell, I know my kid is!* ***[Pride]***
>
> *I always worry though about [my child] reaching a plateau and one day finding that [my child] is 16 going on 12* ***[Fear]***
>
> *I have NO idea how we are going to do this, because sitting in that chair may already prove to be troubling point no. 1 and then opening her mouth.... to let a stranger look inside!...* ***[Worry]***
>
> *Honestly I will try ANYTHING to defuse [my child's] attention-seeking aggro* ***[Desperation]***
>
> *AUTISM BLESSING: [My child] as usual didn't sleep the whole night, walked about the house talking in his special world. In the mornings (sic) hour he walked to my side of the bed, said something as I was waking up still and passed something imaginary to me with both his hands. I said thanks [my child] as I always say when [my child] does this, then [my child] said clearly "It is a special Only Blessing Dad". I clearly and humbly said "Thank you my [my child]." I asked for a hug* ***[Thankful]***

The parents' reactions to the ASA campaign indicated that a deep sense of trust in an organisation that they believed to carry their and their children's best interests, were violated, which sparked feelings of anger and outrage. Many of the parents expressed a disbelief that an organisation with professionals, that seemingly had a wealth of knowledge, could be so certain of the success of a campaign they (the parents) felt did more harm than good:

> ***Comment 1:*** *I find this ad and the rest […] f#*#@#*g appalling... It screws up all the hard work of awareness and education other organisations and individuals throughout the country have been doing, including ASA... This takes people 10 steps back... If these ads are meant to educate and inform the people of this country about our kids, then the majority of our people can't even access the internet... So websites and links in fine print are of no use... I'm shocked and bloody disappointed...*

> ***Comment 2:*** *We NEVER expected an organisation like ASA, supported by award winning ad agencies, to be this inept that they did not see how this was not the same thing! One tends to give people who are in the know (supposedly) the benefit of the doubt.*

A few parents posed questions for comments by others about the reason why no one acted against the campaign sooner, before the graphic advertisements were released. Many of the responses indicated that their initial reactions toward ASA's notification of the campaign were left unattended, and that they trusted a professional organisation to do the right thing:

> ***Parent post:*** *I am curious... I hated the ASA ad campaign when I saw it on Monday for the first time...however, […] I have come to realise that many people knew of the actual words to be used in the campaign via THAT email...some did contact ASA according to what I've read...I'm wondering why didn't we raise hell BEFORE it hit the public? Why did those who knew not STOP this from happening and get such an effective result before any billboards were put up...*

> **Comment 1:** *I did send them a message expressing my concern but they never responded and I took the attitude that they are professionals who have been doing this for longer than I have been in the autism world - PLUS they had at least 2 advertising agencies on board. I thought they knew what they were doing more than I did. Also they made it sound that the correction of the myth would be more prominent than it was in reality. At that time they did not show us their graphic images.*

Underpinning the majority of interactions surrounding the release of the ASA campaign was a feeling of utter disbelief that such a campaign could ever be successful in the South Africa context, when taking into account statistical factors with regards to internet access. The premise of the ASA campaign was based on the assumption that the controversial statements would lead people to go the ASA website for more information, where the statements (referred to in the campaign as myths) would be refuted by truths about autism, and as such create more awareness. Additionally, the parents felt that these statements would further reinforce the stigma that exists about disabilities in general and autism specifically:

> **Comment 1:** *The consequences of a school child (whose thinking is concrete) seeing a poster that says autistic people are violent - when he walks into his classroom he is going to look at the autistic boy differently. ASA assumes that he is going to "ask about autism" - he is not. When the taxi goes by and the young girl reads that poster, when she gets home she is going to look at her neighbour who is autistic differently. ASA assumes she is going to "ask about autism". She is not. The social consequence of this is that ASA are putting people at risk.*
>
> **Comment 2:** *As my [spouse] has just said: imagine someone seeing this and a few minutes later seeing a meltdown - the notion of violence and autism as synonymous sealed forever.*
>
> **Comment 3:** *A 2012 survey showed that 5% of our population access the internet via a computer, iPad or droid from home, a further 22 or 27% access the internet via their cellphones - so out of every 3 people who saw that billboard potentially 1 can easily access the web address - if they were*

> *motivated to do so - but with such a negative message who would be? At best if you took into account everyone who has access to the internet in some way (e.g. An internet cafe) that stat would go to 1 in 2. That alone should say to any thinking person - this will not work in SA.*

The emotional impact of the ASA campaign was further expressed by the various parents in the electronic interviews, as well as within the group, with the result that some of them withdrew their participation from the Facebook support group:

> ***Parent 3:*** *I don't need the negativity in my life.*
>
> ***Parent 7:*** *Since [April], I have refrained from posting or commenting on the Support group. The huge negativity and hate-mail that went around after the Autism South Africa Advertising Campaign was too much for me to deal with.*
>
> ***Parent post:*** *I need to destress and will be off Facebook until I decide otherwise.*
>
> ***Parent post:*** *I left ASA and got off their mailing list. I am going to leave here (Facebook support group) for a while too (at least).*

Despite the negative impact of the ASA campaign on these parents, their exchanges within the Facebook support group before and during the campaign presented a different dimension to the research, in that it enabled me to observe how they constructed their identities as parents, which will be discussed in the next section.

4.3.2. Parent identity

The parents within the Facebook support group continuously constructed their own sense of parent identities, especially with regards to being an autism parent. Their exchanges indicated that being an autism parent seemed to mean two things: being experts with regards to their own children with autism, as well as being advocates for the rights of people with autism. Along with being an autism parent, these parents were also able to empathise with other parents in the group because they understood what it meant to be such a parent:

Parent post: *I’ve always known that being a mother was going to be a challenge but being a mother to an autistic child is even harder!!!! The looks, the comments, being disregarded, getting no support… The list is endless… I wonder if things will ever get better… It’s emotionally draining…*

Comment 1: *There is no easy answer and a great deal is very true. Without support it is even harder, but perhaps through this group you can find someone near you that you can get in touch with. This is also the reason this group is here - to share and help - so feel free to scream and rant.*

Comment 2: *Hats off to you […]! Dit is nie maklik om 'n outistiese kind groot te maak en om dan 'n verskillende rol aan te neem om mamma te wees vir die neuro-tipiese kinders nie. (It isn’t easy to raise an autistic child, and then to don a different role to be a mother for neurotypical children as well)*

This poem was also posted by a parent, as an affirmation of what it meant to be a parent of a child with special needs, and seems to me to be the essence of all of the parents who participated in this research:

special needs moms
A look inside

You may think us "special moms" have it pretty rough.
We have no choice. We just manage life when things get really tough.
We've made it though the days we thought we'd never make it through.
We've even impressed our own selves with all that we can do.

We've gained patience beyond measure, love we never dreamed of giving.
We worry about the future but know this "special" life's worth living.
We have bad days and hurt sometimes, but we hold our heads up high.
We feel joy and pride and thankfulness more often than we cry.

For our kids, we aren't just supermoms. No, we do so much more.
We are cheerleaders, nurses, and therapists who don't walk out the door.
We handle rude remarks and unkind stares with dignity and grace.
Even though the pain they bring cannot be erased.

Therapies and treatment routes are a lot for us to digest.
We don't know what the future holds but give our kids our best.
None of us can be replaced, so we don't get many breaks.
It wears us out, but to help our kids, we'll do whatever it takes.

We are selfless, not by choice, you see. Our kids just have more needs.
We're not out to change the world, but want to plant some seeds.
We want our kids accepted. That really is our aim.
When we look at them we just see kids. We hope you'll do the same.

-April Vernon

Figure 4.3: A poem about being a special needs mother (28 May 2013)

4.3.2.1. Parents as experts

As the poem above indicates, the experiences of raising a child with autism bring with it the development of a unique set of skills and knowledge about being a parent. Many of the interactions within the Facebook support group pointed to parents seeing themselves as knowledgeable in the realm of autism, specifically because they were the ones that dealt with it on a daily basis:

> ***Comment 1:*** *It's only when you live with Autism that you will truly know.*
>
> ***Comment 2:*** *The thing is while I am not an expert, I do know something and do care.*

Comment 3: *I have found that my [spouse] has ways and means to heal the aggression and negativity out of [our child] by making [our child] laugh.*

Comment 4: *The home remains the best place to desensitise because the child is in a safe place.*

Parent post: *My child has an I.E.P – Involved Educated Parent*

Parent post: *You all have a wealth of expertise that I would be honoured to draw on.*

4.3.2.2. Parents as advocates

Another dimension of parent identity came to the fore with the ASA campaign, where being an autism parent was synonymous with being an advocate for autism. Despite the emotional impact the campaign had on them, it also motivated them into taking action to protect the rights of their children, and prevent the continuation of the stigma surrounding autism:

Comment 1: *It is my opinion and the opinion of many others that your campaign is harmful and will hurt autistic people and their families. I concur. Your e-mail informing people of this campaign referred to a "United Army". Reaction to your campaign is to have united the army against you. Your logic is flawed if you believe this will create awareness. All it has done is raise the ire of those already aware of autism and who daily battle to counteract the notions you have plastered in the public view - a public that will see and accept at face value* (A parent's direct response to ASA about the campaign)

Comment 2: *We always have to stand up for our kids because others will not.*

Comment 4: *Judging from the support that I have received […] and by the wonderful way that our community embraces [my child] - my advocacy and awareness must be working.*

Being advocates for autism also seemed to have had a bonding effect of being together in the fight against the effects of the campaign:

> **Comment 1:** *Well done to EVERY PARENT AND SUPPORTER OF OUR LOVED ONES WITH AUTISM! That was some major ass-whipping and you ALL truly have BLACK BELTS in autism!*
>
> **Comment 2:** *We won. That campaign is over.*
>
> **Comment 3:** *THANK YOU - to the people who drive this page - you gave us a voice. For people in our community who stand up, speak up and fought the good fight ("all it takes for evil to flourish is for good men to keep quiet"). Imagine if we each had to take on this ill-conceived campaign on our own! You might be "a cluster" but, BOY, you are an AWESOME cluster. I am proud to know you.*
>
> **Comment 4:** *I say let this bad thing be behind us now; […]. So proud to be on this group.*

4.3.3. Discourse around autism

My observations of the exchanges between the parents in the Facebook support group revealed that they were faced with two distinct, but often overlapping, discourses regarding their children and their abilities. Professional and public discourse focus largely (or perhaps solely) on the disabilities of people with autism, and as such, parents often have to hear about the things their children will not be able to do. In reaction to this, these parents have developed their own discourse in opposition to what professionals and the public assume about their children. This section will firstly focus on the interactions that indicated professional and public discourse around autism, and will conclude with the parents' own constructions and discourses around autism.

