

**EMPOWERMENT OF SOCIAL WORKERS WHO WORK WITH SIBLINGS OF AUTISTIC
CHILDREN**

by

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Submitted in part fulfilment of the requirements for the degree of

**MAGISTER DIACONIOLOGY
(DIRECTION: PLAY THERAPY)**

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: Dr Herman Grobler

Date: November 2009

DECLARATION

I hereby declare that:

EMPOWERMENT OF SOCIAL WORKERS WHO WORK WITH SIBLINGS OF AUTISTIC CHILDREN

is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



Cindy Marais
Researcher

30 November 2009

DECLARATION OF PROOF READER

Hereby I declare that I have language edited and proof read the thesis *Strategies for social workers to empower siblings of autistic children* by Cindy Marais for the degree MDiac. I am a freelance language practitioner after a career as editor-in-chief at a leading publishing house.

Lambert Daniel Jacobs (MA, MDiv)
20 November 2009

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ACKNOWLEDGEMENTS

My gratitude and appreciation to the following people:

- My supervisor, Dr Herman Grobler – for his excellent guidance and endless patience and support;
- Lambert Jacobs – for the technical and linguistic maintenance;
- My late dad (Pieta) and Ma – thank you for believing in me and sharing my dream and vision for my future. Ma, thank you for your love, prayers and endless encouragement;
- My family and friends – for your interest, support and encouragement through this process;
- Fellow students and comrades – for your inspiration and encouragement;
- The respondents – thank you for your time and participation;
- The experts – thank you for your time and knowledge in this field
- All praise to my God and my Shepherd, who gave me strength, an open mind and calmness of heart to succeed in this study;

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SUMMARY

EMPOWERMENT OF SOCIAL WORKERS WHO WORK WITH SIBLINGS OF AUTISTIC CHILDREN

by

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DEGREE: MASTERS DIACONIOLOGY (PLAY THERAPY)

The main aim of this study was to explore the difficulties and limitations preventing social workers from empowering siblings of Autistic Spectrum Disorder (ASD) children. Specific attention was given to social workers in the London Borough of Greenwich, United Kingdom and siblings who were in their middle childhood phase of development.

Qualitative, applied research of an explorative and descriptive nature was followed. For the purpose of this study, the researcher conducted unstructured in-depth interviews with social workers and the siblings. Six social workers and four siblings were interviewed for this research study. Themes and categories were developed out of data from the unstructured interviews to which the researcher compared and verified it with already existing literature.

Conclusions were drawn and recommendations were made from this research study.

Key terms: Siblings; social workers; Gestalt; unstructured interviews; qualitative research.

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OPSOMMING

BEMAGTIGING VAN MAATSKAPLIKE WERKERS WAT MET SIBBE VAN OUTISTIESE KINDERS WERK

deur

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GRAAD: MAGISTER DIACONIOLOGIAE (SPELTERAPIE)

Die doel van die navorsing is om die struikelblokke te ondersoek wat maatskaplike werkers verhoed om sibbe van outistiese kinders te bemagtig. Die fokus van hierdie studie was spesifiek op maatskaplike werkers van die London Borough of Greenwich, Verenigde Koninkryk en sibbe in hulle middle-kinderjare.

Kwalitatiewe, toegepaste navorsing met 'n verkennende en beskrywende aard is gevolg. Vir die doel van hierdie studie het die navorser gebruik gemaak van ongestruktureerde, in-diepte onderhoude met maatskaplike werkers en sibbe. Onderhoude met ses maatskaplike werkers en vier sibbe is gevoer vir hierdie studie. Temas en kategorieë vanuit die data van die ongestruktureerde onderhoude is geïdentifiseer en geverifieer met alreeds bestaande literatuur.

Gevolgtrekkings en aanbevelings is gemaak na aanleiding van die bevindings in hierdie studie.

Sleuteltermes: Sibbe; maatskaplike werkers; Gestalt; ongestruktureerde onderhoude; kwalitatiewe navorsing.

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CHAPTER ONE

INTRODUCTORY ORIENTATION OF THE STUDY

1.1 INTRODUCTION

According to the United Kingdom's 2001 Census of population, there is an estimated number of 133 500 children under the age of 18 with an Autistic Spectrum Disorder (ASD). The National Autistic Society (2008) in the United Kingdom reports that autism is no longer seen as a rare condition and is thought to affect around 535 000 people in the United Kingdom.

Sibs (2008), a charity organisation for people who grow up with a disabled brother or sister, states that over half a million young siblings in the United Kingdom live with a disabled brother or sister. According to Sibs, these siblings have specific needs that require attention at different stages of their lives, including experiencing lack of parental attention, isolation, ignorance about disability, difficulty coping with their experiences, and the financial impact of disability on the family. Once there is a brother or sister with a disability in the family, the family's dynamics change.

According to the Contact a Family organisation (2008), studies about siblings of disabled people have tended to report mixed findings. It is often a close relationship but there can be some difficulties. Sibling relationships in general tend to be a mixture of love and hate, rivalry and loyalty. Often having to put the needs of the disabled child first seems to encourage an early maturity in brothers and sisters.

All of the above realities make it difficult for social workers to determine appropriate ways in which to empower the siblings with the challenges of their daily lives with an autistic child in the family, as the researcher has found in her professional capacity as a social worker. In the researcher's professional experience the siblings often do not get the level of attention from their parents as their disabled brother or sister because of the sibling's complex needs. Even though it is important to establish and understand the family functioning and the individual

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relationships within the family, the views, wishes and feelings of the siblings can be advocated by their parents, thus not a true reflection of the sibling's experience and views. Furthermore, the researcher also found that the parents want a service and support with their disabled child and do not understand or want to spend too much time exploring and discussing the non-disabled child. The focus is rather on the disabled child and how the family's "normal" functioning is jeopardised. Ives and Munro (2002:68) explain that once a child is diagnosed with autism in a family, the autistic child becomes the centre of the family life and everything revolves around this child. They go further to state that families withdraw themselves socially due to the difficulties often presented with autism. They explain that family life can feel "limited and unrewarding" (2002:69).

Halmos (in Blewett, Lewis & Tunstill, 2007:10) explains that historically social work's therapeutic role was seen as core to the profession. However, Blewett, Lewis and Tunstill (2007:10) state that in the 1980's there was a move to a case management model that appeared to minimise this aspect of the social work role. Social workers rather had the role of a commissioner than the deliverer of therapeutic services. Aldgate (in Blewett, Lewis & Tunstill, 2007:10) argues that this way of working has changed and even though social workers do not deliver formal therapy and are not involved in specialist therapeutic services, the assessment process and interventions delivered could be therapeutic. The researcher is of the opinion that should more time and opportunity become available for social workers to work with siblings of autistic children, therapeutic support could be offered to the sibling and thus ensure empowerment.

1.2 PROBLEM AND RATIONALE FOR THE STUDY

"Unlike their parents, siblings may have no knowledge of life without a brother or sister with a disability" (Featherstone, 1980).

The researcher has a professional interest in this topic as the majority of cases in the researcher's case load, when, she worked as a social worker in the Disabled Children's Team, in Greenwich, United Kingdom, consisted of autistic children and their families. The

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researcher has often experienced difficulties in supporting the siblings of the autistic child. This was a direct result of a lack of knowledge and skills; a lack of time and limited resources and more generally the nature of social workers' expected level of intervention with a family with a child with special needs. It is the researcher's personal experience that there is a limited capacity to empower the siblings as the focus of the social worker's assessment/intervention is mainly on the autistic child.

Knowledge, skills and values are three important factors which can influence the way a social worker practices. According to Beckett (2006:19) knowledge tells people what choices there are and what the consequences might be. He goes further to explain that skills set limits on what choices are practical, but that when it comes to making the choice itself, this will be determined by values (Beckett, 2006:19). Hugman (in Adams, Dominelli & Payne, 2002:15) explains that values are a set of principles that guide practice and underpin the norm that ensure ethical behaviour on the part of social work practitioners and that it elaborates a basis for holding practitioners accountable for their actions.

As a result of the researcher's involvement with children with autism and their families, a need was identified to do research on how social workers can be equipped in order to empower the siblings of the autistic child. The researcher is of the opinion that social workers can benefit from being aware of what is preventing them from providing a holistic service in a multi systemic approach. Also to become more aware of the stresses as well as the feelings of these siblings about their unique life experiences. The research in this study may enable social workers to deliver a more effective service to the families they work with and specifically to empower the siblings of the autistic child. It may be used as a tool to reflect on factors impeding on the service being provided. Other professionals, as well as the parents and teachers, may also benefit from the conclusions and recommendations.

Children in their middle childhood were chosen as respondents. According to Schoeman (2004:18) the middle-childhood period is generally considered the more peaceful development period. Schoeman (2004:18-20) also explains that it should be borne in mind that patterns are being established during these years and that cognitive, social, emotional,

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and self-concept development take place. Geldard and Geldard (2002:73) state that the child's parents are likely to provide a strong sense of emotional influence in the child's life as they generally spend most of their time in the family environment. Siblings of autistic children are often deprived of their parents' attention due to the difficulties the autistic child's behaviours involve. Oaklander (1988:206) states that she "perceives a child who engages in hostile, intrusive and destructive behaviours as a child who has deep angry feelings, feelings of rejection, feelings of insecurity and anxiety, hurt feelings, and often a diffused sense of selfhood." She further states that children might be unable or unwilling and fearful about expressing what they are feeling and that they use the aggressive behaviour as a method of survival. Both Oaklander (1988:206) and Reynolds (in Woldt, 2005:168) are of the opinion that children's environment provokes their antisocial behaviour and that they lack the internal ability to cope with the environment that makes them angry. This might be the case with the siblings of an autistic child and where the siblings lack the attention from the parents to support them, they might start introjecting or retroreflecting their emotions.

For the purpose of this study, the researcher worked from a Gestalt perspective which, according to Blom (2004: 40), focuses on existentialism, phenomenology and holism with the emphasis on obtaining awareness in the here-and-now and the interdependence between people and their environment. The researcher is currently undergoing training in Gestalt Play Therapy. The researcher's own phenomenology is therefore inevitably strongly influenced by Gestalt theoretical perspectives. The Gestalt perspective will form the main underlying theoretical basis of this study, especially during the data collecting process. This will be done by respecting each individual's unique way of being, and by exploring carefully their perception of events, whilst bearing in mind that the individual consists of a self in relation to the environment (field). Yontef (1993:125) defines a field as follows:

The field is a whole in which the parts are in immediate relationship and responsive to each other and no part is uninfluenced by what goes on elsewhere in the field. The field replaces the notion of discreet, isolated particles. The person in his or her life space constitutes a field.

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Perls (1957) describes the field as "... the basis of Gestalt therapy. We are here in a field. In this field there are a number of people, and there is me." For siblings of autistic children, the environment or field would be ever changing, being influenced by self and others.

Fouché (2005a:116) states that, "An exploratory study using qualitative methods usually does not have a precisely delimited problem statement or precise hypothesis. One purpose of qualitative methods is to discover important questions, processes and relationships ...". In the researcher's personal experience of working as a social worker in a Disabled Children's Team in Greenwich, United Kingdom, she repeatedly came across siblings of autistic children who were struggling to cope with the daily challenges of having a disabled brother or sister and often felt ill equipped to assess or meet their needs. Generally siblings (especially between the ages of six and twelve) of children with autism experience internalised (depression) and externalised (aggressive behaviour) behavioural problems more than siblings of children without autism (Verté, Roeyers & Buysse, 2003:193).

It is often due to limitations such as remit (for example mild or severely disabled, and thresholds as to when a case will be accepted to receive support services from the Children with Disabilities Team or not), time, timescales, resources and skills, that a social worker will rather make a referral to a Child and Adolescent Mental Health Service (CAMHS) and young carers' projects than working with the siblings of the autistic child themselves. The researcher has found referrals to be negative in the sense that yet another professional is commissioned to get involved with this family and to support a specific issue or problem, e.g. aggressive behaviour from the sibling of the autistic child. It is often felt that the skills acquired during social work training are not fully accessed and eventually it feels as if the skills are forgotten. For example, during the second year of social work at the Northwest University in South Africa, the focus is on the child development and child centred intervention, equipping the social work student with skills and knowledge in working with a non-disabled child. Working as a social worker in a Disabled Children's Team in the United Kingdom, the focus is on the disabilities of one child in the family when completing assessments. In order to obtain local services it is then difficult to change the focus to the abilities of the non-disabled child in the family.

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The problem that has been identified for this study is the lack of empowerment of the siblings of the autistic child, which holds certain challenges for the social worker who is not equipped to empower the siblings of an autistic child enough to be able to cope with the challenges of the disabled brother or sister.

1.3 GOALS AND OBJECTIVES

Goals and objectives according to Terreblance and Durrheim (2002:39) and Mason (2003:21) will clarify the proposed ends and means of the research project intervention. The goal of this exploratory study is to equip the social workers of the London Borough of Greenwich, United Kingdom, to empower the siblings of children with autism to cope better with their situation.

This study will be exploratory research as it will be conducted to gain insight into a situation, phenomenon, community or individual. Fouché and De Vos (2005b:106) further explain that “exploratory research has a basic research goal, and researchers frequently use qualitative data.” The researcher has found that even though there is extensive information on Autistic Spectrum Disorders (ASD) and the difficulties the siblings face, there is not sufficient information on ways in which to equip social workers, who on a regular basis come across problematic behaviour from the siblings of the autistic child. The objectives of this study will be:

- To provide a paradigmatic framework from which the study will be conducted;
- To conduct unstructured interviews with social workers in order to enquire after the difficulties they experience in empowering the siblings of autistic children;
- To conduct unstructured interviews with siblings of autistic children in order to gain information regarding their needs for empowerment;
- To conduct a literature control that will serve as support for the empirical research;
- To draw conclusions regarding the above and to make recommendations to social workers in the London Borough of Greenwich, United Kingdom, regarding ways of empowering the siblings.

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1.4 RESEARCH QUESTION

From the problem formulation, the research question can be formulated. Fouché and De Vos (2005a:91) and TerreBlanche and Durrheim (2002:33-34) state that one way of identifying a research topic, is questions and problems that emerge from the daily practice of the caring professions. The researcher wants to focus on the needs of social workers working with siblings of autistic children and how to equip them and thus enable them to empower siblings of autistic children. Marshall and Rossman (in Fouché & De Vos, 2005a:91) further argue that research questions can shape decisions about gathering data. For the purpose of this study, the research question led the researcher to conduct unstructured interviews in order to gain information about the social worker's needs regarding the empowerment of siblings of autistic children. The following research question was identified:

How can social workers in the London Borough of Greenwich, United Kingdom be empowered to work with siblings of autistic children?

1.5 RESEARCH APPROACH

The researcher will make use of the qualitative research approach. According to Punch (in Silverman, 2005:6) the method a researcher is going to use in his or her research study, should be appropriate to what he or she is trying to find out instead of it being predetermined. Silverman (2005:6) states that a qualitative method could be chosen if the researcher wants to explore a person's everyday behaviour or life history. In order to gain a better understanding of what is needed to equip social workers in the London Borough of Greenwich, United Kingdom, so that they can empower the siblings of autistic children it seemed best to follow the qualitative route through which in depth information could be gathered. Monette, Sullivan and De Jong (2005:39) explain that the researcher is able to form an understanding of the subjective experiences of people through qualitative research methods. Research can either be basic or applied in nature (Terreblanche & Durrheim, 2003:39; Grinnell & Unrau, 2005:14). Mason (2003:24) and Terreblanche and Durrheim (2003:39) state that qualitative research is characteristically exploratory, fluid and flexible,

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data driven and context sensitive. This research will be applied, with an exploratory and descriptive nature.

1.6 RESEARCH STRATEGY

The strategy of this research will be in the form of a case study (Babbie & Mouton, 2001:280; Graziano & Raulin, 2007:123) where the researcher will explore the needs of social workers in order to possibly empower the siblings in their everyday lives. According to Punch (2005:144) the goal of the case study is to understand the case in depth and in its natural setting, recognising its complexity and its contents. Instrumental case studies (Fouché, 2005b:272) are used to gain a better understanding of a social issue.

1.7 RESEARCH METHODOLOGY

1.7.1 Literature study and review

For this study, the researcher will conduct a literature study and review after the research data is collected. This literature study will form part of the literature control. Leedy (in Delport & Fouché, 2005a:264) states that the findings of a phenomenological study need to be related to an existing body of theory and research and that the literature review (Babbie & Mouton, 2001:47) should be performed after the findings of the research have been formulated.

1.7.2 Feasibility of the study

The study will be feasible due to consultations and discussions with the National Autistic Society family support worker as this professional has a considerable amount of information and resources regarding Autistic Spectrum Disorders and how this disorder affects the rest of the family. This study will also be practical to do as the researcher's work place is within the Disabled Children's Team in Greenwich, United Kingdom. The family support worker supported the researcher in sending out letters to all families who are on the database of the

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National Autistic Society, South East London, United Kingdom.

1.7.3 Consultation with experts

The researcher has consulted with the following experts:

- Lesley Davies, National Autistic Society, Family support worker and also a parent with an autistic child;
- Rachel Muir-Nelson, Manager of Greenwich Mencap, United Kingdom, voluntary organisation supporting families with autistic children. This organisation is also often commissioned to provide support to the family members of autistic children;
- Dr Antonina Ingrassia, Child and Adolescent Mental Health Psychiatrist. All referrals requesting support regarding problematic behaviours in children are made to Dr Ingrassia and her team of psychotherapists;
- Wajdie Solomon, social worker in the Children with Disabilities Team in the London Borough of Greenwich, United Kingdom. Mr Solomon has undertaken a significant number of assessments on families where there is an autistic child and siblings and will be able to give his view regarding the practicalities of these assessments.