4.3.3.1. Professional discourse

Professionals often assume the abilities, or lack thereof, of children when they are first diagnosed with autism. One parent reposted a comment from an adult with autism, which stated this assumption very clearly: "*I heard doctors tell people to give up on me. Countless teachers and principals saying they won't accept me*." Professional discourse also seems to be largely based in the medical model, which dubs autism as a disease, with the implication that it might be cured, as demonstrated by this visual post by a different parent:

Figure 4.4: Autism is not a disease (18 May 2013)

Medication also forms part of professional assumptions around autism, as one parent shared a personal experience with the group: "*I have had doctors ask me if I want them to prescribe Ritalin as soon as they hear my [child] is on the spectrum. This angers me because it makes automatic assumptions about my [child]*." Furthermore, the discussions within the Facebook support group that centred on the release of the DSM V indicated how international medical bodies clarified and understood autism and other disabilities. One of the parents posted an excerpt from an American Psychiatric Association publication regarding the definition of intellectual disability, in order to demonstrate how the DSM criteria came to be:

> **Parent post:** *Here is an example of how the DSM and the ICD […] interacts - the quoted piece comes from the APA publication division called American Psychiatric Publications: "Diagnostic criteria for intellectual disability (intellectual developmental disorder) emphasizes the need for an assessment of both cognitive capacity (IQ) and adaptive functioning. Severity is determined by adaptive functioning rather than IQ score. The term mental retardation was used in DSM-IV. However, intellectual*

> *disability is the term that has come into common use over the past two decades among medical, educational, and other professionals, and by the lay public and advocacy groups. Moreover, a federal statute in the United States (Public Law 111-256, Rosa's Law) replaces the term 'mental retardation' with intellectual disability. Despite the name change, the deficits in cognitive capacity beginning in the developmental period, with the accompanying diagnostic criteria, are considered to constitute a mental disorder. The term intellectual developmental disorder was placed in parentheses to reflect the World Health Organization's classification system, which lists 'disorders' in the International Classification of Diseases (ICD; ICD-11 to be released in 2015) and bases all disabilities on the International Classification of Functioning, Disability, and Health (ICF). Because the ICD-11 will not be adopted for several years, intellectual disability was chosen as the current preferred term with the bridge term for the future in parentheses."*

Lastly, a sense of powerlessness against, and frustration with, the mighty influence of professional discourse was apparent in one parent's post about the diagnostic procedures of the National Institute of Mental Health (NIMH), which specifically impact on the diagnosis of autism, as no genetic cause for it has been established yet:

> **Parent post:** *My beef with NIMH is that they are taking the attitude that medical science leads to medical diagnosis, whereas medical science is meant to serve humans - you see the condition, then you study it, then you ascribe symptoms. According to them, if they do not have the technology to verify it genetically, it does not exist. Yeah right! Scientific arrogance is the most illogical thing!*"

The impact of professional discourse, even out-dated discourse, seems to linger in some educational institutions in South Africa as well, which rightly angers some parents, as professional and public ignorance is thus perpetuated, despite the advances that have been made in awareness and professional knowledge:

Parent post: *The DSM at one stage had autism as a psychotic disorder called childhood schizophrenia (or something like that) and the result of that is that TO THIS DAY the education department of [a South African University] sites autism as an example of a psychotic disorder. All because some educational psychologist who wrote the piece then did not allow for altered insight as more knowledge is gained, nor has [the South African University] corrected her stance. These things do matter!*"

4.3.3.2. Public discourse

Whereas professional discourse seems to be based on a medical approach to disabilities, public discourse appears to focus more on the social aspect of disabilities, and the accompanying assumptions that people in general make about people with disabilities, and even their parents. One parent posted a comment that someone in public made about autism: *"Oh, those crazy kids! And their parents are even worse!"* The parents in the Facebook support group are continuously faced with public opinions, which they find are difficult to change, especially in the light of the ASA campaign, which they felt would perpetuate the public discourse of ignorance regarding autism:

Comment 1: *The ignorance exists all over. It exists in doctor's rooms and in shopping malls.*

Comment 2: *Carly Fleischmann wrote: Why is it ok to assume that someone who is non verbal isn't smart? If you assumed that with Helen Keller, you would be wrong. If you assumed that with Stephen Hawkins, you would be wrong. If you assumed that with me, you would be wrong.*

Comment 3: *Public opinion and beliefs are of the hardest in the world to change.*

Comment 4: *Yesterday when I finally got an answer from ASA why they used these billboards, I learned that they thought that because people see shocking headlines advertising newspapers on telephone poles and trees - and then people buy papers - they thought the same would happen with the billboards*

> **Comment 5:** *The consequences of a school child (whose thinking is concrete) seeing a poster that says autistic people are violent - when he walks into his classroom he is going to look at the autistic boy differently. […] The social consequence of this is that ASA are putting people at risk.*

4.3.3.3. Parental discourse

In response to professional and public discourse around autism, especially the seemingly non-abilities and assumptions about a bleak future for people with autism, the parents in the Facebook support group subscribed to a different discourse around autism in celebration of its unique talents:

> **Parent post:** *(shared a sketch from a child with autism) The pencil work of a sweet, gentle 11 year old with autism at [a specific school]... Innate talent... And [this child] has not received any form of training... [This child] just looks at people and sketches!*
>
> **Comment 1:** *Gifted shows up all sceptics about autism; love it. Our [child] used to attend [art classes] while at […] school and [our child] amazed us. Even some of [our child's] art made it on to a display at the State theatre once. Got to love them, they are natural.*

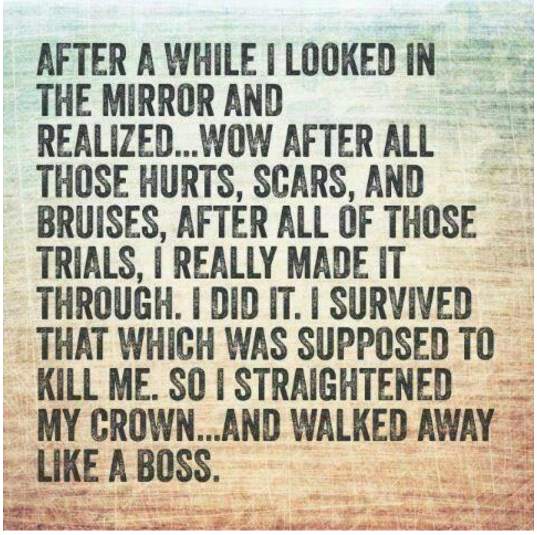
Pride in their children's unique accomplishments was part of their discourse as well. They celebrated success often:

> **Comment 1:** *Yesterday I sent [my child's] facilitator home because she is so sick; and [my child] flew solo. [My child] was a trooper - participating, listening and co-operating. Today [my child will] have to again.*
>
> **Comment 2:** *[My child is] talking more and more now and able to communicate more as well. It's like a flower opening - so beautiful!*

Lastly, parental discourse around autism incorporated an aspect about their identities as parent, as they have come to conclusions about themselves as parents that are worth sharing with others:

> **Comment 1:** *The ignorance exists all over. […]. I think in time you develop a thick skin and the realisation that your kid is better than the arrogant types that pass judgement. Hell, I know my kid is.*

A parent contributed this visual post to the Facebook support group in affirmation of the struggles of being an autism parent, but also in celebration of overcoming them, and assuming an identity of a winner:



AFTER A WHILE I LOOKED IN THE MIRROR AND REALIZED...WOW AFTER ALL THOSE HURTS, SCARS, AND BRUISES, AFTER ALL OF THOSE TRIALS, I REALLY MADE IT THROUGH. I DID IT. I SURVIVED THAT WHICH WAS SUPPOSED TO KILL ME. SO I STRAIGHTENED MY CROWN...AND WALKED AWAY LIKE A BOSS.

Figure 4.5: Overcoming the struggle (21 May 2013)

The next section of this chapter will focus on the discussion of the above mentioned categories and themes of the research findings in an attempt to answer the research questions based upon the literature.

4.4. PARTICIPANT FEEDBACK ON FINDINGS

The presentation of the findings was emailed to each participant for their feedback, as a measure to ensure the credibility of the interpretations, as discussed in section 3.3.1. Unfortunately, feedback was limited. With the nature of this research focussing solely on online participation, face to face contact between me and the participants was not possible, which affected the feedback process. This will be discussed in Chapter Five, where the limitations of the study are set out. However, the feedback I did receive indicated that the parents agreed with the interpretations I arrived at. An excerpt of the parents' feedback is provided in Addendum H.

4.5. DISCUSSION OF RESEARCH FINDINGS

This section of the chapter aims to discuss the research findings in reference to the theoretical framework in which it is grounded, as well as attempting to answer the research questions. As discussed in section 2.3, social constructionism was the theoretical framework chosen for this research, as it seems to be an explanatory theoretical approach through which to understand the ways that parents of children with autism think about themselves, and how their realities are shaped through social interaction. From a social constructionist viewpoint, the research intended to explore the value that the parents attached to their participation within the Facebook support group by looking at their reasons for joining the group, the nature of information shared among them, and how their participation contributed to their meaning-making of their daily experiences, as well as their identities as parents. Social constructionism relates to the phenomenon that these parents' interactions with other parents, professionals and interested parties in the Facebook support group might give meaning to their lives in ways that are different, and maybe preferable, to the identities they develop based on their interactions with the broad society. Thus some kind of value may be added to their daily experiences and which may possibly contribute to creating preferred identities as parents of children with autism.

Discourses on autism are often based on too little information, or even misinformation. Such discourses on autism, as well as on what parenting is, or ought to be, how children ought to behave or not behave, might lead to parents of children with autism to think of themselves in problem-saturated ways (Gray, 1993; Gray, 2002; Neely-Barnes, Hall, Roberts & Graff, 2011; Woodgate, Ateah & Secco, 2008; Worcester, Nesman & Mendez, 2008). In a support group, however, they are potentially free from the judgements of people who do not know and understand autism. As all of the participants know intimately what being a parent of a child with autism means, reciprocal understanding and support might be possible. However, social constructionism refers to a reciprocal process of meaning-making (Freedman & Combes, 1996), which could lead to a variety of understandings of reality and meaning, both negative and positive. Seeing that the research was two-fold in the sense that naturally occurring data from conversations within the Facebook support group was used alongside information from electronic interviews with each of the participants, events occurring in real life, such as the ASA campaign, had an impact on these naturally occurring conversations within the group, as well as on opinions raised in the electronic interviews.

The sub-questions of the research will be addressed first, followed by a discussion of the main research question pertaining to the value of the Facebook support group, and concluding with a reflection on the research findings.

4.5.1. Reasons for joining the Facebook support group

The parents indicated various reasons for joining the Facebook support group, with the most prominent reason being that the group was a platform where information could be shared in order to gain support for themselves, or to lend support to others. The literature suggests that people will seek “out the company of others similar to themselves” (Festinger, 1954, in Buunk & Gibbons, 2007, p. 4), which in this case refers to the Facebook support group which was created specifically for parents of children with autism to find support among other parents experiencing similar difficulties.