1.7.4 Paradigm

A Gestalt and Phenomenological paradigm (Yontef, 1993:182; Joyce & Sills, 2001:24) is chosen for this study. Please refer to page 23 where the Phenomenological paradigm is thoroughly explained. Blom (2004: 10) is of the opinion that Gestalt is concerned with the whole and this whole is more than the sum total of the individual's behaviour, perceptions and dynamics and that each individual moves towards an entity that is more than the individual parts. It is the researcher's view that the siblings of the autistic child can also be considered as a holistic entity, which means that the sum total and behaviour are more than just individual aspects of them, such as their physical needs or just their social needs. The whole field is involved. The essence of field theory (Yontef, 1993:283) is that a holistic perspective towards the person extends to include environment, the social world, organisations and

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culture. According to Lewin (1952:45) field theory can hardly be called a theory in the usual sense; it is rather a set of principles and outlook, a method and a whole way of thinking which relates to intimate interconnectedness. The researcher wants to understand how the siblings relate to their field (Yontef, in Woldt & Toman, 2005:84) and how they could be empowered by social workers whose fields impact on their ability to empower the siblings of autistic children. The researcher will remember that it is the organism-in-environment, person-in-situation, family-in-society that she will be dealing with. The paradigmatic perspective is thoroughly discussed in chapter two.

1.7.5 Universe, population and sample

The universe (Arkava & Lane in Strydom & Venter, 2002:198) of this study is social workers in the United Kingdom and siblings of autistic children aged 8 – 12, living in South East London, Greenwich, United Kingdom. The population (Grinnell & Unrau, 2005:152) in this study consists of social workers and siblings of autistic children in the London Borough of Greenwich, United Kingdom. A sample (Graziano & Raulin, 2007:114; Strydom & Venter, 2002:199) of the population will be included in the unstructured interview process.

Sarantakos (in Strydom & Delpont, 2005:328) argues that in qualitative research non-probability sampling is used as it is relatively limited, based on saturation, not representative and that the size is not statistically determined. The researcher agrees with Punch (2005:187) in that sampling means sampling in a deliberate way with some purpose or focus in mind. The researcher is focusing on the social worker in the London Borough of Greenwich, United Kingdom, and how the social worker can be equipped to support the sibling of the autistic child.

For the purpose of this research study, the researcher has carefully selected a set of criteria required in the identification of participants for this study, which are the following:

- Siblings of children with autism in the London Borough of Greenwich, United Kingdom;
- Age: between 8 years and 12 years;

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- Gender: Male or Female;
- Language: English;
- Belonging to any cultural group;
- Children who are in need of empowerment in order to cope with their situation;
- Social workers who are working in the London Borough of Greenwich, United Kingdom.
- Social workers who would have had involvement with families where there are siblings and autistic children.

1.7.6 Data collection and analysis

Greeff (2005:287) states that interviewing is the predominant mode of data or information collection in qualitative research. Marshall and Rossman (in De Vos, 2005:335) state that data collection and analysis go hand in hand in order to build a coherent interpretation of the data. They further argue that even though researchers are guided by initial concepts and developing understandings, they will shift or modify them as they collect and analyse the data.

Greeff (2005:293) states that, "At the root of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of that experience" (cf Punch, 2005:172). The researcher wants to gain insight into the siblings of the autistic child's experience of their lives in their family and how social workers can be equipped to empower these siblings. In this study the data collection phase will consist of unstructured interview sessions with siblings of autistic children and unstructured interview sessions with social workers until a point of saturation is reached. Saturation according to Seidman (in Silverman, 2005:294; Grinnell Jr. & Unrau, 2005:166) is the point where the researcher begins to hear the same information repeatedly being reported and that he no longer learns something new.

In preparation for the interviews, Punch (2005:294) states that the setting chosen must provide privacy, in a non-threatening environment, be easily accessible and also provide seating arrangements that will encourage involvement and interaction. The researcher will

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interview the social workers at her workplace in an interview room utilising audio tape recordings (Smit *et al.* in Punch, 2005:298; Silverman, 2005:184) and observation. This is easily accessible for the social workers and the researcher. Furthermore, the researcher will ask the parent of the siblings where they would prefer to have the interview. This means that the researcher must be flexible with venues and times. She will confirm all arrangements in writing and will confirm it close to the date.

Creswell (in De Vos, 2005:334-339) identifies the following steps in the process of data analysis:

1.7.6.1 *Planning for recording of data*

The researcher will plan the recording of the data in a systematic manner that will be appropriate for the participants. Furthermore, the researcher will decide which equipment would be more appropriate and effective to use in order to collect the data. The researcher will develop a system to easily retrieve data for analysis (De Vos, 2005:334-335). It is important to have a valid and reliant coding system to control the information through the research process (DiLalla & Dollinger, 2006:242).

To apply the above mentioned guidelines, the researcher plans to develop an appropriate coding and filing system before the start of the research study. A general folder was created on the computer desktop for the research report, under which different folders were created where the different interviews with social workers and the siblings were filed and coded under different numbers and letters, for easy access.

1.7.6.2 *Data collection and preliminary analysis*

Data is collected during the interviews with the participants. The researcher will make field notes (Greeff, 2005:298) after each interview session as it will be still fresh in her mind and give her the opportunity to reflect on her views, feelings and the researcher's experience of the interview.

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Information will be gathered through unstructured interviews with the social workers and the siblings of autistic children. The researcher will make use of audio recordings to record the interviews. Following the interview, the researcher will transcribe the information so that it can be used for the research study.

1.7.6.3 *Managing or organising the data*

Early on in the analysis process, the researcher will organise and store the data and relevant information in files, folders and computer files. Creswell (in De Vos, 2005:336) mentions that researchers have to convert the files to appropriate text units. The researcher will use different folders for the social workers interviewed and for the siblings of the autistic child interviewed. The researcher will transcribe the audio-material and store it on separate computer files. All field notes and data will be made available to the supervisor of the study. In order to access the data effectively, the researcher will keep record of all data gathered during the study at her home and on her personal computer.

1.7.6.4 *Reading and writing memos*

Creswell (in De Vos, 2005:337) quoted Agar (1980) as follows: "Read the transcripts in their entirety several times. Immerse yourself in the details trying to get a sense of the interview as a whole before breaking it into parts." Through reading the researcher will gather information (De Vos, 2005:337). Silverman (2005:158) states that by making field notes, the researcher is not only just gathering data, but also analysing the data at the same time.

1.7.6.5 *Generating categories, themes and patterns*

The researcher will note regularities in the setting of participants (social workers and siblings) chosen for the study (De Vos, 2005:338). The researcher will look out for any relevance and patterns arising in the research.

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1.7.6.6 *Coding the data*

According to Punch (2005:199) coding begins the analysis and also goes on at different levels throughout the analysis. Punch (2005:201) goes further to state that coding is the concrete activity of labeling data, which gets the data analysis underway and which continues throughout the analysis.

The researcher will colour code the tapes of each individual respondent and add general detail such as the participants' name and age. This will make it easier for repetitive listening to the audio recordings.

1.7.6.7 *Testing the emergent understandings*

The researcher will evaluate the data to determine the usefulness and centrality of it (De Vos, 2005:339). For the purpose of this study, the researcher will evaluate all gathered data to determine the centrality of it and whether it can be used to evaluate the research study.

1.7.6.8 *Searching for alternative explanations*

The next phase in the research process is to look at explanations and the linkages among them (De Vos, 2005:339). This means that after the researcher has made conclusions regarding the gathered data, alternative explanations and causes can be explored regarding the findings that were made.

1.7.6.9 *Representing, visualising (i.e writing the report)*

During the final phase the researcher will publish the data through texts, tables or figures (De Vos, 2005:339). In Punch (2005:275) Coffee and Atkinson argue that writing is part of thinking, analysing and interpreting.

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1.7.7 Limitations of the study

This study might be limited in this respect that the researcher was only capable of doing research on a scale possible for one individual within a limited time and scope. Furthermore, the researcher is aware that the empirical data is limited to the individual experiences and phenomenology of the individuals interviewed, as well as by the phenomenology of the researcher herself.

Although the researcher is convinced that this research will be of value to those in society interested in supporting the siblings of an autistic child, she also considers further studies in this field necessary as times, circumstances and personal experiences are constantly changing.

1.8 ETHICAL ASPECTS

Strydom (2005a:57) provides the following comprehensive definition of ethics:

Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

Ethical issues are important in a research project. The following ethical aspects will be addressed (Strydom, 2005a:57, 59; Babbie, 2005:63; Grinnell & Unrau, 2005:36; Graziano & Raulin, 2007:65).

1.8.1 Protection from harm

Babbie (2005:63) states that participants should not be injured regardless of whether they volunteer for the study. The researcher will ensure that the participants are not emotionally

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harmful by informing participants beforehand of the goals and objectives of the study. This disclosure offers participants the opportunity to continue or withdraw from the study. The researcher is registered as a social worker with the General Social Care Council and obliged to work under a code of conduct that safeguards children and their families.

1.8.2 Informed consent

Strydom (2005a:59) states that obtaining informed consent implies that all possible information on the goal of the investigation, the procedures which will be followed during the investigation, the possible advantages, disadvantages and dangers to which participants could be exposed, be rendered to potential participants. Agreement will be sought from the siblings of the autistic children and their parents by sending the parents a letter explaining the nature of the research and requesting their written consent before agreeing to participate in this study. The study will be verbally explained to the siblings, gaining their consent. The parents will also be informed that they are at liberty to withdraw their children from the study at any time they should wish to do so. The researcher will also explain to the children that they might withdraw from this study at any time they wish to do so. Furthermore, where the autistic child is able to comprehend the nature of this study, the researcher will explain this to the children if they questioned what the nature of the researcher's visit was to the family. The researcher agreed with the parents that they will support her in explaining the research to their autistic child. Written agreement will be sought from the social workers working in the London Borough of Greenwich, United Kingdom. Please refer to Addendum A and B with regards to the consent letter to respondents (parents of the sibling and the social worker)

1.8.3 Deception

Babbie (2005:67) states that the researcher should under no circumstances deceive the participants in order to gather any other information during the interview process as this would be unethical. The researcher commits to this by being honest with the participants and their care-givers regarding the purpose of the study. The social workers will be fully informed of the

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nature of the research study. Also that there will be no incentives for participants except for the recommendations.

1.8.4 Confidentiality

This implies an undertaking by the researcher to protect the anonymity of the research participants (Strydom, 2005a:61). In this study, the siblings of the autistic children will have the right to decide what will be shared with their parents. Numbers will be allocated to participants in order to conceal their identities. All participants will be assured that the data will only be used for the stated purpose of the research but that the researcher's study leader will examine the data. It will also be explained that external examiners may also ask to see data and that they will have access to the collected data.

1.9 DEFINITIONS OF TERMS AND KEY CONCEPTS

1.9.1 Siblings

According to the Reader's Digest Universal dictionary (1998:14), a sib is a brother or sister; a sibling. A sibling is also defined as each or two or more children having one or both mutual parents. A sibling is therefore a brother or sister that is connected by their parent(s). The researcher defines siblings as brothers/sisters with at least one mutual parent.

Siblings refer to brothers and sisters (Berns, 2001:559), the children that form part of a family (Berns, 2001:164). Siblings can also be defined as individuals who have the same parents in common, meaning that they have at least 50 % of their parents' genes (Maynard, 2004:232). The researcher identifies siblings as brothers and sisters with at least one common parent.

1.9.2 Middle childhood

Berk (2003:6) defines middle childhood as the period when children learn about the wider world and master new responsibilities that increasingly resemble those they will perform as

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adults. Roughly between the ages of six and twelve, this stage of a child's life coincides in many societies with the beginning of formal schooling and being allowed a relatively unsupervised live. Huston and Ripke (2006:8) explain that middle childhood is the period when children gain the fundamental skills needed for adult life, undergo the early stage of puberty, develop self-awareness and self regulations, and form the foundations for social relationships with age-mates. Erikson (in Feldman, 2004:283) described the period in terms of "industry versus inferiority", because he believed it was so important to establish oneself as a responsible, hardworking, serious minded person at this time. In this study the participants will be between the ages of eight and twelve years and will therefore be in late/middle childhood.

A child is (i) a person from the time of birth to the time he becomes an adult; (ii) a newly born or unborn baby; (iii) a son or daughter at any stage (Cobuild, 1987:234). The researcher would like to believe that a child can be seen as a recently born human being and adding to what the United Kingdom's Children's Act 2004 states that any person 18 years of age and younger. The middle childhood child according to Schoeman (2004:25) would be the child from 6 years to 12 years. The researcher defines middle childhood as a stage between the age of 6 years to 12 years where growth and important developments take place in the child's life.

1.9.3 Autism/Pervasive Developmental Disorder (PDD)

Autism is often referred to as a spectrum disorder. This reflects that the characteristics and symptoms of the disability comes in a variety of combinations and ranges from mild to severe (Rosenberg, 2000:31).

Leo Kanner defined infantile autism for the first time in 1943, explaining the classic abnormalities of children with autism, to be social aloofness and indifference to others, elaborate repetitive routines instead of imaginative and pretend play like that of normal children (Wing, 1980:18). Marshall (2004:1) explains that autism is a complicated neurodevelopmental disorder which affects a child's intellectual, social and emotional

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development, thus affecting his social communications. Autism is best recognised in a group of disorders collectively known as PDD. Autistic disorder is the technical term for autism in the DSM-IV. The term autistic disorder is therefore used to encompass autism and is meant to correspond exactly with what the DSM-IV refers to as PDD.

The researcher defines Autistic Spectrum Disorder as a neurodevelopmental disorder that affects the way people communicate with others and impacts on the social development of a child, namely the child's social interaction, imaginative play and lack of social skills.

1.9.4 Gestalt theory

According to Blom (2004:4) Gestalt is formed on holism and the field theory, which makes it the conceptual foundation of Gestalt therapy. Schoeman (2004:58) explains that people's thoughts and the feelings they are experiencing at the moment, are the most important concern in Gestalt theory. Gestalt theory is based on the principle of holism which is viewed as the most important theoretical concept of Gestalt therapy (Blom 2004:40; Yontef & Jacobs, 2000:304).

Gestalt theory considers people as holistic entities in that the sum total of their physical, emotional and spiritual aspects is more than its components (Blom 2004:10). The researcher defines Gestalt theory as a state of awareness where the person finds himself in and that this state of awareness encompasses various dimensions.

1.9.5 Field theory

According to Yontef (1993:321) field theory is:

... a framework or point of view for examining and elucidating events, experiencing, objects, organisms and systems as meaningful parts of a knowable totality of mutually influencing forces that together form a unified interactive continuous whole (field), rather than classifying them according to innate nature

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or analyzing into discrete aspects and forming and summative wholes. The identity and quality of any such event, object or organism is only in-a-field, contemporaneous and can only be known through a configuration formed by a mutually influencing interaction between perceiver and perceived.

It is impossible to look at a person or his problems without taking into account the context in which he finds himself, also known as his environmental field. The interdependence between the person and his environment thus forms the central concept of the Gestalt approach (Blom, 2004:4). This field is therefore defined by the observer and the client, and is only meaningful when one is able to understand their frame of reference (Yontef, 1993:125).

Aaronstam (in Blom 2004:9) states that although individuals function as independent entities, the healthy individual must also function as a holistic entity, where the environment is used effectively to satisfy his needs. Yontef (1993:301) states:

The field is a whole in which the parts are in immediate relationship and responsive to each other and no part is uninfluenced by what goes on elsewhere in the field. The field replaces the notion of discreet, isolated particles. The person in his or her life space constitutes a field.

1.9.6 Social worker

Options for Excellence (2006) concluded that social workers' main responsibility or activity is problem solving. This is carried out through relationships with individuals, families and groups, when they are facing life problems or challenges. Social workers will help the people to achieve the outcomes they want in the ways they prefer.

The International Federation of Social Workers (2000) defines social work as the following:

The social work profession promotes social changes, problem solving in human relationships, and the empowerment and liberation of people to enhance well-

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being. Using theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work.

The researcher identifies with the definition given by the International Federation of social workers in that a social worker can be seen as a changing agent, always thriving to change situations and circumstances for the better. The purpose of this study is to gain insight into how the social worker can empower the siblings of the autistic child. In order to gain insight and therefore empower siblings, it was important to know everything which might impact on social workers having the opportunity to empower, which in this study, includes the difficulties and limitations social workers are facing.

1.10 CONCLUSION

In this chapter, the basic orientation for this research of limited scope was given. The goal, objectives and research question were explained and asked. A brief summary was given of social workers' involvement with families of autistic children and how this impacts on the siblings.

In chapter two, attention will be given to the paradigmatic perspective from which the researcher worked in order to reach the goal of this study.

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CHAPTER TWO

PARADIGMATIC PERSPECTIVE FOR THIS STUDY

2.1 INTRODUCTION

The Chambers Dictionary (2000:1178) defines the term paradigm as “a basic theory; a conceptual framework within which scientific theories are constructed.” Paradigms, according to Delport & Fouché (2005a:265) can be seen as “a frame of reference that underpins and guides [one’s] study”. Silverman (2006:97) describes paradigms as models which provide an overall framework of how to look at reality and that they tell a person what reality is like and the basic elements it contains (ontology) and what the nature and status of knowledge is (epistemology). The paradigmatic perspective for this study was identified from three components namely; meta-theoretical concepts of the study, the theoretical assumptions and the methodology.

The researcher made use of a qualitative, phenomenological research approach in order to gain a better understanding into what is needed to equip social workers in the London Borough of Greenwich, United Kingdom to empower the siblings of autistic children. For the qualitative researcher, reality is based on people’s perceptions, perspectives and understanding of a particular situation (Leedy in Delport & Fouché, 2005a:264). The researcher wanted to obtain the perceptions, perspectives and understanding of the social worker, working with a family where there is a sibling of a child with an Autistic Spectrum Disorder (ASD). Also, the researcher wanted to explore the sibling of the autistic child’s perception and understanding of their place in the family, as well as the involvement of professionals, particularly social workers, in their family.

2.2 META-THEORETICAL CONCEPTS

The following meta-theoretical concepts form the basis of a holistic approach and will be defined as an integral part of this study:

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2.2.1 Phenomenological and existential perspectives

Phenomenology can be defined as a discipline which helps people to stand aside from their traditional way of thinking and doing things in order to differentiate between what is actually being perceived and felt in the current situation and what is residue from the past. Both that which is felt subjectively, as well as what is observed objectively, are defined by the Gestalt approach to be authentic and important data (Yontef, 1989:1). This can also be explained as the person's experience of the field. The aim of this phenomenological discovery process is awareness of and insight into the person's own existence and relationship with his/her situation, environment (existential), and through the formation of a Gestalt wherein all the relevant factors of the universe fall in place.