Furthermore, this group targeted South African parents specifically, which seemed to be an important factor for joining the group, as it was voiced by a few parents that the South African context differs from other contexts, and being part of a local support group made them feel more comfortable. The literature indicated that cultural norms affect the type of social support that is sought out by people, and contexts in which people feel culturally more comfortable would, therefore, be more attractive to them (Kim, Sherman & Taylor, 2008; Taylor, Sherman, Kim, Jarcho, Tagaki & Dunagan, 2004;).

In comparing the Facebook support group to physical support group meetings, the accessibility offered by the online group was highlighted by all participants. The online nature of the Facebook support group implied that parents could access the group at any time of the day, at times when it suited them best. Therefore, it imposed no time constraints on them as a physical support group meeting would, and participating in the Facebook support group also did not create the difficulties associated with physical meetings, such as arranging childcare or transport. The literature mentions that one of the benefits of online support groups is the 24-hour availability of the internet, as well as the asynchronous nature of participating in such groups (Malik & Coulson, 2010). Members of such groups are, therefore, able to read and attend to posts and comments by or from others at times when it is convenient to them (Malik & Coulson, 2010), and it also allows for a longer time to process and respond to information (Brady & Guerin, 2010; Lamberg, 1996), whereas physical support groups require instant responses from its participants. Additionally, online support groups transcend geographical boundaries (Aho, Paavilainen & Kaunonen, 2012; Braithwaite, Waldron & Finn, 1999; Gary & Remolino, 2000a), meaning that people from various places across the country or the globe can come together in cyberspace to receive or provide support to others (Malik & Coulson, 2010; Meier, 1998), without the constraints imposed by physical support group meetings, such as work, transport costs or childcare (Brady & Guerin, 2010; Huws, Jones, & Ingledew, 2001; Lamberg, 1996).

The parents also referred to another aspect of the accessibility of the Facebook support group, namely, access to a vast source of information that is immediately available. The literature affirms that a key part of modern life includes the ease of access to the body of information that is available through the internet (Baum, 2004; Jordan, 2010).

Furthermore, an underlying reason for joining the Facebook support group, which was not explicitly stated by the parents, but is clear from their demographic composition, is the fact that they have physical access to the internet, either via their mobile phones or via a computer. South African statistics indicate that only a minor percentage of citizens in the country have access to the internet, with 64.8% of households in the country having no access to internet, and only 16.3% of the population having access to the internet on their phones (Statistics South Africa, 2011, p. 12), thus excluding a large proportion of South African parents with children with autism from accessing online support communities. The literature also indicates that it is often mothers of children with disabilities that tend to seek social support (Aho, Paavilainen, & Kaunonen, 2012; Baum, 2004; Boyd, 2002; Mandell & Salzer, 2007), which was reflected in the majority of the members of the Facebook support group being mothers.

Lastly, the Facebook support group provides a sense of anonymity. A few parents indicated that participating in an online support group differed from physical support group meetings in the sense that it was not necessary to establish relationships with other group members first before feeling comfortable to share experiences. It was also mentioned that the anonymous nature of the online group might make it easier for parents to share their experiences, as it was less personal than face to face support group meetings. Suler (2002, in Skinner & Latchford, 2006, p. 159) stated that even if the identities of participants are known in real life, the internet still provides a sense of anonymity which may lead them to “feel less vulnerable about disclosing personal information.” Hurley et al. (2007, p. 859) states that people participating in online groups “are often very forthright in revealing personal information, even to complete strangers.” In addition to this, the anonymity provided by an online group appeared to make it easier for parents to withdraw their participation at any time if they so wished due to various reasons, whereas physical support group meetings have established meetings times, and withdrawing participation halfway through such a gathering might not be acceptable.

The literature indicates that one of the benefits of online support groups is that limited social commitment to the group is possible, and the relative anonymity in such a group makes it easier for participants to come and go as they please without much judgement from other group members (Aho, Paavilainen & Kaunonen, 2012; Owen, O'Carroll Bantum & Golant, 2009). Additionally, Suler (in Skinner & Latchford, 2006, p. 159) proposed that the anonymity provided by the internet creates a sense of “escapability”, meaning it is easier to withdraw participation from the group, because people participating in an online group sees themselves and others as existing “in a different, unreal space, separate from the demands and responsibilities of the real world.”

There is, however, a downside to the anonymity created by online participation, which will be discussed in section 4.5.4.

4.5.2. Nature of information shared

With the purpose of the Facebook group being to provide support for parents of children with autism, naturally the information that was shared among the parents in the Facebook support group largely targeted topics that were relevant to autism. Current newsworthy events were shared, such as recent research findings about autism. Some discussions focussed on certain types of medication that is often associated with autism, and the possible effects thereof on children and adults with autism. Autism-specific resources were shared among parents based on their own personal experiences, such as names and contact details of various therapists, doctors or other service providers that offered autism-specific or autism-friendly services.

Other topics of discussion centred on parenting advice when other parents in the group shared their difficulties with specific autism-related behaviour, and of course the impact of the release of the DSM V. This correlates with the literature, which indicates that the purpose of a support group, by itself, determines the topics that would be discussed among its members, such as autism, grief, disability, chronic conditions, parenting and so forth (Aho, Paavilainen, & Kaunonen, 2012; Ahmed, Sullivan, Schneiders, & McCrory, 2010; Baum, 2004; Bender, Jimenez-Marroquin, & Jadad, 2011; Brady & Guerin, 2010; Greene, Choudhry, Klabuk, & Shrank, 2010; Hurley, Sullivan, & McCarthy, 2007; Huws, Jones, & Ingledew, 2001; Lamberg, 1996; Mellor, 2010). If these topics were not relevant to its members, the support group would not be experienced as supportive any longer, as it does not address their specific needs (Mellor, 2010).

Apart from sharing the above mentioned aspects within the Facebook support group, the parents predominantly shared personal experiences related to their children with autism. These experiences ranged from sharing success stories to sharing difficult experiences. Sharing the joys and accomplishments of their children often received much positive feedback from other parents in the group. It conveyed a sense of pride in their children that was worth sharing with others, as well as knowing that these accomplishments would be understood by the other parents in the Facebook support group. Apart from accomplishments, difficult experiences were also shared, and once more the feedback from other parents in the group was supportive and empathetic, often in the form of giving advice on how to deal with the difficulties, or some verbal encouragement. The literature points out that people experiencing similar difficulties react empathetically towards each other, due to shared understanding (Aho, Paavilainen, & Kaunonen, 2012; Baum, 2004; Braithwaite, Waldron, & Finn, 1999; Mandell & Salzer, 2007; Pagano, Post, & Johnson, 2011).

Research in online support groups focussing on recovering from illness or processing grief showed that members of the group who were further along the recovery process were able to share hope with members who were at earlier stages of the process, which seemed to have a reciprocal effect on coping: the members who share hope have a sense of efficacy, whereas the members receiving the support felt less isolated because they were understood and supported (Gary & Remolino, 2000; Lamberg, 1996; Pagano, Post, & Johnson, 2011). This was seen in some of the Facebook support group parents' responses: those with older children felt they could share advice with other parents whose children were still young, as they had overcome some of the difficulties associated with having a younger child with autism, whereas the parents with younger children with autism felt supported by a community of people who understood their struggles.

Furthermore, research about other online support groups affirmed that being able to share experiences with people in similar situations helped to lessen stress and anxiety related to the difficulties being experienced (Luther, Canham & Young Cureton, 2005; McCabe, 2008; Twoy, Connolly & Novak, 2007). It also created a sense of belonging to a community of people experiencing the same difficulties, and lessened the feeling of isolation that might be experienced (Aho, Paavilainen, & Kaunonen, 2012; Baum, 2004; Braithwaite, Waldron, & Finn, 1999; Mandell &

Salzer, 2007; McCabe, 2008; Pagano, Post, & Johnson, 2011), especially by parents of children with autism.

One parent, however, raised a concern that the information shared in the group is too subjective, and as such, not very reliable. The literature regarding the information shared between peers in medical online support groups caution against the reliability thereof (Brady & Guerin, 2010; Malik & Coulson, 2010). Braithwaite et al. (1999, p. 145) also mention that misinformation might be exchanged between members participating in online support groups, which “may not be corrected or corrected only after a time delay.” However, none of the other parents mentioned this as a concern with regards to information shared in the Facebook support group.

4.5.3. Meaning-making and parent identity

The exchanges between the parents in the Facebook support group indicated that meaning-making about their experiences occurred on various levels, even if some parents did not explicitly think about it in such a way. Some parents were more active in their exchanges within the group than others, although they were still witness to the stories that others shared, which made them draw certain conclusions about their own experiences. As one parent stated, participating in the Facebook support group brought on the realisation that the experiences they faced as a family were perhaps not as difficult as the experiences of some other families. Another parent stated that the Facebook support group made it clearer that each family with a child with autism is uniquely different, and as such, each parent’s interactions within the group would reflect accordingly their unique interpretations of their realities. These statements reflect social constructionist principles, as each parent’s reality is uniquely different.

The phenomenon of social constructionism allows for the representation of a multitude of interpretations of reality, as each person’s context with regards to prior experiences, culture, history, beliefs, and even personality traits, impacts on the way people experience their realities (Assarsson & Aarsand, 2011; Babbie & Mouton, 2001; Burr, 2000; Burr, 2003; Carey & Russell, 2003; Foucault, 1988; Freedman & Combs, 1996; Hare-Mustin, 1994; Krauss, 2005; Merriam, 2009; Winslade & Monk, 2007). However, the discourse of social constructionism further poses that the process of meaning-making with regards to each parent's unique experiences does not happen in social isolation; rather, through interaction with other parents with children with autism, each parent creates meaning about their own experiences (Adams, Collair, Oswald & Perold, 2004; Babbie & Mouton, 2001; Burr, 2003; Foucault, 1988; Freedman & Combs, 1996; Gergen, 1985; Merriam, 2009; White, 1990). As such, the value of the support group to each parent is determined by their unique meaning-making processes, as it was discovered that some parents did not experience the group as supportive or meaningful as I initially thought, whereas other parents valued the support and belonging they received from the group as extremely beneficial to making sense of their daily experiences. Unique interpretations of other parents' words, without the physical cues present in face to face communication, were also seen to be leading to negative experiences for some parents within the group. However, this aspect of the Facebook support group will be discussed in greater depth in section 4.5.4.

Another aspect of the meaning-making process within the Facebook support group is taking on the role of the helper. Many of the parents mentioned that the Facebook support group enabled them to support and help other parents. This occurred through responding empathetically to other parents' posts when they shared their experiences, or by giving advice that they thought might be helpful. According to the Helper Principle (Pagano, Post & Johnson, 2011), people belonging to support groups perceive great benefits to their well-being when able to assist others, which in turn lowers levels of stress (Luther, Canham & Young Cureton, 2005; McCabe, 2008; Twoy, Connolly & Novak, 2007).