A phenomenological perspective helps a person to stand aside and perceive himself as he really is. Existentialism uses this phenomenological method to help a person to focus on his existence and to continuously grow and develop (Yontef, 1993:2-3). The researcher understood these two concepts better through the views of Zinker (1977:77). He describes the phenomenological perspective as whatever it is a person is experiencing as uniquely one's own. A person's world is the totality of experiences of oneself as you are. Phenomenology is thus the experience of the self as it is. The Gestalt approach supports the concept that each person is an expert of their own experience, being able to organise data and give meaning to it. The phenomenological perspectives are dialogued (verbal and nonverbal) or communicated between the participant and the researcher, where differences in perspectives become the focus of experimentation and continued dialogue. Existentialism walks hand in hand with phenomenology, the focus being on the existence of the person's relationships with others, his/her joys and pains as it is experienced directly (Yontef, 1989:3).

The researcher wanted to understand how the social workers viewed their involvement with the siblings and to understand possible limitations which might prevent them from empowering these siblings. The social workers were encouraged to explain their views and opinions on their involvement with the sibling of the autistic child and also explain the mechanisms or ways they used and were able to or not able to use in order to empower this

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sibling. The social workers were encouraged to express their views and feelings about how the ability or inability to empower the sibling affected them professionally and personally.

In addition to this, the researcher wanted to explore the siblings of autistic children's perception and understanding of their place in the family by looking at the family dynamics and the specific role the siblings played in their families. The researcher also wanted to gain a better understanding of the sibling's experience of the involvement of professionals, and in particular social workers, in their family. These findings were used to make recommendations and conclusions with regards to the study (see chapter five).

2.2.2 Gestalt and holism

The German word Gestalt has no direct translations into a single English term. It encompasses concepts such as a shape, a pattern, a figure, a whole form and a configuration (Clarkson, 2004:1). Burnard (1989:34) explains that the German word "Gestalt" is not easily translated but roughly refers to the notion of wholeness or completeness. Latner (in Schoeman, 2005:80) explains that, "Holistically we cannot understand ourselves by summing our understanding of our heart, our brain, our nervous system, our limbs, our circulatory system. We are not simply an accumulation of functions. The ordinary language expression for this is: The whole is greater than the sum of its parts." Blom (2004:3) explains that, "The concept Gestalt can be considered an entity or whole of which the total is more than its component parts ... this aspect is related to holism as on the theoretical concept of the Gestalt theory." Mackewn (2003:43) states that a person is at all times a whole person. According to him, the human being's "body, emotions, thoughts and perceptions function interrelatedly as one complex rational whole." This interrelatedness of the whole makes up for the whole to be more than the sum of its parts. Latner (2000:19) explains that the concept of *whole* as meaning that something is experienced as a unity or singularity although it is made up of elements. Each element in its own right can be considered as a whole. A holistic view is based on the principle that the whole is greater, or different from the sum of its parts (Kepner, 1987:38). The whole has an intrinsic unity of its own, a particular structure and the integration of its parts. Therefore, the person should be seen as "the integrated functioning of various

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aspects of the whole in time and space” (Kepner, 1987:39). Schoeman (2004:79) explains that holism is the essence of the holistic conception of reality in that all nature is a unified and coherent whole. The organismic and inorganic elements of the universe exist together in a continually process of coordinating activity.

Working from a Gestalt perspective the researcher viewed the social worker and the sibling of the ASD child as holistic entities, considering their language, class, ethnicities, cognitive abilities and coping strategies. Their bodies, emotions, spiritual aspects, language and bodily experiences cannot be separated. These aspects should be taken into consideration when conducting the research. Blom (2004:4) agrees and explains that the human being is seen as a whole in Gestalt theory. Parts of the whole, including the physical body, emotions, psyche, language, cognition and behaviour are interrelated and cannot be separated from each other. The whole is different from all the parts together. The whole can only be understood fully in its entirety, although it is composed of different elements. This idea of holism forms the foundation for the Gestalt therapy. Holism therefore is said to describe the whole that creates the parts (Barlow, 1981:10). When understanding it regarding the person, it is seen that man organises things into meaningful wholes and does not perceive things as unrelated units or parts. This organisation occurs due to the ability to perceive, or the perceptual process (Barlow, 1981:10).

2.2.3 Field

The field theory in Gestalt Therapy states that the field is everything and anything and is in constant contact with everything and anything. Everything and anything are constantly influenced by what goes on elsewhere in the field. According to Estrup (2000) the field is everything that exists and it is dynamic and all the parts are interrelated. The field is an important aspect of relations in the Gestalt approach. The field is defined as a network of interactions where all phenomena are linked (Latner, 2000:20). Clarkson (1989:8) mentions that field theory implies that it is impossible to look at a person without taking into account the context of his or her environmental field. She explains further that the interdependence between the person and his or her environment forms a central concept of the Gestalt

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approach. According to Brownell, Crocker, Gunther, Just, Sen, Stemberger and Wolfert (2001:2), "field" refers to the phenomenology of the child, that is, everything that has effect in the life of that child. This view is supported by Crocker (in Brownell *et al.*, 2001:2-3) when she refers to the field as a "sphere of influence".

The social workers' experience of their involvement with the families and the siblings' experience of having an autistic sibling go hand in hand with the field in which they find themselves. The researcher will focus on both the social worker and the siblings within their unique, individual fields and will not consider them to be isolated organisms. This implicates that this research study will be an in depth exercise in which the researcher will explore the field of each participant.

2.2.4 Here-and-now

Blom (2004:249) states that the influence of events from the past and expectations of the future are not denied, but that growth cannot take place by recreating that past or by predicting the future. The therapist only focuses on the present and to make contact the therapist gets involved in an I-thou relationship with the client and this is called dialogue. The subsequent awareness in the here-and-now may lead to change. Yontef and Jacobs (in Blom, 2004:58) explain that direct experience is used as primary tool and the focus is always on the here-and-now. According to Schoeman (2004:79) awareness is a happening in the present moment. Schoeman further states that, "All we can be aware of is what is happening now. If we are totally aware of now, we are in touch with all that occurs from that."

For this study the researcher wanted to explore what it is that is either supporting or preventing social workers from providing sufficient support to the sibling of the autistic child. The researcher wanted to support the social workers to identify barriers that might prevent them from providing a service to the siblings, whether it was a personal barrier or a professional barrier. Furthermore the researcher wanted to explore what is it that the siblings of the autistic child feel they need or want from a professional who could support them in their everyday lives. This information could help with the empowerment of the social workers. The

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researcher focused on how the child experienced his unique field and how this might impact on the child's day to day life. The researcher also focused on what the siblings of the autistic children would like to change in order to be able to enjoy a life where they are in the position to self regulate their lives.

2.2.5 Awareness

Awareness refers to the manner in which one is in touch with one's own existence and with "what is" (Yontef, 1993:139). According to Joyce and Sills (2001:17) awareness is a non-verbal sensing or knowing what is happening in the here-and-now. It is important for the client to be aware of what he is experiencing and feeling in the here-and-now about events in the past, present and future, and also how he is behaving in certain situations. Blom (2006:53) is of the opinion that awareness brings children into contact with their own needs and emotions and they learn to accept responsibility for who they are and what they do. Perls (in Clarkson & Mackewn, 1994:44) considers awareness as,

the capacity to be in touch with your own existence, to notice what is happening around or inside you, to connect with the environment, other people or yourself; to know what you are feeling or sensing or thinking; how you are reacting at this very moment.

Awareness refers to the social workers' knowledge of what they are doing in the here-and-now and the way how they were doing it. The researcher wanted to understand the social worker's awareness of their involvement with families with Autistic Spectrum Disorder children and the opportunities and/or limitations they've had to empower the sibling of the autistic child. Additionally, the siblings' experience in the family dynamics will greatly be influenced by the level of awareness they have of themselves and their environment. The researcher wanted to gain insight into the sibling's awareness of his/her life in a family with a brother or a sister with autism. As the researcher was working from the Gestalt phenomenology, it was important to be aware of the social workers' as well as the siblings' awareness levels in the here-and-now. The researcher encouraged awareness, by making the participants aware of

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what they said, exploring how they felt saying certain things. The researcher also focussed on the non-verbal communication from the respondents such as their posture, facial expressions and body movements. The researcher visited the participants in their environment, ensuring that the interview was uninterrupted. By explaining the focus and the aim of the study, it was hoped that the thoughts of the participants (both social worker and sibling) were centred around it.

2.3 THEORETICAL ASSUMPTIONS FOR THIS STUDY

The following theoretical assumptions formed the basis for this study:

2.3.1 Development perspective

In this research study, the researcher made use of Erik Erikson's Psychosocial development theory as the researcher focused on development, specifically the child in his/her middle childhood (Berk, 2006:18). In his theory, Erikson refers to eight stages of development namely: stage one (trust versus mistrust), stage two (autonomy versus shame and doubt), stage three (initiative versus guilt), stage four (industry versus inferiority), stage five (identity versus role diffusion), stage six (intimacy versus isolation), stage seven (generativity versus stagnation) and stage eight (integrity versus despair). For the purpose of this study, the researcher is only going to focus on the fourth stage of Erickson's, which is industry versus inferiority, as this is the phase between the ages of six to twelve, which is the focus population of this study. Erikson (in Feldman, 2004:283) describes the period in terms of "industry versus inferiority", because he believed it is important to establish oneself as a responsible, hardworking, serious minded person at this time. In this study the participants were between the ages of eight and twelve years and were therefore in late/middle childhood. During middle childhood, children enter school and find a world of new physical environments and new relationships with other people, adults and children from outside the family. According to Collins (in Aldgate, Jones, Rose & Jeffrey, 2002:200) children have a number of developmental tasks as they adapt to the rules of these new worlds:

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- developing a relatively stable and comprehensive understanding of the self;
- refining their understanding of how the social world works;
- developing standards and expectations of their own behaviour; and
- developing strategies for controlling or managing their behaviour.

Louw (in Blom, 2004:244) explains that family support, community structures, school and friendship networks are important sources of opportunity for children in the middle childhood years. Louw acknowledges and stresses the importance of the peer group in the child's social developments and preparation for functioning in the adult world (in Blom, 2004:244).

Feldman (2004:383) states that this developmental stage is where the focus is on efforts to attain competence in meeting the challenges presented by parents, peers, school, and the complexities of the world. Feldman (2004:383) explains that the siblings' sense of self is formed during this developmental stage and that they have the need to attain a sense of industry which will lead to a growing sense of competence. Feldman explains that success in this developmental stage will bring feelings of mastery and proficiency and a growing sense of self or competence. Should the child experience difficulties in this stage, they may withdraw both from academic pursuits, showing less interest and motivation to excel, and from interaction with peers (Feldman, 2004:383). It was important to explore the level of encouragement the sibling receives from parents, teachers, or peers as this would undoubtedly impact on their view on their ability to be successful. Due to the families being mostly from a middle class, most parents were able to pay for or encourage additional tuition or activities for the siblings of the autistic child.

Huston and Ripke (2006:8) explain that middle childhood is the period when children gain the fundamental skills needed for adult life, undergo the early stage of puberty, develop self-awareness and self regulations, and form the foundations for social relationships with age-mates.

Given that the child in his middle childhood phase is greatly influenced by his parents, school and his peers, the researcher chose this age group as it is clear that during middle childhood,

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the child's social development and sense of self is being developed and that any disruption to this development, will affect his overall development.

2.3.2 Role theory

Role theory describes the reasons why family members behave the way they do. The role theory points out that people's behaviour can be predicted according to the roles they play. Mothers are usually the carers and fathers are usually the main breadwinners. These roles dictate guidelines of expected behaviour and expectations on how these roles should be carried out (LePoire, 2006:56). Role expectations are internalised convictions of the ways how people should function in a certain role.

Different roles within a family predict certain behaviours from family members, which will influence and impact on the way the family members interact and communicate with each other. Roles within a family help the family to accomplish certain tasks (LePoire, 2006:58). Role theory assumes that the different roles family members accept is a reflection of the behaviour they will exhibit (LePoire, 2006:19). People are not the roles they play. Roles are behaviours and when people exhibit these behaviours, they are playing a role. Individuals still have the capacity and choice to disregard a certain role and to take on another role or try and fit into a certain role (Turner & West, 2006:123). Role conflict happens in two ways, e.g. when two or more family members want to take on the same role, this will lead to interpersonal role conflict. Another form of role conflict is where there is role conflict within a person. This might be when the role is contradicting with the person's beliefs (Turner & West, 2006:125).

As seen above family dynamics are formed through the different roles within the family. Siblings may take on the role that is given to them within the family. For the purpose of this study family dynamics could be better understood if the researcher understands the role and place the sibling of the autistic child plays.

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In addition to this, the researcher may have a better understanding of the social worker's tasks if there is a clear understanding of the social worker's role and which roles they are playing when assessing a family for support services.

According to Beckett (2006:8) social workers have different roles to fulfil in order to provide a service to families:

ADVOCACY ROLES <ul style="list-style-type: none">• Direct advocate• Indirect advocate
DIRECT CHANGE AGENT ROLES <ul style="list-style-type: none">• Counsellor/therapist• Mediator• Educator• Catalyst
EXECUTIVE ROLES <ul style="list-style-type: none">• Almoner• Control agent• Care manager • Co-ordinator• Responsibility holder• Service developer

Table 1.1: Roles played by social workers

Beckett (2006:9) explains that **advocacy roles** refer to the social worker speaking on behalf of the client or by helping to speak for him or herself. **Direct change agent roles** are roles in which the social workers use their interactions with clients as a means of bringing about or facilitating change: counsellor/therapist, mediator, educator and catalyst (Beckett, 2006:15).

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Executive roles refer to roles in which the social worker draws on other external resources as a means of bringing about change: almoner, care manager, responsibility holder, control agent, co-ordinator, service developer (Beckett, 2006:15). Social workers will change roles according to the need of the individual or family and in this research study, the researcher found the social workers to be mainly in the executive roles.

2.3.3 The family as a system

Palazzoli (quoted by White in Davies, 2002:147) stated that the family is a self governing system which controls itself according to rules formed over a period of time through a process of trial and error. "The essence of family life is that it is complex and changing and that unique situations and combinations of needs continually arise. Families therefore need to be able to act in creative ways to find solutions to their circumstances" (Dallos, in Davies, 2002:147). The family is the primary provider of the emotional, intellectual and physical environment in which children live. This environment will impact on children's views of the world later in life and on their ability to cope with future challenges. Thus, family connectedness and structure will impact on children's adjustment. Clearly, the ability of a family to function healthily will depend on the parent(s) (Geldard & Geldard, 2004:18).

According to Beckett (2006:84) the insight of family systems theory is that many human situations are more helpfully understood in terms of the interactions between individuals rather than in terms of individuals in isolation. The whole of the family is greater than the sum of its individual family members. The family and the communication that takes place in the family cannot be understood by only understanding the individuals in the family (LePoire, 2006:56). White (2002:148) explains that the idea of the family as an "open system" allows the family to become a mediator of internal and external influences such as schools and the media. Turner and West (2006:61) explain that families are complex, hierarchical organisations which consist of individuals and a combination of individuals. Family subsystems – spouses, parents and siblings – are made up according to gender, generations, shared interests and functions within the family. The power of the spouse sub-system is

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central to the stability of the family (Green, 2003:116 and Lehman, 2005:34). Sibling sub-systems give the child their first experience of being part of a group. In a normal functioning family all the sub systems work integrated alongside each other in order to protect the integrity of the family system (Green, 2003:117).

The researcher is of the opinion that the family systems theory directly links to the goal of this study, which is to explore and gain more information on the sibling of the autistic child's experience, perception and opinion of the family he or she is part of.

2.4 METHODOLOGICAL PROCESS

According to Silverman (2006:99) methodology refers to the choices made about cases to study, methods of data gathering, forms of data analysis and executing a research study. Silverman goes further by saying that methodology defines how a person will go about in studying any phenomenon. The Gestalt approach was the framework for this research study in order to understand the social worker's experience as a professional with the ability and opportunity to provide support to a family and to the sibling of an autistic child. The researcher also used the Gestalt approach to explore the siblings of autistic children's experience of the family dynamics and their role and the part they play within the family. This links with what qualitative research is about in that the researcher is enabled to form an understanding of the subjective experience of people, thus *verstehen* (Monette, Sullivan and De Jong, 2005:39).

In order to gain information and an understanding of the experiences, perceptions and opinions of both the social workers and the siblings of Autistic Spectrum Disorder children, the researcher will make use of case studies. Case studies are idiographic examinations of single individuals, families, groups, organisations or societies (Rubin & Babbie, 2005:440). Case studies can form the basis for the development of more general nomothetic theories as the focus is on connecting case study findings to a particular theory (Rubin & Babbie, 2005:440-441). Through the use of case studies, the researcher conducted unstructured interviews with social workers in order to enquire after the difficulties they experience in empowering the siblings of autistic children. The researcher furthermore conducted

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unstructured interviews with siblings of autistic children in order to gain information regarding their needs for empowerment. In carrying out these unstructured interviews, the researcher made use of the following Gestalt aspects: the social workers' and the siblings' field and their experience in the here-and-now and their awareness of who they are and what their role is.

Babbie (2007:31) explains that theories function in three ways in that it prevents the researcher from being taken in by flukes, that it make sense of observed patters in a way that can suggest other possibilities and that it shape and direct research effort, pointing toward likely discoveries through empirical observations. Aspects of the theories discussed under 2.3 have also been taken into consideration when the interviews were conducted. The researcher used Erik Erikson's Psychosocial Development Theory as a development perspective to focus on the development of the middle childhood child, aged eight to twelve years, as they were the focus group of this research study.

Furthermore, the researcher used the Role Theory to understand the importance of roles within the family dynamic as this will influence the experience of siblings within a unique family. The researcher reminded herself of the different roles social workers play in their involvement with families.

The last theory the researcher made use of was the Family Systems Theory in order to understand that the family is seen as a system where the family as a whole is greater than the sum of its individual family members and to remember that the family is influenced by internal and external influences which will impact on the dynamics of the family and its functioning.

2.5 CONCLUSION

This chapter focused on the meta-theoretical concepts for this study as well as the theoretical concepts and the methodological process. The methodological process was the structural framework for the basis from which this research study sprung namely that the researcher wanted to understand (*verstehen*) what meaning the participants of this study (social workers

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and siblings) were attaching to themselves and what they do (Monette, Sullivan & De Jong, 2005:38).

It was seen that there is a definite intertwining between the Gestalt concepts, the psychosocial development theory, the role theory and the family systems theory and how these correlate to the siblings' experience of life in a family with an autistic child. Secondly, there is a relation between the Gestalt concepts and role theory which could be used to explain the experience of social workers with regards to the roles they play in their involvement with families.

It is this relevance and integration between concepts, theories and experiences, which the researcher will explore empirically in chapter three.

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CHAPTER THREE

EMPIRICAL RESEARCH

3.1 INTRODUCTION

This chapter explains the empirical process of the research and will indicate how the results of this research process was evaluated, appropriate to the research method as indicated in chapter one of this research.

Four siblings of autistic children and six social workers in the Disability Team were involved in the study. They were selected on the basis of homogeneous characteristics, namely that they are white, English speaking children and white English speaking social workers. The reason for choosing this sample group was discussed in chapter one.

The research was undertaken by making use of unstructured interviews through which empirical data was collected. Mark (in Fouché, 2005a:116) states that the research objectives should be specific, clear and achievable. Goals and objectives according to TerreBlanche and Durrheim (2002:39) and Mason (2003:21) will clarify the proposed ends and means of the research project intervention.

As described in chapter one, this study was undertaken from a qualitative paradigm to reach the overall objective of the research, namely to explore the experiences of social workers working with autistic children in terms of the needs of Autistic/ Autistic Spectrum Disorder (ASD) children's siblings.

3.2 TRUSTWORTHINESS OF THE STUDY

Marshall and Rossman (in De Vos, 2005:345) explain that all research needs to be trustworthy. Lincoln and Guba (1985:218) further mention that the truth-value of the research needs to be established and eventually explain that trustworthiness needs to be measured

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against the “internal” and “external” validity. Lincoln and Guba (1985:218) explain that there are four better ways to measure the truth-value of the research namely credibility, transferability, confirmability and dependability. These four measures will be discussed below.

3.2.1 Credibility

Lincoln and Guba (1985:219) state that credibility is the alternative to internal validity, in which the goal is to demonstrate that inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described. In this study, credibility was assured by a prolonged working relationship with the social worker (subject) thereby establishing rapport and developing trust through honesty, openness and maintaining anonymity resulting in the accurate capturing of data. The researcher met once with the siblings and talked to them in a non-threatening way explaining what the research study was about and thanking them for participating in this study. The researcher chose this study due to the professional experience of being a social worker who carried out numerous assessments on families who had an autistic child and siblings, which contributed to the choice of this research.

3.2.2 Transferability

Lincoln and Guba (1985:219) propose that transferability is the alternative to external validity or generalisability and is concerned with demonstrating the applicability of one set of findings to another context. One one-to-one interview was conducted with each social worker who is considered to probably be representative of social workers who have had involvement with siblings of autistic children. The researcher is therefore of the opinion that a similar study conducted by another researcher would probably produce the same results. Even though the social workers were white and English speaking, they were from different countries and cultures, for example Romanian, South African and Australian. This represented the cultural diversity in the London Borough of Greenwich, London, where this study was undertaken.

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3.2.3 Confirmability

The ideal is that the researcher should stay objective. Objectivity is that part of the observations and understanding of the research, which is not influenced by the researcher's own prejudice and preferences. It concludes observations and understandings that would be similar to all researchers who do this study (Plug, Louw, Gouws & Meyer, 1997:244-245). For the purpose of objectivity the Münchhausen-objectivity was built into this research. According to Van Zyl (2005:150), the Dutch philosopher Smaling developed a descriptive and explanatory concept of objectivity that is relevant to qualitative research. Smaling is of the opinion that it is possible to define objectivity on a higher abstract level, the so called Münchhausen-objectivity. This objectivity gives validity and rights to the subject of study (cf. Bruinsma & Zwanenburg, 1992:307).

The Münchhausen-approach as described by Smaling (in Bruinsma & Zwanenburg, 1992:307) was used in this study to explore an understanding of the experience of social workers and siblings of autistic children, where the researcher had a mentality of openness, curiosity and interest in each of the respondents.

The researcher made use of a process where respondents were selected from the researcher's work place and social workers' case loads and were seen for 35-40 minutes by the researcher. The researcher had worked professionally with some of the social workers in this study and therefore knew some of them in a professional capacity. The questioning in this context was in the form of unstructured interview schedules. Open ended questions were asked until saturation was reached. The researcher attempted to stay as close as possible to the feelings and opinions of the respondents. The reason for the transcription after the interviews was partly to enable the researcher to stay objective at all times.

3.2.4 Dependability

De Vos (2005:346) states that even though changes take place in research, as the researcher's ideas changed through the process of research, research still needs to be valid

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and that data still need to be of use. The researcher ensured dependability by making notes during the research process as well as listening to the audio recordings over and over to ensure that the data could still be used, without the researcher influencing or manipulating the data.

3.3 DATA COLLECTION AND ANALYSIS

In this section the data collection procedure is described comprehensively, clearly explaining the context and the purpose of the data collection. Furthermore, a description is given of the respondents, the research strategy/design, the sampling plan, as well as the data collection procedures and the steps that were followed. The analysis and interpretation as well as the empirical data are included in this chapter.

3.3.1 Method of data collection

As previously stated, the qualitative approach was found to be the most suitable for this type of research. Unstructured interviews were used to gain the information. When using unstructured interviews the researcher prepared one main question with which to begin and guide the conversation. This predetermined question aimed to explore the social workers' experiences of their involvement with siblings of ASD children. The same was done with the siblings of ASD children (Please refer to Addendum D).

For the purpose of this study the researcher interviewed six social workers who have had involvement with families where there was a child with ASD and siblings. The researcher also interviewed four siblings of children with ASD. Open ended questions were asked to the respondents. The time spent on each interview varied between thirty to forty-five minutes per respondent. These interviews were done one to one, recorded and transcribed. For the purpose of transcribing the interviews a voice recorder was used. All respondents were made aware of this and whilst written consent was given by the parents of the siblings, verbal consent was given by the social workers. The social workers were approached via e-mail and telephone conversation.

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3.3.2 Sample

The sample consisted of social workers that work within the Children with Disability Team in the United Kingdom and siblings aged 8 – 12, of children with a diagnosis of ASD in the United Kingdom. They were chosen on the basis of homogeneous characteristics, such as white English speaking social workers and white English speaking siblings of ASD children. This sample group was chosen as it represented the demographic area the researcher works in. The sample group was six social workers who worked in the Children with Disabilities Team and four children aged 8 – 12, who were siblings of children with a diagnosis of ASD living in South East London in the London Borough of Greenwich. The researcher made use of homogeneous characteristics by choosing white, English, social workers and white English siblings of ASD children. Out of the six social workers, two were males and the rest female. Out of the siblings half were male and half female.

3.3.3 Sampling technique and demarcation of the sample

Strydom (2005b:202) and Mason (2003:121) argue further that when the type of sample is chosen by the researcher, according to elements or characteristics that best represent the focus of the study, the researcher could make use of purposive sampling. The researcher identified a definite purpose for this study prior to commencing with the investigation. Therefore the researcher used non-probability, purposive sampling. In other words, a sample was drawn from the populations on the grounds of specific criteria. The criteria have already been described in Chapter one.

The sampling was purposive and not random, as all the social workers were selected specifically having to have current or previous involvement with families where there were autistic children and their siblings. According to Silverman (2005:129) purposive sampling allows the researcher to choose a case because it illustrates some feature or process in which researchers are interested. This is by no means a simple approval to any case chosen,

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but rather demands that the researcher thinks critically about the parameters of the population studies and that the sample is carefully chosen on this basis.

The researcher identified the siblings of autistic children through the National Autistic Society of South East London, United Kingdom's database. The researcher approached parents of these siblings through letters providing all the relevant information with regards to this research study.

Colleagues of the researcher identified the social workers in this research study. The researcher approached the social workers telephonically and/or by e-mail and provided them with an informative interview. Ten social workers were approached and six interviewed during this study. The researcher interviewed until saturation was reached. The family support worker from the National Autistic Society, South East London, United Kingdom, sent letters out to 43 families where there was a sibling of an autistic child between the ages of 8 and 12. In response to the letters, only four families offered to participate in this research study. Nine families responded telephonically but stated that they will not be able to participate and three families responded telephonically stating that their children did not wish to participate in the research study. The remaining 27 families who were contacted did not respond to the letters.

Ten social workers were e-mailed requesting their participation in this research study. Out of the ten social workers, six were able to participate. Two social workers felt they were too busy, one social worker were going on holiday and one social worker changed jobs, moved and lived too far.

For the purpose of this research study, the researcher carefully selected a set of criteria required in the identification of participants for this study, which were the following:

- Siblings of children with autism in the London Borough of Greenwich, United Kingdom;
- Age: between 8 years and 12 years;
- Gender: Male or Female;
- Language: English;

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- White English speaking;
- Social workers will be working in the London Borough of Greenwich, United Kingdom;
- Social workers would have had involvement with families where there are siblings and autistic children.

3.3.4 Participant information

Firstly, the social workers' identities were concealed by giving each social worker a numeric number for each individual's contribution and involvement. Numbers one through to number six were used. Secondly, the siblings of the autistic children were given letters of the alphabet to ensure their anonymity. Letters A through to D will make reference to the siblings' contribution and involvement.

3.4 RESEARCH STRATEGY

The strategy of this research was in the form of case studies (Babbie & Mouton, 2001:280; Graziano & Raulin, 2007:123) where the researcher explored the needs of social workers by means of unstructured interviews in order to equip them so that they can empower the siblings of autistic children in their everyday lives. The researcher also interviewed four siblings of autistic children in order to gain an understanding of their experience of living with a sibling who was diagnosed with autism.

3.4.1 Unstructured interviews

According to Greeff (2005:293), "At the root of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of the experience" (cf. also Punch 2005:172). The researcher wanted to gain an understanding into the living experience of siblings of autistic children in their families, as well as the experiences of social workers in order to equip them to empower these siblings. Unstructured interview sessions were used until the point of saturation. Saturation according to Seidman (in Silverman, 2005:294; Grinnell Jr. & Unrau, 2005:166) is the point where the researcher begins to hear

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the same information repeatedly being reported and that the researcher no longer learns something new.

Unstructured interviews were conducted over a period of three months. One one-to-one interview was conducted with each respondent with the interviews taking approximately thirty to forty-five minutes. The researcher arranged an appointment which would be most convenient for the social worker to be interviewed. The researcher found this beneficial as the respondent could choose the best setting and time to be interviewed in order to ensure privacy and limited distraction. As it was winter and dark quite early in the day, as agreed with the parents, the researcher visited the siblings at their family homes to undertake the interviews there. Interviews with both the social worker and the sibling were arranged via e-mails and telephone conversations with the social worker and via e-mails and telephone conversations with the parents of the siblings.

3.4.2 Interview schedule

Even though the researcher made use of unstructured interviews in order to allow the respondents to become aware of their unique field, feelings and thoughts at the time of the interview, certain topics arose that were used to guide the interview. These topics were only used for further exploration and not to structure the interviews. The interview schedules used by the researcher served mainly as a guide. Where necessary the researcher would use clarifying questions relating to the response given by the respondent.

3.5 DATA ANALYSIS

3.5.1 Method of data analysis

Patton (in De Vos, 2005:334) points out that analysts have an obligation to monitor and report their procedures. This means that they must observe their own processes, and analyse and report on the analytical process. In qualitative research, there is an inseparable relationship between data collection and data analysis, because as data is collected it is analysed and the

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analysed data can suggest a need to make changes to the data collection procedures (De Vos, 2005:335).

Data analysis involves collecting and recording data, managing data, reading and memo-ing, generating categories, themes and patterns and finally coding the data (Kruger, De Vos, Fouché & Venter, 2005:224).

Once the interviews had been conducted they were transcribed and analysed. The data obtained from the interviews was managed by organising the collected data into electronic audio files, which were easily retrievable from the researcher's computer. Those audio data files were converted into text, known as a transcription. The researcher read the transcriptions many times to get a sense of the interview and to become familiar with the data while reading the data, the researcher made notes of any ideas or key concepts that came to mind.

The next step was to generate categories, themes and patterns from the data. This involved reducing the volume of raw information, sifting significance from trivia, identifying significant patterns and constructing a framework for communicating the essence of what the data revealed (De Vos, 2005:333). The data was then divided into themes, categories and patterns. From these findings a comparison will be made with existing literature.

3.5.2 The analysis process

According to De Vos (2005:337), generating categories, themes and patterns in the data is the most difficult phase of the data analysis. De Vos (2005:338) argues that this phase is an analytical process whereby the researcher makes comparisons, looks for categories and identifies themes, ideas and belief patterns. The researcher did identify themes, which were broken down to categories. Where applicable, sub-categories were identified.

Firstly, the researcher carried out an interview and then analysed the collected data as mentioned above. Other interviews then followed from which data was again analysed. Any

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new themes and categories that arose were added to the themes and categories from the first interview. This was repeated until no new themes or categories were found. The researcher then interpreted the data. Finally, the data was presented.

3.5.3 Reading and writing memos

Creswell (in De Vos, 2005:337) quoted Agar as follows: “Read the transcripts in their entirety several times. Immerse yourself in the details trying to get a sense of the interview as a whole before breaking it into parts.” Through reading, the researcher gathered information. Silverman (2005:158) states that by making field notes, the researcher is not only just gathering data, but also analysing the data at the same time.

3.5.4 Generating main categories and themes

The researcher noted regularities in the setting or people chosen for the study (cf. De Vos, 2005:338). The researcher looked out for any relevance and patterns arising from the interviews listened to. The researcher read and re-read all the written transcriptions of each interview with each sibling and social worker to form patterns, general ideas, feelings and thoughts. The researcher then used these general patterns, ideas, feelings and thoughts and combined them to form themes and categories.

3.5.5 Coding of data

According to Punch (2005:199) coding begins the process of analysis and also goes on at different levels throughout the analysis. Punch (2005:201) goes further by stating that coding is the concrete activity of labelling data, which gets the data analysis underway and which continues throughout the analysis. The researcher colour coded the tapes of each individual participant and added general detail such as the participant’s name, age and gender. This made it easier for repetitive listening to the audio recordings.

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3.5.6 Testing emergent understandings and alternative explanations

For the purpose of this study, the researcher evaluated all gathered data to determine the centrality of it (cf. De Vos, 2005:339) and whether it could be used to evaluate the research study. The next phase in the research process was to look at explanations and the linkages among them (cf. Kruger, De Vos, Fouché & Venter, 2005:229). This means that after the researcher made conclusions regarding the gathered data, alternative explanations and causes could be explored regarding the findings that were made.

3.6 EMPIRICAL DATA

The research report is structured so that all the main themes and categories are listed. The main themes were identified by analysing and coding data and were based on information provided by respondents that related to the aim of the study. The data that was found relevant to these themes was then provided in transcribed form. The themes and categories were then explored and compared with existing literature. This literature control is discussed in Chapter four.

3.6.1 The main themes and categories regarding the social workers' experiences

3.6.1.1 The role of assessment undertaken by social workers

All the social workers explained that their role is to carry out assessments to identify need and risk and to make recommendations about available support and services which families with autistic children can benefit from.

Respondent one explained that, *"A core assessment is an assessment which looks at the child's developmental needs, the capacity of the parent to meet the child's basic and developmental needs and their capacity to ensure that the child is safe ... The social worker also has to look at external factors which may impact on the parents' parenting and which may also prevent them from meeting their children's needs."* Respondent one further

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explained that, *“During these assessments the family’s functioning will be explored to gain information into how the family functions as a whole and as a system.”*

Respondent three sees the core assessment as, *“a problem focussed assessment where there is a problem, a diagnosis and that the social worker will look at how to support this problem identified.”* Respondent three explained that he also looks at the family composition and the different roles and relationships within each family.

Respondent four explained that they use the assessments, *“to gain information on how the families are affected by a child’s diagnosis of Autistic Spectrum Disorder.”* Respondent four further explains that from these assessments come recommendations which are used to ensure that, *“... the family was getting a support package that was well rounded.”* With a *“support package”* he meant anything from *“... a supporting letter, looking at respite services to give the parents a break from the caring role for their ASD child ... or a referral to a community resource ...”*

In a follow-up telephone interview with respondent two, she was asked about her view on assessments. Respondent two stated that *“to carry out assessments are important, but in order to do so you have to gain information to complete these assessments. I struggled to get the children to willingly talk to me as they obviously did not trust this strange person in their house and I didn’t have enough time to work on building trust with the child. With not having enough time to establish an environment where the child can trust me enough to share information with me, made the process of obtaining a true sense of this child’s wishes and feelings quite difficult.”*

In a follow-up telephone interview with respondent five, his view was that, *“Well, we use assessments to gather information which will assist us in identifying need and risk. This is very important as the purpose of our work is to support families with their need and to help reduce the risks of injury, family breakdown and exclusion, whether this is from school, community resources or just having a support network.”*

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Respondent six explained that, *“assessments are used to identify need and risks and looking at what forms of intervention can be used to meet these needs and to reduce the risks. In working with families where there is an Autistic child, there are so much more risks in an around the family home that it is almost necessary to carry out a separate risk assessment to address the different risks, if the family has not already have something in place looking at limiting risks.”*

The following categories were identified from this theme:

- To identify risk and need;
- Basis for planning;
- Central in delivery of services.