The meaning-making process of the parents' daily experiences is intricately linked with the process of constructing identities as parents of children with autism. The construction of identity relates to social constructionist thinking about dominant discourses (Adams, Collair, Oswald & Perold, 2004; Assarsson & Aarsand, 2011; Burr, 2003; Foucault, 1988; Hare-Mustin, 1994; Winslade & Monk, 2007). Dominant discourses refer to those taken for granted truths about life and reality that often guide people's interactions with one another (Adams, Collair, Oswald & Perold, 2004; Burr, 2003; Hare-Mustin, 1994; Winslade & Monk, 2007). One such discourse, as mentioned by a parent in a study by Neely-Barnes et al. (2011), is that children that do not seem to have any outwardly signs of a disability, should therefore “act normal.” However, as described in section 2.3.3, there are many characteristics of autism that people who do not know and understand autism would interpret as out of the ordinary.

This discourse about normality creates expectations in people in general about the way “normal looking” children should behave. Consequently, the parents of children with autism have to bear the brunt of this discourse, as their children often do not behave the way others expect, which in turn also creates embarrassment to them as parents (Bishop, 2012). White (1990) states that these dominant discourses can often lead to problem-saturated stories or identities, which people take for granted as being the truth about their lives. With research showing that autism is one of the disabilities that creates the most stress and levels of depression among mothers of children with autism (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005, in Neely-Barnes, Hall, Roberts & Graff, 2011; Olsson & Hwang, 2001; Montes & Halterman, 2007; Tunali & Power, 2002; Sanders & Morgan, 1997, in Boyd, 2002; Sounders, DePaul, Freeman & Levy, 2002), one could easily assume that the negative reactions they receive from people in public could exacerbate the creation of a problem-saturated identity. It is in such instances that support groups seem to play an integral role in providing a platform to parents of children with autism to create preferred, and alternative, identities.

The interactions of the parents within the Facebook support group indicated that they often had to bear the effects of dominant professional and public discourses. It would appear as though they experienced the dominant professional discourse of autism as largely medically focussed. This professional discourse impacts on the way autism is diagnosed, and can be seen through the parents’ reactions towards the release of the new DSM V. Professional discourse also impacts the way medical professionals view autism: as a disease that can potentially be rectified with medication. As one parent mentioned, as soon as the doctor heard that this parent’s child has autism, the doctor wanted to prescribe Ritalin. The parents often regarded professional discourse as ignorance, as they felt professionals made generalised assumptions about the abilities of children with autism, with which they did not necessarily agree.

The parents' experiences of public discourse indicated that they felt stigmatised and judged by society, which is reflected in the literature (Gray, 1993; Gray, 2002; Huws, Jones & Ingledew, 2001; McCabe, 2008; Neely-Barnes, Hall, Roberts & Graff, 2011; Randall & Parker, 1999; Twoy, Connolly & Novak, 2007; Woodgate, Ateah & Secco, 2008; Worcester, Nesman & Mendez, 2008). Another aspect of public discourse that the parents are faced with became quite apparent through analysing their interactions regarding the ASA campaign: society's ignorance about and assumptions of autism. They experienced the ASA campaign as threatening to the efforts that have been made to fight against societal assumptions and ignorance about autism, as they felt that people in general would take the slogans on the billboards as truths, and thus it would further perpetuate the stigma around autism.

In light of the professional and public discourse that the parents participating in the Facebook support group face on a regular basis, the group seemed to be a space where they could vent about their experiences, and at the same time create alternative identities as parents of children with autism: identities as parents who are the experts in their children's lives, who can appreciate the unique talents and successes of their children, and who are advocates for their children. Constructing these preferred identities does not occur in isolation, which can be seen quite clearly from the interactions of the parents within the Facebook support group. By sharing their experiences, emotions, grievances, and successes with others in the group, they are continually constructing their identities in relation to the feedback they receive from others in the group. Even the negative experiences of some parents within the group added to their meaning-making processes, as well as their identities, as parents that have autism in common, but each with unique contexts, beliefs, values, experiences and needs. Carey and Russell (2003, p. 5) affirm the social construction of a preferred identity within a narrative framework by stating the following:

> *Narrative practice is founded on the idea that the stories we tell about ourselves are not private and individual but are a social achievement. We probably all know that it is difficult to maintain an identity claim in isolation – we look for someone who will reflect back to us what it is we wish to claim for ourselves. An important part of our identity claims will be the values that we wish to live our lives by. In maintaining our connection with our values we probably have all experienced the power of sharing those values with like-minded people.*

With the three sub-questions of the research discussed, the concluding section will focus on a discussion regarding the overall value of the Facebook support group to the parents.

4.5.4. The value of the Facebook support group

Upon reflecting on the value of the Facebook support group in these parents' lives, it would seem that it symbolises a rich source of information, whether it is in the form of sharing experiences, learning from others' experiences, witnessing the journeys of others, making sense of their own contexts as being unique and different to others', or obtaining factual information and resources. It appears, therefore, that online support as provided by the Facebook support group does, in fact, to a more or lesser extent, contribute to these parents' sense-making of their experiences; however, this largely depends on their personal needs. For some of the parents, the subjective nature of the information shared in the Facebook group was not deemed as valuable, mostly because their needs were aimed at factual and objective information, which they found to be more reliable. For other parents, the subjective nature of the support they received from their participation in the group is what they valued most, as it afforded them the opportunity to share, and to be part of a community that understood. In either of these scenarios, however, it was apparent that the parents have made sense of their personal needs and experiences, and as such, their online interaction was conducted accordingly. It can, therefore, be said that the Facebook support group fulfils multiple roles in the lives of its participants, whereby each participant attaches their own value to their experiences within the group, depending on their unique needs, viewpoints, beliefs and circumstances at any given point.

The value of the Facebook support group was further juxtaposed against the parents' experiences of physical support groups, as well as alternative online support forums such as blogs and other Facebook groups. Although the accessibility of the Facebook support group was seen as a positive attribute, many parents mentioned how easily misinterpretations can occur without the physical cues that mediate social interaction. This occurrence is supported by the literature, as the absence of tone of voice, facial expressions and body language creates difficulties in interpreting the true intention of written words (Gary & Remolino, 2000b; Høybye, Johansen & Tjørnhøj-Thomsen, 2005; Hurley, Sullivan & McCarthy, 2007; Huws, Jones & Ingledew, 2001; Malik & Coulson, 2010; Owen, O'Carroll Bantum & Golant, 2009; Perkins & LaMartin, 2012).

It was also apparent that the ASA campaign created conflict within the group, which negatively affected the parents' experiences of the group, and consequently saw a decrease in participation within the group. Some of the parents expressed that in this instance, they found the group to be not as supportive as it used to be, and preferred to engage in alternative online support through subscribing to other blogs or writing their own blogs, belonging to other Facebook groups that they found to be more sensitive and supportive, or using their personal Facebook profiles as platforms to continue sharing their experiences. As mentioned in section 4.4.2, participants in support groups will only find them beneficial as long as they address their specific needs (Mellor, 2010), and as many of the parents indicated, they did not need the negativity as an aftermath of the ASA campaign in their lives.

In conclusion, the value of the Facebook support group depended largely on each parent's subjective experiences, including the way in which the interactions with other parents in the group were interpreted by themselves. These parents ascribed value to being part of a community where information and resources can be shared instantly, and where there is an understanding of the unique experiences of autism. However, to some of the parents, the value of the Facebook group, and as such the support they derived from it, was affected by conflicting interactions regarding the ASA campaign. Damaging as it might have been to the cohesion of the group, it does reiterate the social constructionist principles that were at work.

4.6. PERSONAL REFLECTIONS

Merriam (2009, p. 219) makes the following statement with regards to the importance of engaging in a reflective process throughout the research:

> *Investigators need to explain their biases, dispositions, and assumptions regarding the research to be undertaken. Even in journal articles authors are being called upon to articulate and clarify their assumptions, experiences, worldview, and theoretical orientation to the study at hand. Such a clarification allows the reader to better understand how the individual researcher might have arrived at the particular interpretation of the data.*

Before even starting with this research, when the possible research questions I had were still just simmering in my mind, I had already begun making my own assumptions about the interactions which I have had the opportunity to observe within the Facebook support group. My assumptions were based on the value *I* attached to these interactions, and as such, I thought the value *I* perceived would be similar to the parents' values participating in the group. This research process, however, has been extremely enlightening. Firstly in the sense that I realised I was part of the outsider group of people (referred to in Chapter One, section 1.2) that made assumptions about these parents without truly understanding their perspectives, even with my seemingly good knowledge of autism. I never considered that there might be parents in the group who did not experience the group setting as less supportive than what I thought, because *my* assumptions were that the information shared was extremely valuable. And secondly, realising that my assumptions were exactly that – *my assumptions* – it was truly a journey of discovery: not only of myself by being confronted with my own perceptions and assumptions, but also of each parent's unique experiences, and the way that it shapes their lives differently from one another, which truly made theory come to life. Social constructionism was merely an abstract term of which I had little knowledge at the start of this project, but through this research, I saw theory in practice. Each parent, and myself as the researcher, brought different meanings to this process, based on our own experiences, perceptions, beliefs and interpretations of the unique lives we live. Although this thesis was physically written by me, it was collaboratively storied by each parent who participated, which made this process even more authentic than I could have imagined at the start.

4.7. CONCLUSION

The research findings indicated the multifaceted role that the Facebook support group plays in the lives of each parent who participated. The amount of support they derived from the group and the value of the group depended on each parent's unique needs and experiences, as well as their unique interpretations of the interactions within the group. Their interactions within the group showed, however, that the group provided a platform where they were able to construct their own identities as autism parents who are the experts of their children's lives, as well as advocates in the realm of autism. Their experiences resonated with international literature on online support groups.

The last chapter of this thesis serves as an overall conclusion to the research, by discussing its strengths and limitations, and providing recommendations for future research.

CHAPTER 5

CONCLUSIONS, STRENGTHS AND LIMITATIONS, AND RECOMMENDATIONS

5.1. INTRODUCTION

The aim of this study was to explore the value that parents of children with autism attached to their participation within a specific Facebook support group from a social constructionist viewpoint by looking at their reasons for joining the group, the nature of information shared among them, and how their participation contributed to their meaning-making of their daily experiences, as well as their identities as parents. Social constructionism relates to the phenomenon that these parents' interactions with other parents, professionals and interested parties in the Facebook support group might give meaning to their lives in ways that are different, and maybe preferable, to the identities they develop based on their interactions with the broad society. Thus some kind of value may be added to their daily experiences and which may possibly contribute to creating preferred identities as parents of children with autism.

This research was based within a qualitative interpretivist paradigm, with social constructionism as the theoretical framework, in an attempt to answer the above mentioned research questions. This was achieved by observing and collecting the exchanges of the parents within the Facebook support group over a three month period, as well as conducting electronic interviews via an open-ended email questionnaire.