3.6.1.2 Social workers feel that there is not enough time to complete their work and too many timescales and targets to be reached

Most respondents mentioned that time is a key factor in their work and how their work is done. Respondent two clearly stated that, *“... there is never enough time to do the work required. This is influenced by the pressure of timescales and required performance indicators which is dependent of government funding.”*

Respondent one explained that, *“... it is so important to have time: time to plan, time to reflect, time to assess and time to build trusting relationships, not only with family but also with other professionals.”* Respondent one also mentioned that, *“Social workers do not always have the time to arrange another visit to see the siblings and spend time to explore their wishes and feelings.”*

Respondent three also stated that, *“... we have limited time as it is to spend with families ...”*

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Respondent four stated, *“It is important to spend time with each family so that both you and the family can work in partnership. This will lead to thoroughly identified needs and risks and also support to address each need and risk.”*

Respondent three also mentioned that, *“... targets [need] to be reached, such as timescales to complete these assessments, timescales to ensure that a support package is presented to a funding panel ... it takes up valuable time to complete the government required and local authority required paperwork.”*

In a follow-up telephone interview, respondent five stated that, *“With regards to the targets, well, there is a target-driven culture in social work in this country, which is exactly what makes social work so difficult. Targets and timescales are used as a measure or indication of performance and we all know that the government awards money for services to Local Authorities on the basis of these performance indicators.”*

Respondent six mentioned that, *“Time is always an issue as there is never enough of it. We need more time to spend doing ‘the job’ of social work and not spending 70% of the time on the computer. The timescales for completing different assessments and processes as they are now is more or less completely arbitrary.”*

The following categories were identified from this theme:

- Quality and standard of work;
- Opportunity to be reflective of their practice;
- Prevented them from building relationships with families.

3.6.1.3 Social workers experience limited resources and funding from the local authority to provide essential services

Respondent three explained that, *“... it is not always possible to fund and ensure the support they need ... not always enough local resources available ...”*

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Respondent six said, “[I am] *accepting that I can only do what our services allow to do and allow to fund, so [they are] really limiting certain appropriate and required interventions and support.*”

Respondent five explained the procedure of getting funding as, “*we have to go to a funding panel to get agreement for funding for any support which requires funding. These funding panels meet fortnightly which means that more time was spent before the family could get a support package. This all takes time.*”

Respondent three also thought that, “*social workers must know their resources available and know how to link the families with the community resources.*”

Respondent six further mentioned that, “*I had difficulty in getting them (the parents) to understand the process and procedures I have to follow in order to get them the support they needed, i.e. completing the assessment, presenting it to a funding panel etc. etc.*”

Respondent one was clear about the limited resources that, “*Limited resources and services available to support the sibling, the autistic spectrum disorder child and the parent. There are just not enough local services to support these families, and this is one of my biggest frustrations. I have the skills to assess the need of these families, but we don’t have the resources or finances to put in place to support them.*”

In a follow-up telephone interview, respondent two stated that, “*The lack of resources impacts on the preventative services that can be offered to children in need to keep them safe. At the moment, we have to rely on charities such as the National Autistic Society to support families as there is just not enough money.*”

Respondent four feared that the pressure of working with limited information resources and inadequate supervision will push social workers to the brink of burnout.

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The following categories were identified from this theme:

- Follow different processes and procedures;
- Rely on support from charities.

3.6.1.4 Social workers experience a lack of knowledge, training and experience in Autistic Spectrum Disorder

Respondent three mentioned that, *“social workers don’t always take the opportunity to attend training as they are too busy ...”*

Respondent two explained that she did not have a lot of knowledge of Autistic Spectrum Disorder (ASD) and *“... felt a bit out of my depth ... I did not know anything about ASD ... I had not had experience in working with ASD children before and did not know what to expect.”* Respondent two goes further to say that, *“I was shocked and felt really not equipped enough to be able to assess the family situation appropriately.”*

Respondent five mentioned she felt frustrated by *“a lack of knowledge and practical skills ...”* Respondent five further mentioned that she requested training in Autism Awareness and Makaton – which is a vocabulary used for people with learning difficulties, rooting from British Sign Language.

Respondent two also did not think that, *“... any social worker should have to work with a family where there is an ASD child without sufficient training or knowledge on this disability”* and that, *“... social workers’ managers should have appropriate training in ASD too ... as they don’t know how to support or supervise appropriately.”* Feelings of insecurity and uncertainty are amongst the emotions felt by social workers.

Respondent four felt that it is important to be aware that some siblings carry out caring tasks for the autistic sibling and that, *“it is important for social workers to be aware of what it means to be a young carer and how this affects and impacts on the child’s development and life.”*

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Equally to be aware of and have knowledge of local community resources available to support the sibling who helps caring for their autistic siblings. Respondent one stated, *“Be resourceful, know your area and services around, talk to people and don’t hold information for yourself, share.”*

In a follow-up telephone interview with respondent six he explained that, *“It is important to have the appropriate skills how to better empower our clients and make them less dependent on Social Services.”*

The following categories were identified from this theme:

- Resourceful and knowledgeable of services;
- Training and knowledge.

3.6.1.5 Social workers experience multi-agency working as difficult at times

Respondent three mentioned that families might work in partnership and receive support from external agencies such as health agencies, education department, benefits agencies, housing departments and community charities.

Respondent five explained that, *“... lack of knowledge from staff at the education department, understanding how this disability affected the whole family ...”* was a big problem and shocking.

Respondent two expressed her frustration with some agencies who would *“... often use the expert model, talking down to and telling how to instead of working in partnership with the parents and other professionals.”*

Respondent one explained that it is important to, *“... build trusting relationships, not only with families but also with other professionals.”* Respondent one further stated, *“Networking in a multi-professional way is very important and sadly, but true, does not always happen. It will make work much easier if communication between agencies can be improved as this is often*

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the case that agencies do not talk to each other and do not know what the other professional's role and responsibilities are." Respondent one also mentioned, "I would like to be able to work more closely in partnership with other professions involved..."

Respondent six explained that, *"... it took some time to arrange as we had to arrange the meeting around the available time of the psychiatrist. I found this frustrating as I left numerous messages and were never contacted back. I had to do all the following up."* Respondent six further mentioned that, *"I felt frustrated with the system as it sometimes appears that by excluding a child from school is the easier and safer option – not always truly understanding the consequences."*

In a follow-up telephone interview with respondent four, she stated that, *"The understanding of risk and when to refer within Health and Education Services needs to be better understood. Sadly I think what is happening is that more and more children are being referred to Social Services by other agencies for us to conduct those assessments and we are becoming overwhelmed by these referrals meaning that the quality of our assessments decreases as managers put more pressure on to churn the work out within Government timescales and it is more likely that children will slip through the net."*

The following category was identified from this theme:

- Communication and understanding of different roles and responsibilities.

3.6.1.6 Social workers experience loss of acquired knowledge and skills

Respondent one felt, *"... frustrated and often hopeless because what is the point of studying all those years and acquiring all these skills and knowledge if you cannot ensure that these families get the support you recommended due to lack of funding and resources."*

Respondent three mentioned that, *"... you don't get to use all your knowledge and training as services in this country tend to be more specialised."*

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Respondent one did however explain that other social work skills and tools like interviewing skills and relationship building skills, good listening skill and good observations skills will assist in getting a better picture of how families function.

In a follow-up telephone conversation with respondent two she stated that, *"I feel the real impact is on the amount of time we have available to spend with children and families and a reduction in developing the necessary observation and assessment skills that can only come from direct work."*

Respondent four explained that, *"Due to specialisation in services, such as adult services and children services, certain knowledge and skills get rusty and you end up not using these skills learnt."*

The following categories were identified from this theme:

- Specialisation and sub-specialities;
- Personal effectiveness.

3.6.1.7 Social workers experience problems with the local authority's computer system

Respondent two mentioned that she, *"... really struggle with the computer system. I know training is available but I just don't have enough time."* She goes further to say that, *"The system is too complicated to understand and it takes ages to complete the required forms, which means that valuable time is wasted in front of the computer which could have been spent with families."*

Respondent three expressed his frustration with, *"... the local authority's computer system and database which required a lot of paperwork and computer forms ... which will be used as performance indicators ..."* (for funding from the Government). Respondent three also further stated that, *"This computer system is not always working and presents with a lot of challenges to the social worker as it takes up valuable time to complete the government required and local authority required paperwork."*

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Respondent one mentioned that, *“You have to be computer literate and our computer system is very complex to use and you need time to go on training on how to use this system.”*

In a follow-up telephone interview with respondent five he stated the following, *“(computer system) is rubbish and there is a tendency to let the computer dictate how we are supposed to be doing our work rather than them facilitating our needs.”*

Respondent four expressed her frustration with the computer system, stating, *“There is always something wrong with the computer system preventing you from recording your work on cases. This is frustrating because you are not able to complete the required paperwork in time for things like meetings, Child Protection Conferences etc*

This makes you look bad in front of other professionals. It also takes up so much of your time as you often have to be on the telephone with the helpline trying to get them to fix the problem. This is time wasted.”

3.6.1.8 Social workers have too high case loads

Respondent two explained that too high caseloads often meant that not enough and sufficient time is spent with the family and subsequently the sibling to establish their wishes and feelings.

Respondent three had the following to say with regards to the caseloads, *“It is a challenge to stay positive with all the work we have to do, the unrealistic caseloads which leaves you to feel burnt out.”*

Respondent five explained that, *“... cases get allocated depending on the urgency of the family’s need and the availability and caseload allowing. Because of big caseloads, it is not always possible to spend time beforehand to prepare yourself properly before visiting the family. You might have time to read the last case notes, transfer summary or closing summary, but that is it.”*

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In a follow-up telephone interview with respondent one she stated that *“My main concern is not only is there an ever increasing workload but also the expectation of improving the quality of my work, this leaves me feeling quite anxious, but that’s the way government works. Push us to breaking point and then complain when we break.”*

Respondent six explained that, *“A smaller caseload means increased time for reflection, case discussion and management consultation, it allows greater liaison with other professionals and increased time to see the child and family. Following the recent death of a child, the referrals have increased significantly, making our workloads intolerable and creating the possibility for dangerous practice.”*

3.6.1.9 Social workers experience high levels of stress

Respondent two explained that by having high case loads and subsequently not enough time to do the job, it creates stress – it is actually guaranteed. Respondent two explained that she is constantly stressed about being able to juggle between carrying out home visits, attending various multi-professional meetings, writing up everything from telephone conversations to direct work sessions with children and completing assessments electronically and within timescales.

Respondent three did not mention the word stressed but explained his attitude towards social work in general by stating the following, *“My attitude is always that of a positive one, but I know in general (amongst colleagues), lately, that the feeling is that of negativity towards our profession. It is a challenge to stay positive with all the work we have to do ...”*

In a question about stress, respondent one explained that there is always work-related stress involved in her work. *“... whether it is stress about the client, managing time or even managing the administration, I do not know any social worker who is not stressed.”*

Respondent four stated, *“social workers all suffer from work related stress, some social workers are burnt out but just keep going, no wonder there is an increase in the sickness rate*

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of social workers. Social workers have their own lives as well which could also be stressful, so it is just a negative experience all round."

Respondent five thought that, "Stress in the workplace is inevitable as there is pressure from the government right down to your supervisor about time scales, certain required practices like computerised recording etc. The thing is, you don't get supported enough to reduce the factors which causes the stress, you might discuss this in your supervision, but whether this will actually be addressed, is a complete other issue."

Respondent six explained in a follow-up interview that, "I have psoriasis which is a skin condition, which gets very inflamed and can cause quite a lot of pain and discomfort. Psoriasis is brought on by stress. At the moment, I have had to get specialised treatment because of uncontrollable psoriasis. I have been booked off by my GP due to stress at work and I can guarantee you I am not the first and only one getting ill due to work."

3.6.1.10 Social workers are aware of expectations from parents to receive support

Respondent one explained that, "... the main focus seems to be around the child with autistic spectrum disorder ..." Respondent one goes further to say that, "... parents are usually in need of immediate support due to the stressful role of caring for their ASD child."

Respondent three mentioned that parents, "... really just want support with their disabled child or a break from the caring for their disabled child ..." and that, "... most of the time, the parents' focus is on the disabled child."

Respondent six explained that she, "... found it hard to explain to the parents that the services and support they were expected, they were not going to get because of limited resources and funding."

Respondent three did not think that the parents are focussed enough on the sibling. "I don't know if parents understand that by getting the views of the sibling, is actually an indirect form

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of support to them and the sibling ... there is a definite incentive to the parents here, but they are not taking it up."

Respondent four stated that, *"I make sure to explain to the family that I can only do what I can to support them but that there is limitations, restrictions and remit as to what can be offered to the family. Most of the time, they understand but sometimes I find it hard because when people want something they can't always see beyond that."*

In a follow-up telephone interview with respondent two she felt that, *"It's more a desperate hope than an expectation. I think that they (parents) want too much and we provide too little. Often they've been given an unrealistic expectation of what they can expect by medical staff and so we look bad."*

Respondent five thought that, *"Parents to have an expectation to be helped, even if it is just with practical advice, a group they can join like for instance the National Autistic Society parenting group in the area where they live or financial support. I don't have a problem with parents having expectations to be helped, but when they demand help as they feel they are entitled to it, I find it challenging to work with the parents then."*

3.6.1.11 Social workers don't spend enough time with siblings

Respondent one said: *"I don't even see the sibling of the ASD child as in some cases, the sibling will be upstairs, keeping herself busy."* Respondent one was of the opinion that this is often the case because, *"they are used to people coming into their family home to assess their disabled sibling ... that they don't even bother to come down stairs, as they are never required to be part of what was really going on in the family."*

Respondent three mentioned that he always asks the parents to ensure that all the children are present for when he visits the family but that, *"the siblings of the ASD child do not always make themselves available."*

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Respondent two explained that she was only able to spend time with the sibling by visiting the sibling at school and that, *“I would have liked to have more time to explore how that sibling understood ASD and how they were dealing with it ...”*

Respondent three is in support of more time to be spent with the sibling as, *“I feel that with time spent with the sibling, it will make them feel valued and that their wishes and feelings are considered too. Respondent three explained why time should be spent with the sibling, “that by getting the views of the sibling, is actually an indirect form of support to them and the sibling. Any problems that siblings might have or face could be identified early on and support can be put in place to prevent any further problems.”*

Respondent six explained her difficulty: *“I tried to talk to the younger sibling to get his views but it was not possible as he did not want to leave his room and when he eventually did, he did not want to engage in a conversation with me.”*

Respondent two felt that because of her big case load, it was not possible to spend more time with the siblings of the Autistic child. She further stated, *“... I would have liked to have more time to explore how the siblings understood ASD and how they were dealing with it and also to explore how they see my involvements as a social worker.”*

Respondent four also would have liked more time with the sibling as it was possible for her to identify some difficulties even in spending ten minutes with the sibling. In a follow-up telephone interview with respondent five, she stated the following, *“It is not always possible to spend more time with the sibling, unless you specifically arrange to see them separate from their ASD sibling, and the likelihood of this happening is very slim as the focus is more on the disabled child.”*

3.6.1.12 Summary

From the data gathered the researcher found that when working with families, social workers use assessments to identify need and risk and those assessments are also used as the basis

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for planning in terms of identifying support services for families. Social workers' quality of work and opportunities to be reflective of their practice are often affected by the lack of time. Furthermore, the data evidence confirms that a lack of time prevents social workers from building relationships with families. Social workers explain that different processes and procedures have to be followed in order to ascertain funding of services for families but that a lack of funding and limited resources mean that they have to rely on charities to support families.

A lack of experience, training and knowledge in Autistic Spectrum Disorders affect social workers' ability to support families adequately, leaving them feeling insecure. From the data it became clear how important it is to be resourceful and knowledgeable of services. Communication with multi-agency professionals was experienced to be difficult at times leaving agencies unclear about different roles and responsibilities of the different professionals. Social workers felt that their knowledge and skills were affected by specialisation of services such as adult services and children services. The local authority's computer system proved to be a real problem for social workers and often a cause of great frustration and a waste of time.

Social workers explained that having too many cases prevented them from providing quality services to families as there is just not enough time. This leaves social workers feeling pressured, stressed and anxious. Stress was identified as being inevitable due to government pressures, lack of time and unmanageable case loads. Some social workers' health was affected due to stress at work. Parents have certain expectations from social workers to receive services, which it is often not possible and often wrongly given by other professionals involved.

Social workers are aware that they don't spend enough time with siblings and have identified the limitation and barriers preventing them from doing so.

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3.6.2 The main themes and categories regarding the siblings' experiences

Through the interviews with the siblings it was clear that each sibling experiences their disabled sibling's diagnosis very differently. It was also clear that each sibling is affected differently by their autistic brother and sister. In support of the main themes and categories regarding the siblings' experience the researcher has decided to incorporate the social workers' responses.

3.6.2.1 Siblings might experience feelings of social isolation

Respondent three thinks that, "... the sibling is often being made 'disabled' by not having the opportunity to develop their social skills and relationships as a child without a disabled sibling would be able to do." Respondent three further said that siblings of autistic children's free time, "... will be used to help care for their disabled sibling whereas the child who does not have a disabled sibling of their age, will be accessing community activities, building friendships and relations and so develop their social skills."

Most siblings do not have a lot of friends, they tend to have friends who also have disabled siblings and tend to go to the same holiday clubs and after school activities. Respondent A explained that he will only sometimes go out with his friends.

Respondent B stated, "I just wish that I can sometimes stay with my friends because I only see them during the holidays and then never again. I have a few friends who also have brothers with autism and we hang out most of the time as we go to similar holiday clubs and activities."

Respondent C stated that she only plays with her friends at school and she hardly ever has friends over to play at her house. In a follow-up interview with respondent C the researcher asked how she felt about not having her friends over more often in which she responded, "I would like to have my friends over more but my brother does not give me any privacy and does not understand that he needs permission to come into my room. He scares my friends."