This chapter serves as a conclusion to the whole research process, by discussing the final conclusions regarding the research findings, as well as the strengths and limitations of this study. Recommendations for further research, based on the findings of this study, will also be given.

5.2. CONCLUSIONS TO THE RESEARCH FINDINGS

The research process was two-fold, as the parents' responses to the electronic questionnaire in conjunction with my observations of their exchanges within the Facebook support group provided insight into their experiences, their meaning-making processes, as well as the value of the Facebook support group in their daily lives. Their exchanges in the group along with their responses to the questionnaire revealed the multifaceted nature of support in each parent's life, as well as the way they constructed their identities as parents through interaction with each other in the group and in response to professional and public discourse.

The support and value they derived from the Facebook support group seemed to rely mostly on their unique needs as parents. This indicated the multiple roles that the Facebook support group can fulfil, as some parents benefitted from factual information shared, whereas others benefitted from the social support they derived. Social support provided through the Facebook support group included the sharing of information, resources and experiences with each other, which in turn allowed for the construction of alternative identities as autism parents. These identities were constructed based on their shared experiences and also in response to the dominant discourses around autism they have to face on a daily basis. Their interactions in the Facebook support group allowed a platform where preferred identities as parent experts and advocates could be created. It also became clear that, even though there were instances where the interactions within the group were not experienced as positive, these interactions were still interpreted and incorporated by each parent in a different way, adding to their understanding of their own needs and own identities as parents, which might be different to any other parent who also has a child with autism. The conclusion, therefore, is that each parent of a child with autism shares the common bond of autism, but based on their unique experiences, they each have their own perspectives, and as such, the value of an online support group will be different in each one of their lives.

5.3. STRENGTHS OF THE RESEARCH

Many qualitative research designs employ focus group interviews as the main source of data collection. This study, however, combined interview data with observations of naturally occurring talk, which provided an extra level of depth to the interpretations I was able to make. By giving each participant the opportunity to voice their own opinions about the Facebook support group, their interactions within the group were put into context by the unique meanings they attributed to it. Additionally, with the seemingly non-existent research of online support groups in South Africa, let alone with regards to autism, this research could be seen as contributing significantly to the gap in South African academic knowledge of the unique experiences of parents of children with autism participating on an online support group.

5.4. LIMITATIONS OF THE RESEARCH

With the scope of the research focussed on the value of a Facebook support group, a limitation of this study is the lack of face to face contact between myself and the participants, as they were located around South Africa. Therefore, I had to rely on textual information from their exchanges within the Facebook support group as well as their responses to the electronic questionnaires. As the literature indicates, an overreliance on text alone might misconstrue the intended meanings of words. To counter possible misconceptions, I sent my interpretations of the research data to each participant for their feedback. However, the feedback I received was limited, which might be attributed to the added demand on each parent’s time to read the lengthy document. A focus group interview, or individual face to face interviews, might have elicited better feedback and thus member checking, which highlights the main limitation of this study as the lack of face to face contact.

Additionally, research where individual or focus group interviews are used as a data collection method seems to build rapport between the researcher and the participants. With me being a non-participant observer within the group, the building of rapport was limited to email exchanges between myself and the participants.

Furthermore, the parents who participated in the research all had access to internet, which locates them in a specific demographic group that has the means to access the internet. With South African statistics indicating the limited amount of citizens that have access to internet via their mobile phones or computers, it would, therefore, appear that the results of this study are skewed in favour of a specific demographic group of parents of children with autism.

Lastly, the sample of participants in this study was relatively small, and the results of this study indicated the uniqueness of each parent's experiences within the group. It is, therefore, not possible to predict if other online support groups would yield similar results.

5.5. RECOMMENDATIONS FOR FUTURE RESEARCH

Seeing that research about online support groups in South Africa is seemingly non-existent, it is recommended that further research is conducted in this regard to add to the understanding about the dynamics of such groups. This could be used to provide a foundation upon which models of alternative online support services can be built to reach a wider population, especially people who do not have access to the internet.

Furthermore, the lack of face to face contact during this study can possibly be bridged in future studies by utilising video calling options, such as Skype or FaceTime, to conduct individual interviews and feedback sessions. If this is not possible, a telephone conversation could be the next alternative.

Another recommendation would refer future researchers in this field to explore different internet platforms which can provide access to a wider audience. An example of this is Mxit which can provide access to similar support services for non-smartphone users. Therefore, people who are currently excluded from benefitting from internet-based support groups may also be provided for through these alternative means.

5.6. CONCLUSION

This research reflected to a large extent the findings of international literature. However, within the South African context, it has highlighted the possibility of utilising alternative platforms than face to face support groups to provide support to parents of children with autism.

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ADDENDUM A

Letter of ethical clearance by the Research Ethics Committee

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Approval Notice

Response to Modifications- (New Application)

21-Jun-2013
Gerber, Karin K

Proposal #: HS925/2013
Title: Exploring the Value of a Facebook Support Group for Parents of Children with Autism

Dear Ms Karin Gerber,

Your **Response to Modifications** - ***(New Application)*** received on **13-Jun-2013**, was reviewed by members of the **Research Ethics Committee: Human Research (Humanities)** via Expedited review procedures on **21-Jun-2013** and was approved.
Please note the following information about your approved research proposal:

Proposal Approval Period: **21-Jun-2013 -20-Jun-2014**

Please take note of the general Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

Please remember to use your **proposal number** (**HS925/2013**) on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Also note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required. The Committee will then consider the continuation of the project for a further year (if necessary).

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 0218839027.

ADDENDUM B

Explanation of the research to participants to obtain informed consent

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STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Exploring the Value of a Facebook Support Group for Parents of Children with Autism

You are asked to participate in a research study conducted by Karin Gerber, a Masters student from the Department of Educational Psychology at Stellenbosch University, supervised by Mariechen Perold. The results of this study will contribute to her thesis. You were selected as a possible participant in this study because you are a parent of a child with autism participating in a Facebook Support Group.

1. PURPOSE OF THE STUDY

The worldwide increase in the diagnosis of autism, the immense pressure parents experience in raising a child with autism, as well as the accessibility of internet-based support groups, creates a unique opportunity to research parents' experiences in such an online community. Knowledge about their experiences, the value and meaning of an online support group in their daily lives, as well as which parents access online support, could shed light on how online communities could possibly be better utilised in providing instant and low-cost information and support to parents that are otherwise excluded from face-to-face support groups due to various constraints. Additionally, research about online support groups for autism in South Africa seems to be non-existent. This research could contribute significantly to the gap in knowledge about South African parents' experiences.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

2.1. Electronic Interview

An electronic interview via email correspondence will be conducted where there is a likelihood of follow-up questions to clarify answers and ensure that a rich description is gathered of your unique experiences as a parent. To ensure privacy of information exchanged through email correspondence, the student will use an email security program from Comodo (www.comodo.com) to encrypt messages and safeguard it against any unauthorised access. You will also be given the option to download this program if you deem it necessary.

2.2. Observations

The activity within the Facebook support group, such as posts and comments, from all participants that give consent will be observed and recorded for a period of 3 months (from May 2013 to July 2013) to form part of the research data. A retrospective observation of posts and comments will be done for the months of May and June, after which an actual (real-time) observation will continue for the month of July.

2.2. Feedback

The student will provide each participant with feedback about her interpretations of answers from the electronic interviews as well as her observations from activity on the Facebook support group. You are in turn invited to give honest feedback regarding these interpretations to ensure that accurate descriptions of your own words and experiences are guaranteed.

3. POTENTIAL RISKS AND DISCOMFORTS

Participation in the electronic interview process might elicit anticipated negative feelings, seeing that your experiences as a parent of a child/ren with autism is the focus of the study. However, such feelings could be managed through participation in the Facebook support group. Additionally, information of psychological services available in your geographic area will be provided through www.medpages.co.za, if the need arises for professional support. Signs and symptoms to consider (lasting at least 2 weeks and that is markedly different to previous functioning) as a precursor for seeking professional support are:

- Depressed mood most of the day, nearly every day
- Marked diminished interest in most activities
- Significant weight loss or weight gain, and changes in appetite
- Difficulty sleeping or oversleeping/hypersomnia (unrelated to your child's variant sleeping patterns) nearly every day
- Feelings of agitation
- Fatigue or loss of energy
- Feelings of worthlessness or excessive or inappropriate guilt
- Diminished ability to think or concentrate, or indecisiveness, nearly every day
- Recurrent thoughts of death

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Participants in this research study will not directly benefit from it, however, the insights gained from this study might add greatly to an understanding of the potential value of online support communities for the South African population.

5. PAYMENT FOR PARTICIPATION

No payment will be received from participating in this research study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Information observed within the Facebook support group by members that are not part of this research study will not be used. Confidentiality and anonymity will be maintained by means of pseudonyms and disguising any other identifying information. All data captured throughout this research will be kept on a password secured laptop that only the student has access to. Data will only be shared with the student's supervisor. Data from email correspondence will be encrypted using an email security program that is available for downloading from www.comodo.com.

The results of this study will be published in the form of a Masters dissertation, however, all means of confidentiality and anonymity as described above will be respected.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Karin Gerber [mrs.karin.gerber@gmail.com; tel.………………..] or Mariechen Perold [mdperold@sun.ac.za; tel. ………………….].

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by Karin Gerber in English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