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In a follow-up interview with respondent D, she also stated that she tends to visit her friends more than they visit her house. She explained that, *"My friends understand about my brother being autistic, but they don't really know how to react when he has a tantrum or something."*

Respondent six stated that, *"... the younger sibling (non-disabled) were being bullied and made jokes of in school by other boys who knew about his brother."* Respondent six further stated, *"... the younger sibling was suffering from Post Traumatic Stress disorder and there were concerns whether he was in fact suffering from depression."*

The following categories were identified from this theme:

- Siblings of autistic children experience bullying from peers;
- Siblings experience mixed emotions about their relationship with their autistic brother or sister.

3.6.2.2 Siblings' relationship with autistic brother/sister

Respondent five's experience of siblings of an autistic child was that, even though they were scared of their older sibling, they were used to their autistic sibling's aggressive outbursts. He thought that the siblings had resilience towards their circumstances and their disabled sibling and that they were even caring towards their autistic sibling. Respondent five mentioned that, *"... no matter what situation, they were still very caring towards their older brother and showed affection towards him."*

Respondent two mentioned that during her involvement with a sibling of an autistic child, she found the sibling to be, *"... quiet, kept to herself and faded back in the background."*

Respondent six also mentioned that the sibling she was involved with became quiet and withdrawn and that it was later established that the sibling suffered from depression.

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Respondent C mentioned that, *“He (ASD brother) is rude towards me and he doesn’t like me, he told me that he doesn’t like me ...”*

Respondent A explained that he was, *“... good friends with my brother and I feel that I understand him more.”*

Respondent B stated that, *“We do play a lot and we play wrestle which is nice ...”*

Respondent A was aware of his brother’s Aspergers Syndrome. *“They are always saying it is the disability that makes him do certain things. I don’t think it is really the case because he is quite clever and I think he knows what he is doing. So, I think he gets away with more things because he has a disability.”*

Respondent D explained that, *“Sometimes I have to be extra nice to J if I want him to be nice with me.”*

Respondent six described the aggression between siblings, *“These two boys were constantly fighting ... the parents were concerned about the level of physical aggression between the two brothers.”*

Respondent four felt one sibling to be concerned with her disabled brother’s safety. *“I could see that she was able to identify risks and knew how to minimise or eliminate any risk that could harm her brother.”*

The following categories were identified from this theme:

- Through teaching, the sibling will experience a more positive relationship with their autistic brother or sister;
- Sibling rivalry.

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3.6.2.3 Siblings being target or victim of their autistic sibling's behaviour

Respondent six explained that in her work with a sibling, she found that the autistic brother directed his aggression and frustration towards the sibling.

Respondent C mentioned that, *"[my brother] is rude towards me and he doesn't like me, he told me that he doesn't like me ..."* Respondent C also explained that her older autistic brother will go in her room, take her belongings and not have respect for her belongings or her privacy.

Respondent A explained that his autistic brother will hit him, *"... but I will just get out under his grip and run away or go the bathroom and lock myself in there and when I'm sure he is gone, I will go out."* Respondent A stated that, *"... he (ASD brother) doesn't get on or like E at all and she always gets the worst part of his moods. He will tease her and will treat her really bad."* Respondent A felt it was necessary to intervene at times, *"When he is horrible and nasty, I try to make things better in the family, like if my brother is behaving badly I will try and cheer everybody up by being really lively and funny."*

Respondent five mentioned aggression directed to a parent, *"He got quite violent and aggressive towards his mother."*

In his follow-up interview with respondent B he mentioned that, *"I am not that much older than my brother, so I can't really fend him off, I will try but most of the times, I will just run to my room and lock myself in or I will try get his attention onto something else."* He went further to say that, *He will tease her and will treat her really bad."* Respondent A felt it was necessary to intervene at times, *"When he is horrible and nasty, I try to make things better in the family, like if my brother is behaving badly I will try and cheer everybody up by being really lively and funny."* *"My brother sometimes wake me up really early or during the night, I hate that."*

Respondent D has suffered aggression from her sibling and mentioned the following, *"I know J so well and will just give him something he likes to take his attention away from what he was*

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angry about.” Respondent D did however experience her sibling's behaviour in a negative way by stating, *“We can't go to any restaurant as J is a fussy eater and because he can't eat certain foods.”*

He will tease her and will treat her really bad.” Respondent A felt it was necessary to intervene at times, *“When he is horrible and nasty, I try to make things better in the family, like if my brother is behaving badly I will try and cheer everybody up by being really lively and funny.”*

3.6.2.4 Siblings' understanding of autistic spectrum disorder

Respondent C could not understand why she had to obey the house rules but that her autistic brother did not care about it.

Respondent B stated that, *“I don't really understand why my brother has to be at school early, maybe it is that they have to prepare him before school starts, maybe to get him to be a little bit calmer.”* Furthermore, respondent B stated that, *“I wonder why my brother gets gifts when he is doing something good and not I.”* Respondent B further stated that, *“Yes, he does and I will encourage him to be good because I know that he will get a train if he behaves and then I can play with it too.”* However, respondent B understood Autism quite good, *“I go with my mother and brother to the Oxygen fabric ... This place helps my brother to get more Oxygen to his brain which calms him down ...”*

Respondent four thought the following of a sibling she talked with, *“... a good grasp of what her brother's diagnosis was and that he needs so much more support and help from her and her mother than she did. She knew that certain things can affect her brother's behaviour like a change in his daily routine. She mentioned that he would scream non-stop if he could not watch his favourite TV show in the morning. She mentioned matter of factly that her brother needs help with everything. She was very aware of making sure that her little brother's needs are being met ...”*

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Respondent five explained her opinion of younger siblings towards their older ASD sibling as the following, *“the siblings were quite used to their older sibling’s outbursts of aggression, they still looked pretty scared and kept at a distance of him, which can only explain that they have been through this kind of situation before.”* Respondent five further stated that the one sibling just said he was having, *“... one of them days again today.”* Respondent five continued that she, *“... thought this was very sweet, but equally thought that they would not know anything else as they were much younger than their brother and were born into the family where this diagnosis was already present.”*

Respondent A thought of his brother as, *“... even though he is older than me he has the brain like of a nine year old boy ... We all ignore my brother at times, it is just easier, because he can go on for some time if he doesn’t get his way.”* Respondent A mentioned that, *“I find that I can sometimes convince him to play the games I like.”*

In a follow-up interview with respondent D, she explained the following, *“I kind of know what Autism is, my mum gave me some books to read which is for siblings of Autistic children.”*

The following categories were identified from this theme:

- Siblings had awareness of their brother/sister’s special needs;
- Some siblings did not understand why they were treated differently to their brother or sister.

3.6.2.5 Siblings’ relationship with their parent/s

Respondent C said that, *“... my father never listens to me, they are too busy, they never really listen ... I would like my dad to listen to me and to go out with me and also my mum to listen to me.”*

Respondent B likes the time his dad spends with him and said that, *“I like it when my dad reads Treasure Island to me at bedtime.”*

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Respondent four mentioned a statement from a child during a home visit, “... *she wished her mother could have more time to help her a bit more with the rehearsing of her part in the school play ... I could see that she longed for more attention and time from her mother.*”

Respondent A thought of his parents' reaction as, “*I don't always think it is fair in the way my parents respond to certain things my brother does and doesn't do, but then, they could just as well be tired. Both my parents work.*”

Respondent four mentioned the following about seeing a sibling, “*She appeared sad by the fact that she did not get as much attention from her mother as her brother, but that she was somewhat used to it so did not bother making a fuss about it or ask for more time with her mother.*”

In a follow-up interview with respondent D she stated that she and her mother plan a lot of things and that she has alone time with her mother when her brother goes to circus or visits his dad. It appeared that respondent D had a good relationship with her mother, who is a single parent. She helped her mother out with the daily tasks of caring for her ASD sibling and did not appear to be too negatively affected by her sibling's diagnosis.

The following category was identified from the theme:

- Siblings did not receive as much attention from their parent(s) as their ASD brother or sister.

3.6.2.6 Siblings' understanding of the role of the social worker

Respondent B was aware of different people coming to their house, asking questions and looking around, but did not felt listened to. “*I would like people to listen to me and really listen and not just want to come and look what is in the house ... they don't really ask me what I want so what's the point.*”

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Respondent four found that, *“Children go by what their parents say and both parent and child do not always understand why a social worker cannot do certain things like get them money to go on holidays, change a situation immediately, get a carer immediately etc.”*

Respondent five thought that, *“... their parents only told them that someone was visiting the afternoon to speak to them about their brother.”*

Respondent one stated, *“It could be because they are so used to people coming into their family home to assess their disabled sibling all the time and focussing on their disabled sibling, that they don’t even bother to come down stairs, as they are never required to be part of what was really going on in the family.”*

Respondent A did not know what social workers were and thought the following, *“We never really needed one as both my parents work and they are able to pay for everything themselves. They help you to get things isn’t it?”*

Respondent D stated, *“... no social worker has visited us yet. We are quite busy, we visit my nan and family and we are quite busy.”*

Respondent six explained the following, *“... the child with ASD told me that he does not like professionals as they all think they know what he needs but that they don’t.”*

In a follow-up interview with respondent C, the researcher explored her understanding of social workers, and her response was the following, *“I know my friend’s brother has a social worker who helped them to get him into a special school. We had a social worker when I was younger but don’t anymore now that my brother is older and going to college. I think they left when my brother stopped going to school and got home tuitioned.”*

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3.6.2.7 Summary

From the data gathered the researcher concludes that siblings experience bullying from their peers leaving them feeling potentially socially isolated. Siblings had mixed emotions about their relationship with their autistic brother or sister, having a relationship which was characterised by sibling rivalry and not always knowing or understanding their brother or sister's behaviour.

From the data, the researcher found that siblings are often the victim or target of their autistic brother or sister's behaviour. Siblings had an awareness of their brother or sister's special needs but did not necessarily understand why they were treated differently to their disabled brother or sister. Siblings do not receive the same level of time and attention as their autistic brother or sister and this proves to be an ongoing challenge for parents. From the data, siblings did not have an understanding of the role of social workers.

3.7 CONCLUSION

In this chapter, the researcher gathered information to inform the empirical research process of her study. From the data collected through the interviews with the respondents (social workers and siblings of autistic children), themes and categories were drawn and further elaborated upon. In the next chapter, literature control will ensure that the themes and categories drawn from the empirical data collection process are evidenced and supported.

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CHAPTER FOUR

LITERATURE CONTROL

4.1 INTRODUCTION

In this chapter the literature control is used to compare and contrast the data generated from the research findings in chapter three with already existing studies (cf. Delport & Fouché, 2005a:263). The results of this study are reflected in the light of present literature to establish similarities and differences, and to recontextualise the data appropriately to the research design (cf. Morse, 1994:34).

4.2 THEMES AND CATEGORIES DERIVED FROM INTERVIEWS WITH SOCIAL WORKERS

The following themes and categories (in bold) were derived from interviews with social workers:

4.2.1 Theme: **The role of assessment undertaken by social workers**

In the first category that was identified from the data analysis in chapter three the social workers indicated that a prominent role of theirs was to carry out assessments **to identify need and risk**. They explained that assessments are processes in which information on the family and their circumstances are gathered through which needs and risks are identified with the end result being recommendations which could improve the situation. According to Coulshed and Orme (2006:24) an assessment is an ongoing process which assists social workers and where clients have the opportunity to participate in order to help social workers to get a better understanding of people and their environment. They go further to say that assessments help to improve or support a change in a person's life or environment, which makes assessments a basis for planning (in terms of how to establish change). Beckett (2006:10) explains that social workers try to allocate limited resources as fairly as possible by

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making judgements about levels of need and risk. He explained that this is done through the assessments social workers carry out and it is regarded as of the main purposes of social work assessments. Assessment is also a **basis for planning** what needs to be done to maintain, improve or bring about change in the person, the environment or both. Bevan (in Thompson, 2006:143) states that,

Assessment should bring together information relevant to the physical, psychological, social and spiritual dimensions of the situation. Once this is gathered, the worker needs to make sense of the information by understanding the person as part of many systems – for example, family, school, friendship and the religious and cultural dimensions of their lives. For assessment to be both accurate and adequate, it is imperative to acknowledge the influential factors of race, culture, gender and disability. Importantly, the assessment needs to recognise the structural and social dimensions and the way these disparities impact on a person's coping resources.

Thompson (2005:64) explains that assessments are holistic processes which allow the social worker to gather information on a person or family allowing them to form a picture of the situation, the needs and problems and looking at how best these can be addressed. From the empirical research, it became evident that assessments are often **central in the delivery of services** provided to families. Thompson (2005:83) also, as do Coulshed and Orme (2006:24), believes that assessments are a basis for planning and interventions as outcomes will be drawn as a result of these assessments, determining how, when, whether and what services could be offered to families.

4.2.2 Theme: Social workers feel that there is not enough time to complete their work and too many timescales and targets to be reached

According to the empirical research, social workers were of the opinion that time is central to the work they completed. All the social workers were of the opinion that time is often lacking and that through the lack of it, the **quality and standard of work** is often not as thorough as

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it could be. Orme (in Adams, Dominelli & Payne, 2002:243) explains that effective systems take time to manage workloads and if time is not taken, the quality of services will be compromised and resources, including human resources, will be wasted. UNISON (UK, 2008) reported that the rigidity of timescales for completing assessments can act as a detriment to the quality of work done and mean that this work can take priority over child protection work.

Furthermore, the social workers were of the opinion that the lack of time impacts on the **opportunity to be reflective of their practice**, identifying possible improvements and to learn from research. Thompson (2005:235) argues that even though time often prevents practice evaluation, it is important to evaluate one's practice as this is beneficial for the person, his organisation and the clients he works with and that it will prevent false and dangerous economy. Lord Laming (2009:32) reported a concern that the tradition of deliberate, reflective social work practice is being put in danger because of an overemphasis on process and targets, resulting in a loss of confidence amongst social workers. UNISON (2008) reported from a survey that social workers felt they needed time for reflective practice including time to revisit decisions. UNISON (UK, 2008) further reported that current performance indicators and performance targets act to skew priorities and fetter professional judgement by social workers.

All the social workers thought that the lack of time often **prevented them from building relationships with families** which subsequently impacted on the aim of working in partnership with the families. In a research study done by Burton and Van den Broek (2008) they found that social workers felt their practice was constrained by the requirements to spend more time recording client and service details, taking up time they felt could be better spent with clients.

4.2.3 Theme: Social workers experience limited resources and funding from the local authority to provide essential services

From the empirical study it became evident that in order to get services for a family, social workers have to **follow different processes and procedures** such as presenting families'

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cases to funding panels. Neill (in Milner & O'Byrne, 1998:10) explained that resources available to social workers have always been restricted. He further states that there is pressure on workers to fit their assessment of individual need into existing provisions (in Milner & O'Byrne, 2002:10). Davies (2002:388) explains that instead of social work practice being a user-centred service, it has now changed to a "needs led provision" and "value for money" service as a result of the government being budget driven. Milner and O'Byrne (2002:16) state that assessments are the process of objectivity defining needs and determining eligibility for assistance against stated policy criteria. Orme (in Adams, Dominelli & Payne, 2002:240) explains that budgets (for services) are allocated according to formulas which include raw data, predictions based on research evidence and political expediency. The National Autistic Society (UK) explains that even though the pathway to services can sometimes be a long, drawn-out process to receive the help that is needed, some local authorities do not have the provisions to offer a particular service or they may disagree with the amount of help that they think is needed. Coulshed and Orme (1988:231) state that, "... notions of individualised packages of care have been curtailed by controls such as eligibility criteria and restricted resources." Horwath (2002:198) explains that the Chief Social Services Inspector recognised finance and capacity issues as an obstacle to performance. He offers to explain that Councils (Local Authorities) identify budget pressures, lack of resources and increased demand for services barriers to progress. Milner and O'Byrne (2002:16) explain that a client's needs are defined and eligibility for assistance are determined against policy criteria from clients, service users and other involved agencies.

The empirical data pointed out that most social workers felt that there was not enough resources and funding to families and that they often have to **rely on support from charities** locally and nationally. Ives and Munro (2002:104) provide information on Family Fund Trust, which is an independent charity funded by the government, supporting families with once-off funding for something like a washing machine or family holiday. UNISON (UK, 2008) reported from a survey they conducted in December 2008 on social workers in the public sector, the budget restraints, cost-cutting, year on year efficiency savings and recruitment freezes meant preventative work with children in need is being cut.

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4.2.4 Theme: Social workers experience a lack of knowledge, training and experience in Autistic Spectrum Disorder

It became evident from the empirical study that it is important for social workers to be **resourceful and knowledgeable of available community services** as it may happen that families will be referred to these services for support. Marshall (2004:101) explains that Social Services may be able to provide a range of other kinds of help with accommodation, healthcare, education, funding and grants, thus evidencing the importance of having to be resourceful.

Training and knowledge are important to ensure that social workers have an understanding of the ASD diagnosis, the characteristics and how to manage certain behaviours. From the empirical study, some social workers mentioned that there is not enough time to attend training. In a research study conducted by Preece and Jordan (2007) they found that social workers working with disabled children had a good understanding of some aspects of ASD. However, they found that there was confusion about other important characteristics, terminology, lack of understanding regarding approaches to interventions and an overly optimistic belief in the ability of generic services to meet the needs of autistic children compared to the actual ability of organisations. Preece and Jordan (2007) supported the necessity for provisions of ASD-specific training for professionals working with children with ASD and their families, focussing on the characteristics, needs and experiences of children with ASD and their families, the difficulties that they face, and appropriate ways of meeting their varied and often highly individualised needs.

In a research study by Woodcock and Tregaskis (2008) parents found social workers who took time to communicate with their child and who demonstrated an understanding of the impairments of their child's disability very helpful. Lord Laming (2009:10) acknowledges that the challenge is that data systems need to be improved to support professionals better, but that, ultimately, the safety of the children depends on staff having the time, knowledge and skills to understand the child, young person and their family circumstances.