____

Name of Participant

____ ____________

Signature of Participant **Date**

SIGNATURE OF INVESTIGATOR

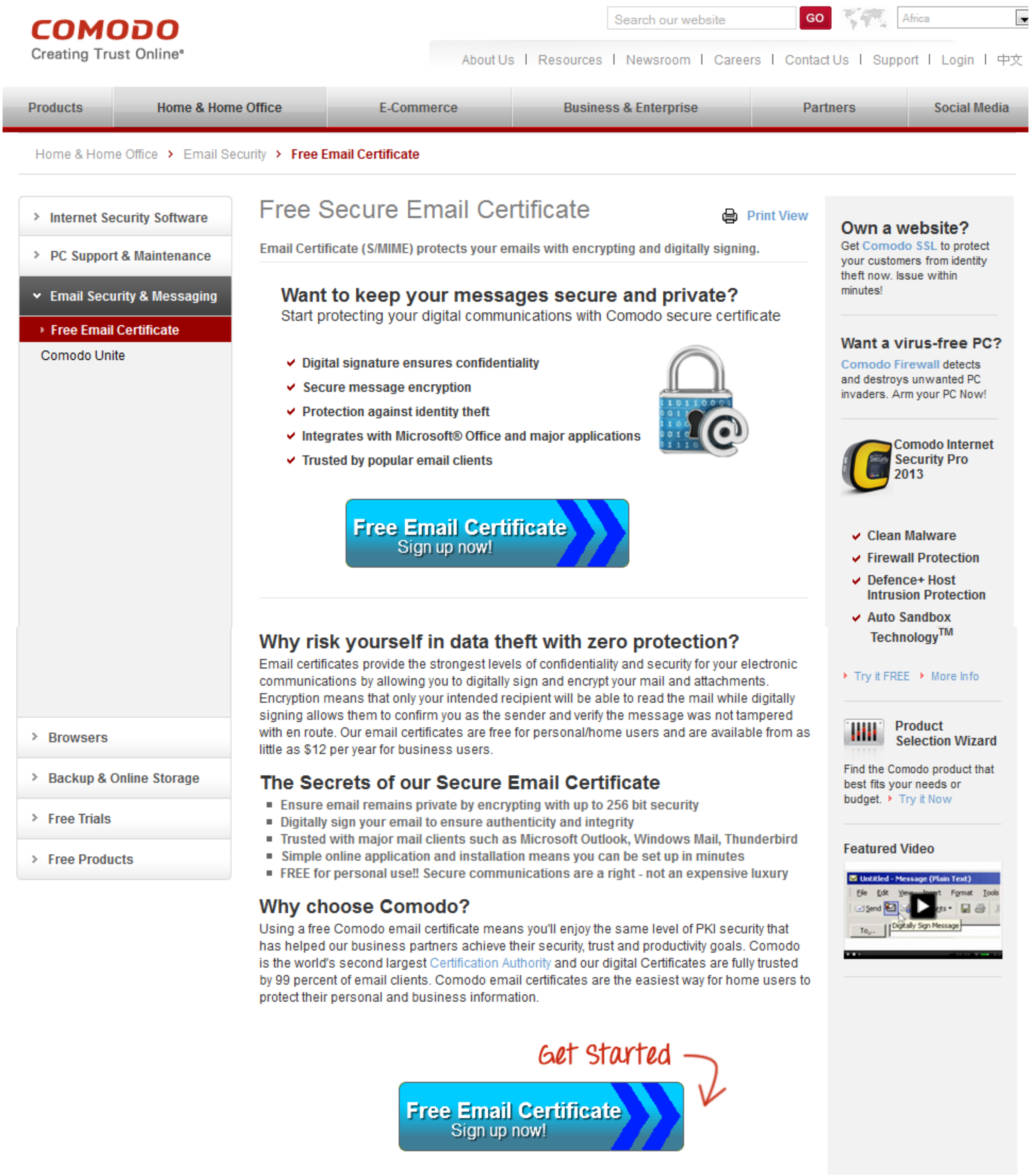
I declare that I explained the information given in this document to ________________________________. *[He/she]* was encouraged and given ample time to ask me any questions. This conversation was conducted in English via electronic email correspondence and no translator was used.

____________________________________ ____________

Signature of Investigator **Date**

ADDENDUM C

Encryption programme used to protect email correspondence from interception



Free Secure Email Certificate

Email Certificate (S/MIME) protects your emails with encrypting and digitally signing.

Want to keep your messages secure and private?

Start protecting your digital communications with Comodo secure certificate

- ✓ Digital signature ensures confidentiality
- ✓ Secure message encryption
- ✓ Protection against identity theft
- ✓ Integrates with Microsoft® Office and major applications
- ✓ Trusted by popular email clients

Why risk yourself in data theft with zero protection?

Email certificates provide the strongest levels of confidentiality and security for your electronic communications by allowing you to digitally sign and encrypt your mail and attachments. Encryption means that only your intended recipient will be able to read the mail while digitally signing allows them to confirm you as the sender and verify the message was not tampered with en route. Our email certificates are free for personal/home users and are available from as little as $12 per year for business users.

The Secrets of our Secure Email Certificate

- Ensure email remains private by encrypting with up to 256 bit security
- Digitally sign your email to ensure authenticity and integrity
- Trusted with major mail clients such as Microsoft Outlook, Windows Mail, Thunderbird
- Simple online application and installation means you can be set up in minutes
- FREE for personal use!! Secure communications are a right - not an expensive luxury

Why choose Comodo?

Using a free Comodo email certificate means you'll enjoy the same level of PKI security that has helped our business partners achieve their security, trust and productivity goals. Comodo is the world's second largest Certification Authority and our digital Certificates are fully trusted by 99 percent of email clients. Comodo email certificates are the easiest way for home users to protect their personal and business information.

Own a website?

Get Comodo SSL to protect your customers from identity theft now. Issue within minutes!

Want a virus-free PC?

Comodo Firewall detects and destroys unwanted PC invaders. Arm your PC Now!

Comodo Internet Security Pro 2013

- ✓ Clean Malware
- ✓ Firewall Protection
- ✓ Defence+ Host Intrusion Protection
- ✓ Auto Sandbox Technology™

Product Selection Wizard

Find the Comodo product that best fits your needs or budget. › Try it Now

Featured Video

Comodo Website Link:

http://www.comodo.com/home/email-security/free-email-certificate.php?key5sk1=6816645ec0fc79caad9fa19924d3a230504df3ab&key5sk2=&key5sk3=1379880387000&key5sk16=2403&key5sk17=1379878289000&key5sk18=&key5sk19=1379880416000&key5sk20=&key5sk21=1379880806000&key6sk1=&key6sk2=FF240&key6sk3=7&key6sk4=en-us&key6sk5=ZA&key6sk6=1&key6sk7=http%3A%2F%2Fwww.comodo.com%2Fsupport%2Fproducts%2Femail_certs%2Findex.php&key6sk8=118800&key6sk9=1366768&key6sk10=true&key6sk11=b83ecf321b577510b8117f97bc782c3ad097c9a5&key6sk12=2034&key7sk1=57&key7sk2=60&key1sk1=dt&key1sk2=http%3A%2F%2Fwww.comodo.com%2Fsupport%2Fproducts%2Femail_certs%2Findex.php

Karin Gerber

From: Certificate Customer Services <secureemail@comodogroup.com>
Sent: 22 September 2013 09:34 PM
To: Karin Gerber
Subject: Your certificate is ready for collection!

COMODO

Tel Sales : **+1 888 266 6361**
Fax Sales : **+1.201.963.9003**

Your Comodo FREE Personal Email Certificate is now ready for collection!

Dear Karin Gerber,

Congratulations - your Comodo FREE Personal Secure Email Certificate is now ready for collection! You are almost able to send secure email!
Simply click on the button below to collect your certificate.

Click & Install Comodo Email Certificate

Note:- If the above button does not work, please navigate to https://secure.comodo.com/products/!SecureEmailCertificate_Collec2 Enter your email address and the Collection Password which is: W7AwtSX7llhcGcl3
Your Comodo FREE Personal Secure Email Certificate will then be automatically placed into the Certificate store on your computer.
Click "Yes" if you see a "Potential Scripting Violation" window asking "Do you want this Program to add Certificates now?"
Please visit http://www.comodogroup.com/support/products/email_certs/index.html for guidance on configuring your email client to use your certificate to secure email.
Note:- We strongly recommend that you export your certificate to a safe place in case you need to reload it later. For details, please see http://www.instantssl.com/ssl-certificate-support/server_faq/ssl-email-certificate-faq.html.
You can revoke your certificate by clicking on the button below.

Revoke Comodo Email Certificate

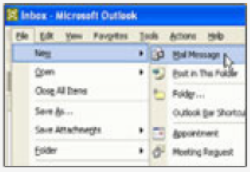
If you need to revoke your Comodo FREE Personal Secure Email Certificate then please navigate to
https://secure.comodo.com/products/!SecureEmailCertificate_Revoke You will need to enter your email address and revocation code.
Thank you for your interest in Comodo.

Comodo Certificate Services Team
secureemail@comodogroup.com

How to encrypt mail

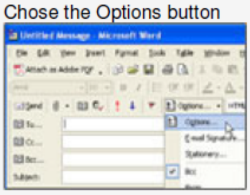
Step 1

Create a new Mail



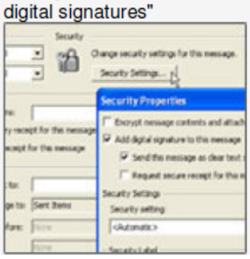
Step 2

Chose the Options button



Step 3

Choose "Security Settings..." and click "Add digital signatures"



ADDENDUM D

Electronic interview questionnaire

Electronic Interview Questionnaire

Exploring the Value of a Facebook Support Group for Parents of Children with Autism

Indien u sou verkies om hierdie vraelys in Afrikaans te beantwoord, laat weet asseblief die navorser onmiddellik en 'n Afrikaanse vertaling van die vraelys sal verskaf word.

1. Please provide the following demographic information	
Name	
Age	
Gender	
Marriage status	
Highest level of education	
Current occupation	
Have you ever received professional psychological support in the past? If so, what would you say was the most important reason for seeking psychological support?	
Are you currently receiving psychological support? If so, what would you say is the most important reason for seeking psychological support?	
2. Background of your child's diagnosis	
Gender of your child	
Current age	
Age at diagnosis	
In your words, what impact did the diagnosis have on you personally?	
What were your most prominent feelings at the time of diagnosis? The literature indicates the following feelings: - Depression - Anxiety - Fatigue	

- Momentary relief at having a diagnosis Are there any of these that specifically resonate with you? If so, kindly provide a description of your own experiences, and feel free to add any other details that are unique to you.	
After receiving the diagnosis, where did you find support and information? You might want to think of the following categories: - Doctors - Other professional specialists (such as paediatricians, neurologists, speech therapists, occupational therapists, psychologists, psychiatrists) - Family - Friends - Support groups - Other?	
3. Support groups – if you have ever participated in support group meetings, please complete this section. This does not include the Facebook support group	
How many support groups have you attended in the past and do you attend currently?	
What was/is the nature of each of these above-mentioned support group/s? This refers to the process followed in the group/s.	
What does/did each group target specifically, such as parent training, coping, peer support etc?	
How do/did you experience these physical support group gatherings?	
Is/was it possible to attend every support group meeting?	