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4.2.5 Theme: Social workers experience multi-agency working as difficult at times

From the empirical study, some social workers were of the opinion that it is important to build relationships with other agencies and that networking is an important aspect of working in partnership with both families and professionals. Coulshed and Orme (2006:236) explain that multi-disciplinary teamwork is crucial whenever there is an attempt to put together a rounded picture of someone's circumstances. Sadly, many social workers felt that there is a lack of **communication and understanding of the different roles and responsibilities within a multi-disciplinary team**. Miller (2004:132) explains that organisational and professional partiality and territoriality are detrimental to service users and that this has contributed to policy failure which is due to philosophical, organisational and cultural differences and restrictive practices of different agencies. Petch (in Coulshed & Orme, 2006:237) pointed out that many of the tensions that arise amongst interdisciplinary team members relate to the myths and stereotypes that they hold about other professions. He explains that stereotyping can be overcome through joint training, working and peers supervision activities in multidisciplinary teams. The Department for Education and skills (DfES, 2005) identified challenges for practitioners involved in multi-agency teams to be difficulties in defining roles and responsibilities, working with new processes and systems and developing skills required for collaborative working.

Lord Laming (2009:10) reported that despite considerable progress in interagency working (often driven by Local safeguarding Children's Boards and multi-agency teams who strive to help children and young people) there remain significant problems in the day-to-day reality of working across organisational boundaries and cultures sharing information. Beckett (2006:137) is also of the opinion that different agencies have different jobs to do and limited resources to do these jobs and that these can result in one agency having different priorities to another in any given situation and this in turn can result in frustration and mutual mistrust. Contradictory to the difficulties social workers have in multi-agency working at times, Thompson (2005:184) acknowledges that, even though social work involves working with other people and the difficulties they face in multi-agency working, which could be frustrating at times, there is a source of joy in working in and as part of a team.

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4.2.6 Theme: Social workers experience loss of acquired knowledge and skills

Specialisation and sub-specialities within certain areas of work often are one of many causes of the loss of skills and knowledge according to more than half of the social workers involved in the empirical research. “Others have complained that they can no longer use their social work skills as they would wish. There are simply too many forms to complete and there is little scope for individual discretion or for creativity in the work (Rickford in Adams, Dominelly & Payne, 1998:26).

From the empirical study, the researcher has found that time is a dilemma social workers are faced with on a daily basis. Thompson (in Thompson, 2005:93) explains that good people skills have their roots in **personal effectiveness** in that if a person is not able to manage his own time, he or she will be left with less time and energy to work effectively with service users and colleagues. Thompson (2005:94) argues that it is important to develop skills which will assist and support a person with stress and time management as this could impact on a person’s ability to cope. He feels that not enough time and attention is given and spent on this important skill (stress and time management).

4.2.7 Theme: Social workers experience problems with the local authority’s computer system

From the empirical study, it was clear that the social workers experience frustration with the computer system in that it does not always work, presents with too many form-filling exercises and dictating how work should be done rather than assisting social workers. UNISON (UK, 2008) the United Kingdom’s largest public sector workers union , explains from reports they received, that the direct impact of the (computer) system is to delay, frustrate and disrupt the flow of work in busy and overstretched teams.

UNISON (UK, 2008) adds in reporting that in addition, this computer system adds to a sense of disempowerment and demoralisation among social workers when there is little management response. Lord Laming (2009:33) further reported that professional practice and

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judgement are being compromised by an over-complicated, lengthy and tick-box assessment and recording system.

4.2.8 Theme: Social workers have too many cases

From the empirical study it became evident that too high case loads lead to a myriad of problems which include lesser time with families, a general feeling of burn out, possibility of dangerous practice and unrealistic expectations of improved practice. Thompson (2005:172) states that, "Having too many demands on our time is a fact of life in social work, and we often have to make very difficult decisions about who we say no to, about what does not get done." With regards to the feeling of burn out, his opinion is that the pressures of social work can easily lead to a situation characterised by demoralisation, defeatism and cynicism (Thompson, 2005:178).

UNISON's (UK, 2008) survey on social work case loads concluded that excessive and unsafe caseloads are the knock-on effect of continuing and chronic staff shortages. It was reported that poor working conditions in social work mean that errors, misjudgements or things being missed are more likely to occur. Lord Laming (2009:22) reported that the United Kingdom Government's *Every Child Matters* came about as a direct result of a failure of services to safeguard children. *Every Child Matters* is intended to organise services and resources around children, their safety and proper development, and improve their well-being. However, it's reported that the pressure of high case-loads for children's social workers, has meant that staff often do not have the time needed to maintain effective contact with children, young people and their families in order to achieve positive outcomes.

4.2.9 Theme: Social workers experience high levels of stress

On this theme, the researcher found that most of the social workers were experiencing stress in their workplace. Thompson (1996:62) explains that stress can be a barrier to learning in that when work or other pressures reach the point that they become harmful, the stress involved can make clear thinking difficult. He argues that stress makes people lose sight of

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what is going on around them. He explains that when this occurs, learning opportunities very much takes a backseat and at times of stress people become preoccupied, and that this has the effect of making people less open to new learning. Preston-Shoot and Agass (in Thompson, 2005:171) commented that:

Increasing workloads, multiplying responsibilities contrasting with static or contracting resources, the emotional and physical impact of the work, the deletion of posts in some fields to meet financial targets of the demands of child protection work, apparently contradictory public expectations and vitriol from the media which often sees little other than tragedies: these are all reflected in low morale, vacancy levels and burn-out.

Thompson (in Thompson, 2005:169) states, "... there is a lot of evidence to suggest that there are many stress factors which, if not exclusive to social work, are at least very closely associated with it ...". Balloch (quoted by Orme in Adams, Dominelly & Payne, 2002:237) argues that role ambiguity is a cause of stress in workers in social services as the workers are being exposed to conflicting demands and being expected to do things which are not part of their job and/or being unable to do things which are part of the job. Thompson (1996:59) explains that there is a danger that social workers may suffer from burn-out which is a form of emotional exhaustion in which workers conduct their work in an unproductive routinised way. Burn-out causes a person to have minimum thought and feeling and Thompson explains that this is not only dangerous for the worker, but also for the service users and the organisation they are employed in. Continuous professional development can play a crucial role in preventing this problem from arising.

4.2.10 Theme: Social workers are aware of expectations from parents to receive support

Most of the social workers in this research study were of the opinion that **parents were unaware** of or did not understand the limitations and procedures involved in getting support or services for their child or family. Thompson (2005:162) argues that priority systems and the

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fact that demand generally exceeds supply often means that social workers can either not provide services requested by the client on the level they expected or that social workers have to explain to clients that there is no service at all. This means that clients get disappointed as the social workers cannot come up with services requested or wanted by clients.

Some social workers thought that **parents were misled** by other agencies or professionals as to what they could expect to get from social workers. Ives and Munro (2002:99) state that following diagnosis, parents will be provided with various information and knowledge depending on the person they approach but that in the end decisions about the services available will depend on their child's needs as there is no definite legislation or government guidance stating what their entitlement to services for having a child with autism is.

From the empirical research it became evident that social workers felt that most of the times the **parent's focus was on their disabled child** and on getting support services to help them. The researcher found it difficult to obtain literature to support this category, but as all the social workers in the empirical study strongly experienced this dilemma, the researcher decided to keep this category as it is significant for this research study.

4.2.11 Theme: Social workers don't spend enough time with siblings

From the data gathered during the empirical process it is clear that more than half of the social workers wanted to have the opportunity to spend more time with the siblings. UNISON (2008) reports that there appears to be a dramatic increase in the amount of time spent by social workers on paperwork, form-filling and report-writing. This in itself would suggest that not only are the social workers almost prevented from spending time conducting the assessments on families but even more so to see the siblings of autistic children.

SIBS (UK) advise professionals to spend time with siblings during home visits and acknowledging any feelings that the sibling expresses. This is sound advice, but coming from the empirical research, it is evident that either the social workers **do not have the time to**

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spend with siblings or **the siblings are not present** during home visits. Two of the social workers explained that the siblings did not make themselves available for discussions with them. Lord Laming (2009:33) reported that direct interaction and engagement with children and families, which is at the core of social work, is at risk due to the assessment and recording systems of local authorities.

4.2.12 Summary

The researcher agrees with Barclay (1982:vii) who explains that,

Too much is generally expected of social workers. We load upon them unrealistic expectations and we then complain when they do not live up to them ... There is confusion about the direction in which they are going and unease about what they should be doing and the way in which they are organised and deployed. When things go wrong the media have tended to blame them because it is assumed that their job is to care for people so as to prevent trouble arising. They operate uneasily on the frontier between what appears to be almost limitless needs on the one hand and an inadequate pool of resources to satisfy those needs on the other.

Social workers have a duty and responsibility to serve the community in which they work. From the data gathered during the empirical study and literature, assessments are at the heart of social work practice, being a process in which needs and risks are identified in order to construct and formulate a work plan, which will subsequently lead to the recommendation and identification of support services.

Literature supports the fact that time, or the lack of it, is one of the biggest barriers for social workers in their daily practice. Time challenges the quality and standard of social workers' practice and often leads to the loss of the opportunity to be reflective of their practice. Social workers might expect to be supported in their workplace and training to provide these services confidently, however, after qualifying many find it difficult to access these. Limited time meant also limited opportunity to build relationships with children and families. From the

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empirical study and gathered literature, it is clear that the majority of social workers' time is spent on different processes and procedures required in ensuring essential support services, recording of data on the local authorities' computer systems and trying to establish effective communication and working in a multi-agency setting.

From the empirical research and relevant literature, it is evident that social workers were found to have high levels of stress, anxiety and burn-out which is directly linked to a lack of knowledge, training and skills in the area of their practice, too high case loads and often unrealistic and optimistic expectations from parents to receive services. These services often do not exist or are difficult to come by due to limited resources and lack of funding from the local authority.

A social work qualification is a relatively generic degree in a field in which there are numerous specialities and sub-specialities and much training is needed. While social workers are able over time to become experts in their field, the lack of training means that they are often lacking in knowledge outside their particular speciality. However, as found in the research study, and already pointed out earlier, social workers often do not have the time to attend training courses.

With these barriers and obstacles social workers are faced with on a daily basis, it is extremely worrying that the focus of being concerned with achieving change in the lives of people who face difficulties, has shifted to the bureaucratic demands in social work.

4.3 THEMES AND CATEGORIES DERIVED FROM INTERVIEWS WITH SIBLINGS OF AUTISTIC CHILDREN

The following themes and categories (in bold) derived from interviews with siblings of autistic children:

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4.3.1 Theme: Siblings might experience feelings of social isolation

From the empirical study, it arises that some siblings of autistic children **experience bullying** from their peers. Ives and Munro (2002:95) stated that siblings are concerned about being teased and sometimes being bullied by other peers due to their siblings being different. Sibs (UK) explain that through their close relationship with the disabled child, siblings often experience prejudice, bullying, limited family activities and exclusion from mainstream activities. National Autistic Society (UK) states that younger people who have a sibling with autism might experience teasing from other children, lack of privacy, and disruption of home life and a feeling of resentment that the whole focus of the family is always on the person with autism.

Burke (in Burke, 2009) states that due to the disability within the sibling's family home, siblings might encounter social stigmatising experiences outside of the family home, which actually, in effect, disable them by association. Rao and Beidel (2009:439) explain from previous studies that siblings have increased levels of loneliness, depression, and more behavioural problems than siblings of children with no disorder.

Bägenhold and Gillberg (in Orsmond, Kuo & Seltzer, 2009:60) explain that siblings of children with an ASD were feeling more isolated and lonely than siblings of children with other disabilities. Richman (2001:126) explains that if siblings do not have the emotional or verbal knowledge and tools, they may not know how to cope and manage teasing from their peers.

The empirical study showed that some siblings experience **mixed emotions and feelings about having an autistic brother or sister**. Barbarin (in Mandelco, Olsen, Dyches & Marshall, 2003:369) argues that siblings experience anger, shame, shyness, or social isolation because they or their brother or sister are teased and/or embarrassed by others. This is a stigma usually associated with having a child with a disability in the family.

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Ives and Munro (2002:94) explain that siblings may even try and model themselves as the perfect son and daughter in an effort to compensate for a sibling they do not regard as normal. This correlates with respondent A, who stated, “... *that is because my brother was behaving so badly and I feel that I have to make up for it ...*”

4.3.2 Theme: Siblings' relationship with autistic brother/sister

From the empirical study, the researcher found that the siblings were affected differently and that the impact of the Autistic Spectrum Disorder varied on each sibling relationship with his or her autistic brother or sister. Munro (2002:94) states that the impact of autism on a sibling is much more demanding than with another disability, such as Down's syndrome. Richman (2001:135) explains that parents may find cultivating a positive sibling relationship a difficult task but that parents could help siblings to develop stronger sibling relationships through **teaching** the siblings about autism, creating a sense of equality, increase positive sibling interactions and relating to the siblings as individuals. Harris (1994:24) explains that the child with autism has less capacity to play with the normal developing child and that this may impact on the sibling relationship and that it also may require more caretaking from parent(s).

From the empirical study it became evident that siblings were arguing with each other and that some arguments turned aggressive. Feldman (1998:398) explains that **sibling rivalry** does occur and that it can be most intense when the children are of the same age and gender. He explains that parents can intensify this rivalry by being perceived as favouring one child over another. Harris (1994:77) states that research suggests mothers spend more time with a child with a disability than with a non-disabled child and that the difference in attention can lead to feelings of jealousy of other children in the family.

4.3.3 Theme: Siblings being target or victim of their autistic sibling's behaviour

From the empirical research it became evident that siblings are sometimes target and victim of their autistic brother or sister's behaviour. Marshall (2004:91) states that siblings of autistic children may be the target of aggressive outbursts. She further explains that aggressive

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behaviour is a distressing, yet typical aspect of autistic spectrum disorders (2004:72). Sibs (UK) explains that siblings can experience challenges that other children do not and that they regularly find themselves in situations that can be difficult to manage; situations such as dealing with a brother or sister's challenging behaviour. Harris (1994:18) explains that the child with autism may destroy toys, be aggressive, or have tantrums when approached by a sibling and, after consistent rejection from their ASD brother or sister, may give up trying to play with his brother or sister.

4.3.4 Theme: Siblings' understanding of autistic spectrum disorder

From the empirical research, the researcher found that the siblings had an **awareness** of their brother or sister's special needs and that they behave differently. Ives and Munro (2002:95) explained that if a child is well versed about autism, he or she is more likely to handle comments, questions and insults with confidence. Munro reiterates the important task parents have in finding time to tell their children and even though it may not be the first priority, it has to be addressed (2002:92).

Richman (2001:127) explains that in order for a sibling of an autistic child to be able to cope with feelings towards situations that may arise within the family or with their peers, parents have the task or responsibility to ensure that they explain to the sibling about their brother or sister's disorder. In doing so, this will eliminate any misconceptions, confusions and fears and instead provide the sibling with security, love and an understanding of their brother or sister's behaviour. Harris (1994:30) agrees with what Richman is stating, by explaining that the sibling might experience fear, which can be caused by ignorance, again, also stating the importance of a sibling knowing about their brother or sister's disorder, and in doing so, improving their own emotional well-being. Sibs (UK) explains that siblings deserve to get information about disability when they need it and that it is better to get the proper facts from their parents. It is explained that some parents get upset, in doing so, but much rather prefer their children to ask for information than to keep their concerns to themselves. Harris (1994:30) and Richman (2001:125) both explain that the sibling might not understand certain behaviour from the

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autistic brother or sister and they might not understand why their autistic brother or sister's bad behaviour might be tolerated, which will lead to them feeling angry.

The researcher found that half of the siblings **did not understand** why their parents treated them differently from their autistic brother or sister. Harris (2004:96) explained that, "Seeing the autistic child 'get away with' bad behaviour is likely to rouse fury in the mildest of children." Richman (2001:125) also explained that it may be difficult for a sibling to understand the nature of autism and why his or her brother or sister exhibits certain behaviours. National Autistic Society (UK) posts that children with autism can have challenging behaviour, or may not understand the consequences of their behaviour (hence they might do things that appear "naughty" to their brothers or sisters).

4.3.5 Theme: Siblings' relationship with their parent(s)

From the interviews with the siblings, more than half of the children wanted more time and attention from their parents. This is also evidenced in interviews with social workers in their involvement with siblings. Richman (2001:125) explains that siblings may feel that they are **not receiving as much attention** as the child with autism.

Ives and Munro (2002:91) state that where there is a child with a disability in the family, the balance of family life is shifted and interaction between family members has to accommodate this shift. They further argue that a child with special needs occupy a larger slice of parental attention compared with other unaffected children as they require more time and energy. Harris (1994:12) reiterates that parents should be aware of how important a role they play in supporting siblings of middle childhood as they help their children solve problems, comfort their distress and share a range of activities and interests.

Wing (1980:148) is of the opinion that the hardest thing for the sibling to deal with is to come to terms with the fact that they do not receive the same level of attention or amount of time from their parents, like their brother or sister with autism gets. Sibs (UK) states it is very common for siblings not to get enough time with a parent. Siblings grow up in a family where,

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regardless of the age of the sibling, the majority of family resources, parental attention, and professional services are directed, indefinitely, towards another child (i.e. the disabled child). Children and young people feel good if they get some special time each day with a parent. Siblings like parents to set aside time just to be with them. It makes them feel loved and cared for. Marshall (2005:89) explains that the siblings' adjustment is influenced by how positive the parents' attitude is.

4.3.6 Theme: Sibling's understanding of the role of the social worker

From the empirical research study it was found that the siblings **did not have an understanding** of what social workers and their roles were. One sibling thought that social workers provide tickets to adventure theme parks. As an explanation for the siblings' unawareness of the role of a social worker, the researcher wants to explain that the siblings involved in this research study were all from a middle class family. These families chose not to make use of government services such as Social Services and preferred to pay for services privately.

4.3.7 Summary

Relationships with a sibling are often the longest relationship in a person's life. Whether this is a good or a bad relationship, it will impact on a person's development. From the empirical research and literature it is clear that siblings of children with Autistic Spectrum Disorders (ASD) face a myriad of challenges in their lives. The empirical research, supported by literature, pointed out that siblings of ASD children were experiencing bullying and social exclusion from their peers which left them with an overwhelming feeling of social isolation. From the empirical research and literature siblings were found to have varying relationships with their ASD brother or sister, which varied from understanding their siblings' disorder and playing with them, to not understanding their ASD brother or sister's behaviour and being victim or target of their challenging behaviour. The empirical research showed that some of the siblings did not have an understanding of their brother or sister's disorder and did not understand the reasons for different reactions from their parents, stressing the importance

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and essential tasks parents have in ensuring that the sibling is aware of their brother or sister's disorder.