If not, please provide reasons.	
Is/was the support group meeting facilitated by a counsellor, doctor, psychologist etc., or by a fellow parent?	
How does/did this person facilitate the support group meetings?	
Please describe the positives of attending the support group meetings.	
Please describe the negatives of attending the support group meetings.	
Please describe any other value attached to the group that you may have experienced.	
Please provide your reasons for not participating in support group meetings anymore (if applicable).	
4. Facebook support group	
For how long have you been a member of this group?	
What was your reason for joining the group?	
Please provide a description of your experiences from participating in the group, positive, negative and/or any other.	
Are there differences, in your opinion, between the online support group and a physical support group meeting?	
If so, please describe such differences in detail.	
Are there similarities, in your opinion, between the online support group and a physical support group meeting?	
If so, please describe such similarities in detail.	
Do you have a preference	

between the online support group and a physical meeting? Please provide an explanation for your answer.	
According to you, what kind of information is shared among parents in the Facebook support group?	
How does this shared information contribute to how you make sense of your daily experiences as a parent of a child with autism?	
How do you think the information *you* share contributes in the lives of other parents in the group?	
The literature indicates that the following aspects of online parent-to-parent support are valuable: - It is a powerful coping strategy from knowing that there are others going through similar experiences - It provides a space for debriefing - It provides constant support - Support is available at any time of the day Are there any of the above mentioned aspects that are particularly true for you? Please explain your answer, and feel free to add any additional information.	
What is the most helpful information to you that is shared in the group and why? Some of the information shared in the group have covered the following topics: - Toileting - Behaviour modification - Diet	

- Therapies - Schooling - Services (doctors, dentists etc) - Uplifting fellow members through encouragement - Any other?	
What do you believe of yourself as a parent *now* that you might not have believed before joining this support group?	
If you were not able to be a member of this group anymore, what impact will it have on you?	
Has this group ever contributed negatively to your daily experiences, for instance through the content of other members' posts, conflict within the group or in differing opinions? If so, please provide an explanation.	
5. Utilising other online forums	
Do you make use of any other online forums related to being a parent of a child with autism, such as blogs? This could refer to both having your own blog, and/or regularly reading other blogs related to autism, or being a parent of a child with autism.	
If you have your own blog, how does this contribute to the way you make sense of your daily experiences as a parent? What impact do the comments of followers of your blog have on you?	
If you follow other blogs related to autism and being a parent of a child with autism, how does this contribute to the way you make sense of your	

daily experiences as a parent? What impact does the content of these blogs have on you?	
Imagine you will never be able to access the internet again, and thus you will not be able to blog or follow blogs anymore. What impact will it have on you?	
6. Personal opinion	
Is there any other information you wish to share that has not been covered in the previous sections?	

ADDENDUM E

Autism South Africa’s letter regarding the “*Let’s Talk About Autism*” campaign

Dear Friends of Autism South Africa,

Please take a few minutes to read right to the bottom of this letter – the content is very important.

Join our Autism Awareness Army and help us spread the word!

We are taking on April as "Autism Awareness Month" with a bang!

As you know, April 2nd is World Autism Awareness Day, and April is known as "Autism Awareness Month" worldwide. So we decided that it's the perfect time to make a real difference in the lives of children and adults with autism – to get people talking about autism and to spread acceptance and acknowledgement of those with an Autism Spectrum Condition.

That's why we're launching a radical and controversial awareness campaign – and we need your help, understanding and support to make this campaign a success.

Meet the experts

We're exceptionally lucky that through a company called "Independent Agency Search", we have been taken on by 4 top media and advertising companies on a purely pro bono basis:

- **House of Brave** – Providing the creative content (www.whoswho.co.za/house-of-brave-77421)
- **Wetpaint Advertising** – Enhancing our Social Platform and Public Relations presence (www.wetpaint.co.za)
- **MediaCom South Africa** – Seeking high profile placement of the awareness material across the country in all forms of media (www.mediacom.com)
- **Sweet Spot Content** – Creating a TV Advert to bring autism to the forefront of people's minds. (www.ssc.tv)

What is the campaign all about?

Here are a few of the slogans that you will start seeing in the media once our campaign rolls out as of 2nd April:

- **Autism is for Blacks only**
- **Autism is for Retards**
- **Autism is for Whites only**
- **Autism is for Possessed People**
- **Autism is for Violent People**

All of these are very common (and unfortunate) misconceptions that we need to dispel. These are the 5 slogans suggested by House of Brave and approved by the National Executive Committee of Autism South Africa. With these highly controversial statements we're aiming to shock people – to start a vital conversation and to get people asking questions about autism.

The aim will be that people will then go to the new web page that is shown under all the slogans to investigate these statements, as well as ask people they know, like yourself, what this is all about, and this is why we appeal to you to join us on a significant awareness campaign as outlined below.

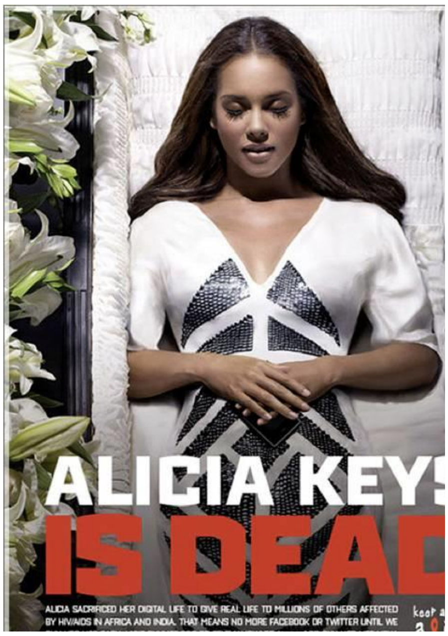
New website

The new website is www.aut2know.co.za that was built by Wetpaint, specifically for this campaign. When visiting the website, once the media campaign is launched, users will be greeted by a "Splash Page" that will disprove all of the statements made in the advertising campaign, and offer the truth about autism. People can also find more information on understanding, accommodating and embracing the effects of autism on the website.

Why the controversy?

We've had some long and involved discussion about this approach, and in the end we've decided to take a leap of faith and put our trust in the highly acclaimed experts who are donating their wealth of experience and expertise.

What we've come to see is that autism isn't really talked about, and it's definitely not understood. We need to remember that our society is over-burdened, and we need to use an impact that will interest them. We've all seen the endless HIV/AIDS campaigns that simply "wash over" people. But we were shown a radical campaign launched by a number of celebrities where the results were excellent because people talked and acted!



So with this campaign, we're hoping to overcome ignorance and to get a lot more people to take an interest in autism.

The Autism Awareness Army - We're going to start our very own Autism Awareness Army.

We all know Herbalife – and we know about them because they are one of the world's top direct sales 'armies', simply by having a significant number of people to wear badges saying "Lose weight now. Ask me how". That's what we want to achieve for autism in 2013.

Please join our army

We ask that you please wear a badge that says "Ask me what autism is", provided by Autism South Africa, at least for the month of April (or hopefully even longer!). We'll also provide you with information about autism that you can keep on you at all times. Then you simply get yourself out there and encourage people to ask questions about autism, and if they don't, give them a description anyway!

Please email claudia@autismsouthafrica.org with your name, telephone number and PHYSICAL address, along with the number of badges you need – depending on how many informed family and friends you can ask to join the "Autism Awareness Army" – and we will courier you your artillery.

Part of the "artillery" will be small leaflets with basic information on Autism Spectrum Conditions for you to carry around to give to people who ask you about autism. The leaflets do not carry the ASA logo, but provide a block that you can provide local or preferred contact details.

Let's take on ignorance together.

We know this is a controversial approach.

We are sure we're going to receive some criticism.

But even criticism will help us to achieve our goal – to get people

TALKING ABOUT AUTISM!

From there it will be up to all of us, to take on the war against stigmatisation and ignorance – a war, to date, we most certainly have not come close to winning.

We have received communication from differing schools as regards the success of their "Light It Up Blue / Dress It Up Blue" campaign last year and asked whether they should repeat it again this year? I would say that if this campaign worked well at your school and within the surrounding community, it would be sad for you not proceed again this year, and then if you are in agreement, couple your "Light It Up Blue / Dress It Up Blue" project with Autism South Africa's **"Talk About Autism to Overcome Ignorance"** campaign.

South Africa is one of the 13 members of Autism Speaks "Global Leadership Advocacy Network" and therefore we are in regular contact with Autism Speaks. If you do proceed with "Light It Up Blue / Dress It Up Blue", the please send us photos and a small write up that we will cluster and send to Autism Speaks asking them to load your photos onto their international "Light It Up Blue" site.

Let's stimulate conversation, let's **Talk About Autism to Overcome Ignorance.**

Thank you.

Kind regards

Jill Stacey. National Director.

ADDENDUM F

Excerpt from responses to the electronic interview questionnaire

Except from responses to the electronic interview questionnaire		
Participant responses	**Coding**	
	Categories	**Themes**
How many support groups have you attended in the past and do you attend currently?		
1. SA twice a year maybe for the formal support group. Also attend a “social/ coffee” support group 2. I attended two meetings in Fourways in 3008 after making contact with Autism South Africa. Unfortunately I was not able to attend more due to work constraints. The scheduling was such that I could not attend. 3. I generally attend two groups (past and present) 4. One in the past and none now. 5. I have attended the Association for Autism support Group although not on a regular basis. 6. None 7. 3 in the past. Currently one 8. Tea group; facebook groups; family fun day group	SUPPORT (physical support group)	Physical support group Social support group Accessibility
How do/did you experience these physical support group gatherings?		
1. It was for receiving information as there was very little interaction with other parents. Coffee group related and feel comfortable among other parents of children with ASD 2. Positively. 3. I enjoy the first group as it gives me an opportunity to meet new people and hear their stories. I also get to catch up	SUPPORT (physical support group)	Physical group – minimal interaction, getting information Physical group – meeting new people and hearing their stories Social group – mutual

with others who I haven't seen for a while. I also really like the second group. It is not a 'woe is me' group and we are generally upbeat and positive. For sure, we are there to lend a shoulder and a listening ear if needed. Having the emotional and physical presence with other parents is uplifting. 4. Pleasant 5. I usually found strength and understanding knowing that I am not alone and that other parents are going through the same as what I am. 6. Not applicable 7. Very helpful to be amongst other parents experiencing the same difficulties 8. Helpful if one has a particular question. It is difficult though because our community is so diverse and our kids so different and the therapies extreme		understanding, sharing experiencing, receiving social support from peers Positive experience
Is/was it possible to attend every support group meeting? If not, please provide reasons		
1. No, I only attended if the topic was relevant to me. 2. No, time/work constraints 3. I don't attend every meeting of the first group, as at times the topic for the month is not something that I may be interested in or perhaps I already have enough knowledge in the subject. I always attend the second group due to the fact that it is organised by me! 4. No, Transport issues. 5. No, due to the distance and time of the	SUPPORT (physical support groups)	Choosing physical support group meetings according to relevant topics Reasons for not attending physical support group – work and schedule, transport

meeting. 6. Not applicable 7. No – other commitments like lectures, child unwell, parent illness/hospitalisation, transport cost 8. No, sometimes I was just too tired		
Please provide a description of your experiences from participating in the group, both positive and negative.		
1. Some info sharing has been helpful. Also notification of upcoming events. Since I am seasoned in the ASD walk much of the general discussion are questions I had early on but have now overcome. 2. Receiving input from other parents or autistic adults in a local setting provides me with better insight into past experiences, as well as possible future developments for my son, 3. Sigh. To be honest, I have never found it to be a supportive group. Each person has their own agenda. I also find some of the members to be extremely closed minded and then there are others who dominate the page. People are quick to take offense, which goes to show that it is impossible to have a conversation when you are actually not in front of that person OR even on a phone call. Words alone are not enough. We need to see facial expression, body language and hear what is being spoken. 4. The experience has been on the whole very positive. I have learned a great deal and been able to give back to the	SUPPORT DIVERSE EMOTIONS VALUE OF FACEBOOK SUPPORT GROUP DISCOURSE SUPPORT	Value of support group – sharing and getting information – mutual understanding Relevance of the information shared in the group not as applicable with having an older child with autism Being equipped with resources/guidance Not-so-supportive nature of the online group Human reactions in online group Physical interaction can mediate situations – where it is absent in online communication

autism community. One of the problems at times is that words can sometimes be taken of context as there are no visible clues as to their intent.	VALUE OF FACEBOOK SUPPORT GROUP	
5. I find that the group is mainly of the younger generation whose Autistic children are still young. One ultimately needs a group for Adult Autistics. I was hoping to be able to share more with parents who have Adult Autistics and who can help with their experiences. At times as a parent one feels that you are all alone and it truly helps if you realise that you aren't and the advice given from others could help.	SUPPORT PARENT IDENTITY	
6. I have made good friends who are happy with me with any progress and I am happy with them if things go well with their child/ren. I also found that they do not ever judge!		Making friends Non-judgemental
7. Initially, excellent support as we were dealing with strangers so we could share the best and worse of our experiences with ASD. As members became more familiar with each other, and friendships were formed, focus shifted from support to proving who was RIGHT/KNEW THE MOST about ASD. Many people on the group were intolerant of the views of others. Groups of people who believe in Bio Medical Intervention had the view that they were going to CURE their child's AUTISM and others who believed otherwise fought back. It became a huge mud slinging fight which left xxx with no choice but to		Not-so-supportive nature of the online group - competitiveness Conflict – clash in opinions

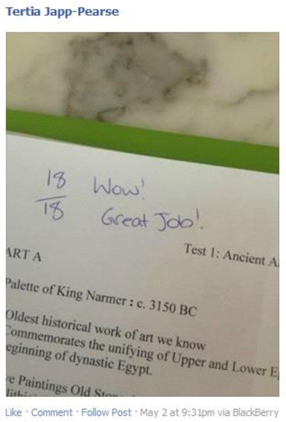
shut down the group. The new […] Group which currently exists was formed [by various parents]. The second group was responsible for helping many a parent with much needed advice, support and comfort. I personally celebrated the little successes experienced with my child on the support group whenever it occurred. 8. Positive – I made friends in this new world I live in. Positive – I learned a lot. Negative – I got “conned” (but no seriously so). Just enough to make me step back.		Sharing personal experiences
What are the differences, in your opinion, between the online support group and a physical support group meeting?		
1. Yes the on line group has no accountability. The live group people control their language and are respectful in their expressions if they disagree with something. 2. Online support groups are always accessible, even if I lie awake at night with a question; there are not time constraints to posting a question or a comment. The internet is patient. It is however; easier to misunderstand a comment or post, as there is no interpersonal cues to follow on interpreting something. Physical support groups helps in that a virtual hug is simply not the same as a real one. The support is more real in physical groups. 3. Oh absolutely, being present during a physical support group meeting is a	VALUE OF THE FACEBOOK SUPPORT GROUP SUPPORT VALUE OF THE FACEBOOK SUPPORT GROUP	Differences between online and physical – no accountability versus respect, anonymity removes certain social boundaries Nature of online group – accessible, no time constraints, Misunderstandings Nature of physical support group Physical interaction can mediate situations – where it is absent in online communication

much more positive experience then the online group. Using all modes of communication to express ourselves gives a true reflection of what we want to say. I find that people are much more polite face to face. The internet tends to be anonymous; therefore people feel they can say whatever they wish without regard to how the words may be perceived.	SUPPORT	
4. The primary difference is accessibility. Barring internet connection issues, the group is available to post to 24/7. There is no schedule as such and no topic at a given date and time. The other main difference is that it exceeds the boundaries of your geographical area, giving access to others outside the town or city they live in.	VALUE OF THE FACEBOOK SUPPORT GROUP	
5. You can express your feelings easier face to face. Also the empathy and concern from a fellow parent is at times necessary.		
6. Online support groups are immediately available, they do not expect you to leave your home or your work or your child to attend the group. Online support groups provide you with a wide variety of people with a wide variety of knowledge and contacts for help		
7. Yes. People online can be very understanding without being judgemental because we are dealing with strangers. Some people are more comfortable asking strangers for advice or a supportive ear without the added		Anonymity of online group Online group – no

stress of forming a "relationship" first. Also, it is helpful to have many different views regarding one issue		need to establish a relationship Variety of views
8. Anonymity. One can "log out" if one needs to. One can learn a great deal from first-world citizens – they have a more "entitled" attitude to science and therapy. We are more polite in SA; we don't say what we think as much as some do – lest we offend.		

ADDENDUM G

Excerpt from participants’ interactions in the Facebook support group

Except from participants' interactions in the Facebook support group					
Date and time	**Post**	**Interactions**		**Coding**	
		Amount of Likes and Comments	**Comment responses**	**Categories**	**Themes**
02-05 05:19	3.45 am! now at 5am I am tired. I am starting to think that I should go to bed at 7pm and see if I can "reset" my internal clock to match hers instead of the neurotypical, adult world! We have had breakfast and now XXX is ready to go back to sleep. Marvelous. NOT.		(02/05 06:26): If it will help do it. I think continued tiredness destroys people at the deepest possible level. Destroys the soul. If you can find a way to sleep more I would do it.	SUPPORT	Tired Sarcasm empathy
02-05 21:33	 Tertia Japp-Pearse Like · Comment · Follow Post · May 2 at 9:31pm via BlackBerry This photo was posted on the wall of Carly Fleischmann. With the accompanying message: "Perfect test! This test cost my parents over a half $1 million. It took me countless hours and years of sitting at a table and working nonstop. It took many days months and years for me wishing to find a way to communicate.	4 likes		SUPPORT DISCOURSE	Pride Thankfull AS can learn and perform Professional discourses ? interaction

	This test took the strength with in me to find my way into this world. I heard doctors tell people to give up on me. Countless teachers and principals saying they won't except me. To all them all I can say is one thing: It sucks to be you! This test is for every child that is being diagnosed today with autism. We can do it."				
03/05 08:54	You all have a wealth of expertise that I would be honoured to draw on as I am compiling training notes for the new facilitator. If there is a teaching method tip or a behavioural management tip that has helped you; please post it here or inbox me. (I am thinking those "out-the-box-thinking-stuff-that-you-do-that-is-not-in-the-'schools-of-thought'-that-you-figured-out-through-common-sense-and-necessity").	8 comments – all about sharing methods	(03/05 15:39): Increase wait time for processing information (at least 45 seconds). Use experience sharing language (20% imperative, 80 % declarative). Think *out loud* so that the child hears your thoughts. Don't be repetitive.. cut back on the talking! At all times be mindful of giving the child lots of opportunities to *think* for him/herself.	PARENT IDENTITY SUPPORT	Parents as experts Sharing methods
02/05 21:39	 (From: Autism with a side of fries). Like · Comment · Follow Post · May 2 at 9:39pm via BlackBerry	7 likes 6 comments (2 her own) – about understanding the need for coffee/caffeine	(02/05 21:45): XXX, I am loving that you like this, especially considering that I nearly drove into you this morning in the lane. BAHAHHAHHA - so little sleep I was in	SUPPORT	Sarcasm Empathy Tiredness interaction

	ME ME ME!		"OH MY GOSH!" mode!		
31/05 11:33am	Statistically less than 1 out of every 3 people in SA has regular access to the internet (5% on home, IPad or droid), 22% via cellphone. At best if people are prepared to pay to use internet cafes etc 56% of SA population has access to the internet. (2012 figures). The rest are taking these printed ad and incorporating it into mental schemata as fact. Your nanny, her kids when the paper goes home with her. If ..... These printed ads continue and someone calls our kids "retarded", "spastic", accuses them as the culprit because they are "violent" - then, we must shut up because we are allowing this monster to roam in our communities. When you hear of a child being exorcised - it will be everyone of our fault because these papers are finding their way into every area of our country. Don't cringe when you hear about it. ASA has clearly taken down their billboards that turned our children into freaks - but not their printed ads. To everyone of you who is pledging your support to them - you	24 comments	[Parent]: left ASA and got off their mailing list. I am going to leave here for a while too (at least). I do not really want to talk to people who are okay with people who turn our kids into retards, spasrics, possessed or other freaks. May 31 at 11:51am via mobile · Like · 3 [Parent]: i just wonder how they could EVER have thought that stating harsh, unkind untruths will have a possible positive effect in the end? People do not have TIME to go look for a different truth, if the untruth is in bold on posters. And unless you are affected by autism of a child or family member, you are not going to put in the effort to know better because some or other sick poster is supposedly challenging you to think differently.. If one wants to debate an issue, you start with the Truths... not the myths! May 31 at 12:55pm · Like · 1 [Parent]: ive seen those comments... those people obviously do not understand the extend of harm that skewed	DISCOURSE ADVOCACY SUPPORT (effects of ASA campaign) DISCOURSE	Interaction Internet access in SA Public perceptions about autism/public discourse Need to debrief/distress – not finding the group as supportive anymore… Not feeling support Continuation of the stigma of autism – judgement Anger Being a parent of a child with autism Public perceptions

	have a hand in this.		perceptions can cause... May 31 at 1:24pm · Like · 1 [Parent]: I have a contact at Carte Blanche May 31 at 1:29pm · Like · 1	ADVOCACY	Blame

ADDENDUM H

Excerpt from participants’ feedback

Parent Feedback	
Parent 1	**From:** xxx **Sent:** 22 September 2013 08:49 AM **To:** Karin Gerber **Subject:** Re: Research Findings and Feedback Hi Karin I am not sure what feedback you are looking for! I must admit that I do find it a little unsettling that you have used the Facebook group for your thesis, although of course I do understand that the people you asked to participate could have declined! :) Another thing that concerns me is that you haven't spoken to some of us (all?) face to face, hence you don't know our personalities. […] I guess I am not surprised that you brought in the ASA debacle. […]. I was shocked to see a very different side of people that I actually know, and it wasn't pretty. Funnily enough I recently saw a very similar campaign being used overseas (think it was the UK) and there didn't seem to be any fallout. One thing that really stands out for me is that all participants have different stories. We are as varied as our autistic children. An online relationship lends to having carte blanche with being open with our words which can cause numerous problems. People are far more polite in a real time social situation. I know which one I would choose! Let me know if you need any more info! Best wishes xxx
Parent 3	**From:** xxx **Sent:** 30 September 2013 07:46 PM **To:** 'Karin Gerber' **Subject:** RE: Research Findings and Feedback Hi everything seems fine, all the best with the completion of your study. xxx
Parent 7	**From:** xxx **Sent:** 29 September 2013 06:42 AM **To:** Karin Gerber **Subject:** Re: Research Findings and Feedback Wow Karin! That was an excellent piece of hard work! Well done! Reading some of the comments which I recognise made me squirm a bit! As I am

	sure will happen with others who participated! But well done...a good reflection how things have unfolded and also that it is a place where people can seek help. Many thanks xxx