The empirical research supported by literature highlights the fact that siblings of ASD children do not enjoy the same amount of time and attention from their parents like their disabled brother or sister does. Considering the important role the parent of a middle childhood child plays in his or her life, it is crucial that parents ensure that they spend time with the sibling of the ASD child.

The fact that the siblings in this research study did not have an understanding of the role of a social worker did not make it a less important theme in the empirical research, as the siblings were mainly from a middle class family.

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CHAPTER FIVE

EVALUATION, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the researcher will discuss whether the aims and objectives of the study were attained and relevant. The recommendations in this chapter are based on the theoretical and empirical research undertaken in this study, as well as on the researcher's knowledge and experience as a social worker. The researcher will also draw conclusions regarding the information obtained in the study and provide social workers with strategies on the empowerment of siblings of Autistic Spectrum Disorder (ASD) children.

5.2 SUMMARY OF CHAPTERS

5.2.1 Chapter one: Introduction

The rationale for this study was explained in chapter one and the reader were orientated about the process of this planned study. The context of the problem was elaborated on and a formal problem statement was conducted as: "Social Workers are not equipped to deal with the difficulties siblings of autistic children were experiencing, as siblings of autistic children were disempowered.

The formulation of the problem lead to the research question, which was formulated as: How can social workers in the London Borough of Greenwich, United Kingdom be equipped to empower siblings of autistic children? The research question was answered through themes and categories, which were identified from the empirical study and compared with literature.

Aims and objectives were formed as a reaction to the research question and these aims and objectives served as guidance for this research study. The objectives were explorative and descriptive of nature. Unstructured interviews were conducted with social workers and

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siblings of Autistic Spectrum Disorder children to gain an understanding of the limitations and difficulties which prevented social workers from empowering these siblings.

5.2.2 Chapter two: Paradigmatic perspective for this study

Objective one

To provide a paradigmatic framework from which this study was conducted.

Chapter two focused on the paradigmatic perspective used for this research study. The research paradigm was a phenomenological Gestalt paradigm and the focus throughout this study was on the understanding (*verstehen*) as opposed to the explanation (*erklärung*). The paradigmatic perspective was presented through meta-theoretical concepts, theoretical assumptions and the methodological process in which the experiences of the social workers and the siblings were explored. The researcher used the meta-theoretical concepts which formed the basis of a holistic approach, namely:

- Phenomenological and existential perspectives;
- Gestalt and holism;
- Field;
- Here-and-now; and
- Awareness.

The researcher made use of the psychosocial developmental theory from Erikson, role theory and family systems theory as theoretical assumptions to guide her through the research process. Through the interviews with the respondents, the researcher worked phenomenological in that the researcher was aware of the respondent as an organism of Gestalt (the social worker's and sibling's environment of which they are part of and the different relationships within their environment); their awareness of themselves (how they perceived themselves, their situation, how they felt and how they responded to the dialogue between themselves and the researcher); their fields (being part of a family, school, work,

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community or culture). The researcher observed the respondents' reactions, responses, verbal and non-verbal communication to questions throughout the interviews. An example was when the researcher noticed one of the social workers smiling when asked about workload, to which the researcher explored this reaction by noting it and asking the social worker how she felt being asked about why she was smiling, creating an opportunity for awareness and being present in the here-and-now and encouraging the social worker to explore this response and feelings.

5.2.3 Chapter three: Empirical research

Objective two

To conduct unstructured interviews with social workers in order to enquire after difficulties they experience in empowering the siblings of ASD children.

Objective three

To conduct unstructured interviews with siblings of ASD children, in order to gain information regarding their needs for empowerment.

This study was conducted in line with the qualitative understandings of De Vos (2005). In this study, the researcher took the view to understand (*verstehen*) as opposed to explain (*erklärung*), social phenomena. The researcher wanted to explore the relevance and integration between concepts, theories and experiences of both social workers and siblings of autistic children. This placed the focus on this research on naturalistic observations, as opposed to controlled measurements and the use of the subjective benefit of the insider's view as opposed to the outsider's view as one finds in qualitative research. The researcher conducted individual unstructured interviews with six social workers and four siblings of Autistic Spectrum Disorder (ASD) children. Through the unstructured interviews and the transcriptions process the researcher was able to gain an understanding of the difficulties and barriers preventing social workers from empowering siblings of ASD children. Equally, the researcher was able to gain an understanding of how the siblings of ASD children experienced life with an autistic brother or sister (Chapter three). The researcher, as a social

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worker by occupation, had already formed a relationship with some of the respondents (social workers), as she previously worked alongside them. From this information it is clear that the researcher could not have a complete objective stance in the research and was somewhat subjectively involved with the research participants.

Despite the subjective nature of the research, objectivity was maintained through the Münchhausen-objectivity into this research to maintain objectivity as discussed in Chapter three. Trustworthiness in this study was established through external, rich explanations from the participants (cf. De Vos, 2005:346 and Lincoln & Guba, 1985:218). The data gathering techniques, namely basic individual unstructured interviews and observations gave rich understandings of the respondents being either a social worker or a sibling to an autistic brother or sister. Examples were attentive listening and making of field notes during these interviews.

The researcher achieved the goal of this study through the use of these techniques. The data analysis was achieved through generating themes and categories from the respondents' explanations (De Vos, 2005:336-338).

5.2.4 Chapter four: Literature control

Objective four

To conduct a literature control that served as support for the empirical.

In chapter four themes and categories which arose from the unstructured interviews with the social workers and the siblings (Chapter three – empirical research) were described and compared with existing literature in order to verify data/findings of this study. Through the unstructured interviews with the social workers eleven main themes were identified, to which some of them categories could be formed. These findings were summarised and these findings describe the difficulties and limitations social workers came across which prevented them from empowering siblings of Autistic Spectrum Disorder children. Furthermore, these findings suggested the needs of both social workers and siblings of autistic children.

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Below is a table with the main themes and categories from the interviews with both social workers and siblings of Autistic Spectrum Disorder:

Interviews with social workers	Theme	Category
	The role of assessment undertaken by social workers	<ul style="list-style-type: none"> • To identify risk and need • Basis for planning • Central in delivery of services
	Social workers feel that there is not enough time to complete their work and too many timescales and targets to be reached.	<ul style="list-style-type: none"> • Quality and standard of work • Opportunity to be reflective of their practice • Prevented them from building relationships with families
	Social workers experience limited resources and funding from the local authority to provide essential services.	<ul style="list-style-type: none"> • Follow different processes and procedures • Rely on support from charities
	Social workers experience a lack of knowledge, training and experience in Autistic Spectrum Disorder.	<ul style="list-style-type: none"> • Resourceful and knowledgeable of services • Training and knowledge

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	Social workers experience multi-agency working as difficult at times.	<ul style="list-style-type: none"> • Communication and understanding of different roles and responsibilities
	Social workers experience loss of acquired knowledge and skills.	<ul style="list-style-type: none"> • Specialisation and sub-specialities • Personal effectiveness
	Social workers experience problems with the local authority's computer system.	No categories
	Social workers have too many cases.	No categories
	Social workers experience high levels of stress.	No categories
	Social workers are aware of expectations from parents to receive support.	No categories
	Social workers don't spend enough time with siblings.	No categories

Table 5.1: Themes and categories arisen from interviews with social workers

Interviews with siblings of ASD children	Themes	Categories
	Siblings might experience feelings of social isolation.	<ul style="list-style-type: none"> • Siblings of autistic children experience bullying from peers. • Siblings experience mixed emotions about

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		their relationship with their autistic brother or sister.
	Sibling's relationship with autistic brother/sister	<ul style="list-style-type: none"> • Through teaching, the sibling will experience a more positive relationship with their autistic brother or sister. • Sibling rivalry
	Siblings being target or victim of their autistic sibling's behaviour	
	Siblings' understanding of Autistic Spectrum Disorder	<ul style="list-style-type: none"> • Siblings had awareness of their brother/sister's special needs. • Some siblings did not understand why they were treated differently to their brother or sister.
	Siblings' relationship with their parent(s)	<ul style="list-style-type: none"> • Siblings did not receive as much attention from their parent(s) as their ASD brother or sister.
	Siblings' understanding of the role of the social worker	No categories

Table 5.2: Themes and categories arisen from interviews with siblings of ASD children

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5.2.5 Chapter five: Evaluation, conclusions and recommendations

Objective five

To draw conclusions regarding the above and to make recommendations to social workers regarding strategies to empower siblings of ASD children.

In chapter five, the research process is drawn together through evaluation, conclusions and recommendations. The researcher looks critically at the research process to which she comes to certain conclusions. Recommendations are made with the view of future research and the limitations in this study pointed out.

5.3 CONCLUSIONS

The researcher concludes that the aim and objectives of the research study have been met. The exploration of difficulties and limitations preventing social workers from empowering siblings of autistic children has been completed successfully. The researcher believes that the research question has been answered through the data collected in the empirical study. The following conclusions were drawn from the empirical data collected during the interviews with the respondents:

- Social workers used assessments as a basis of planning to improve or change a situation. This is done gathering information and through the identifying of need and risk which will lead to recommendations for support services.
- Social workers' practice and the quality of service are affected by the lack of time in the sense that they do not have time to reflect on their practice and evaluate their practice. The lack of time has a direct impact on the opportunity to build relationships with siblings of autistic children.
- Social workers had to follow different processes and procedures to obtain funding and resources for support for families and the allocation of funding and services has always been restricted and governed by measurements such as "eligibility criteria", resulting in social workers relying on support from charities.

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- Social workers had to be knowledgeable of Autistic Spectrum Disorders and resourceful of available community resources as some social workers experienced feelings of insecurity and present as incapable due to the lack of knowledge, training and experience in Autistic Spectrum Disorders.
- There were definite benefits in working in a multi-agency profession, but this was often influenced by the lack of communication, information sharing with each other and knowledge of the various roles and responsibilities of other professionals.
- Specialisation (adult services and children's services), sub-specialisation (children in care and disabled children) and lack of time were often the causes of loss of acquired knowledge and skills and personal effectiveness.
- Social workers experienced frustration, disruption in the flow of their work, disempowerment and demoralisation due to the impact of local authority's computer systems as it is over-complicated, lengthy and does not always work.
- Too high case loads lead to lesser time with families with children with Autistic Spectrum, a general feeling of burn-out and the possibility of dangerous practice and unrealistic expectations of improved practice.
- All social workers experienced high levels of stress which not only affected their practice, but also their health.
- Parents were unaware or did not understand the limitations and procedures involved in getting support for their child or family, this often being influenced or misled by wrong information given to them by other professionals such as health professionals.
- Social workers were aware that they did not spend enough time with siblings due to a lack of time or by siblings not making themselves available during home visits by social workers.
- Siblings often experienced loneliness, bullying and teasing from peers and exclusion from mainstream activities which might make them feel socially isolated. They had mixed feelings about having a brother or sister with Autistic Spectrum Disorders and some siblings tried to compensate for their disabled siblings' bad behaviour.
- Siblings were affected differently by having an autistic brother or sister and the impact of ASD varied on each sibling relationship.

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- Siblings were the target of aggressive outbursts, destroying of toys or experienced constant rejection by the autistic brother or sister.
- Siblings had an understanding that their brother or sister had special needs but did not necessarily understand the diagnosis of ASD or why their parents were treating their brother or sister differently.
- Siblings did not receive the same level of attention or amount of time from their parents like their autistic brother and sister and they actually wanted more time and attention from their parents.
- Siblings from this research study did not have an understanding of the role of social workers, mainly because they were all from middle class/working families who chose to pay for services privately instead of using government services.

5.4 LIMITATIONS

This study has some limitations that warrant discussion:

- It would have been ideal to be able to interview more social workers who worked with families where there are Autistic Spectrum Disorder (ASD) children with siblings. This would possibly have produced more data which could have enriched this study even further.
- It would have been ideal to interview more siblings of ASD children. With only four participants, more participants would have provided a richer and fuller overview of their experiences of having an autistic brother or sister.
- The researcher obtained limited data and literature regarding the siblings' understanding of the role of social workers, which links with the above mentioned limitation. Given that the participants were all from middle class families, it would have provided a more holistic view if there could have been siblings from working class families and families who were receiving support from the local government.
- This research study was only conducted in the London Borough of Greenwich, London, United Kingdom. It would be interesting to see how much comparative

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information there would be should this research study be conducted in any other Borough of London.

5.5 RECOMMENDATIONS

The researcher recommends the following:

- The information from this study could be used as an exploratory, preliminary study with multiple angles to follow up on a larger more comprehensive sample.
- For any further research, the different cultures and classes families find themselves in, should be taken into consideration to ensure a comprehensive and diverse sample.
- Consideration should be given to holidays, time, work and family commitments when interviews are scheduled with participants of the study as this will influence the availability of the participants.
- Social workers should prioritise and schedule time for training in Autistic Spectrum Disorders as this will increase their level of knowledge and ensure that they have a good enough understanding of the disorder and in doing so, be able to support families better.
- More training in ASD will provide social workers with knowledge of local and national support services and resources available to families, siblings of autistic children and even professionals.
- Social workers should have the opportunity to read more about Autistic Spectrum Disorders as there is a vast collection of literature available in this field which will also allow them to be more sufficient and effective in their involvement with families. It will ensure that social workers are up to date with new research, literature available and government initiatives, etc.
- Social workers should have a greater understanding of how siblings are affected by having an autistic brother or sister and how every sibling would react or respond according to their developmental stage. This will ensure that social workers are more aware of and have an understanding of certain behaviours presented by siblings in different developmental stages, for example that siblings in their middle childhood

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value social friendships and peer relationships very high and how by having an autistic brother or sister could impact on this aspect.

- Social workers should become more focused on their own health, their personal limitations and their emotional well-being as this will influence their practice or be affected by their work, which will directly impact on the level of support they are able to offer to families.
- Social workers must become aware of the symptoms of stress at work and burn-out so that they can prevent this from happening or an escalation of this as this might lead to longer term consequences.
- Social workers should become more proactive in their awareness of their limitations and thus prevent burn-out.
- Social workers should continue striving towards an effective multi-agency working partnership as it ensures that the family receives a holistic support package from all agencies involved.
- Social workers should have sufficient support within the work environment, for example supervision or support from colleagues, as this will allow opportunities for critical reflection of their practice and improving of personal effectiveness.
- Social workers should use their employment trade unions in supporting them with the challenges they might face in the work environment as trade unions act as advocates for their members, listening to their difficulties and strive to bring about change – which in effect can change the way social workers are able to support families and siblings of autistic children.

5.6 CONTRIBUTIONS TO THIS FIELD

As social workers, the challenges, limitations and difficulties will always exist in the social work profession. It is important though, to have a better understanding and awareness of the impact these limitations and difficulties have on their role of empowering the sibling of an autistic child. This research contributes not only to the field of social work and autism, but also presents possibilities for future research.

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5.7 SUMMARY

From the information above, this research may have value in any community in London, United Kingdom and it may be used to support social workers and empower siblings of Autistic Spectrum Disorder children and their families. Valuable information came from this study in that the researcher managed to get an understanding of the experience of the limitations and difficulties preventing social workers from empowering siblings of autistic children. Furthermore, valuable information was gathered around the siblings' experience of having an autistic brother and sister.

The challenge, however, will be to take this piece of research and its information and put it into practice as it will mean that social workers may need to change their current way of practice. This might require and involve challenging and confronting the employer or the local authority they work for, which not every social worker is interested in doing. Parents play an integral part in their child's life in that they can influence the effects of an Autistic Spectrum Disorder on the sibling by ensuring that they give sufficient attention and amount of time to the sibling.

The researcher has found this research study enlightening and very rewarding in the sense that she has been able to offer herself as a source of support or "sounding board" for social workers and siblings, giving them the opportunity to express their opinion, wishes and feelings. It is the researcher's wish that this study of limited scope could be of value to any future research.

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ADDENDUM: A

Participant's name: _____ Date: _____

Researcher: _____

Informed consent

1. Title of study:	STRATEGIES FOR SOCIAL WORKERS TO EMPOWER SIBLINGS OF AUTISTIC CHILDREN
2. Purpose of this study:	The aim of the study is to determine the needs of social workers in order to equip them to better support my child who has an autistic sibling.
3. Risks and discomforts:	Possible risks or discomforts associated with this project have been discussed with me.
4. Benefits:	I understand that there are not as yet known direct to my child for participating in this study. However, the results of the study may help researchers to gain a better understanding of whether social workers can be better equipped to support siblings of Autistic children.
5. Participant's rights:	My child may withdraw from participating in the study at any time.
6. Confidentiality:	I understand that the results of testing will be kept confidential unless I ask that they be released. The results of this study may be published in professional journals, but the child's records or identity will not be revealed unless required by law.

I understand my child's rights as a research subject, and I voluntarily consent to his/her participation in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Parent's signature

Date

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ADDENDUM: B

Participant's name: _____ Date: _____

Researcher: _____

Informed consent

1. Title of study:	STRATEGIES FOR SOCIAL WORKERS TO EMPOWER SIBLINGS OF AUTISTIC CHILDREN
2. Purpose of this study:	The aim of the study is to determine the needs of social workers in order to equip them to better support children who have autistic siblings.
3. Risks and discomforts:	Possible risks or discomforts associated with this project have been discussed with me.
4. Benefits:	As a social worker I will have the opportunity to raise my concerns, difficulties and also provide suggestions and advice which could inform this research study.
5. Participant's rights:	I may withdraw from this study at any given point during this research study.
6. Confidentiality:	I understand that the results of testing will be kept confidential unless I ask that they be released. The results of this study may be published in professional journals, but the child's records or identity will not be revealed unless required by law.

I understand my rights as a research subject, and I voluntarily consent to my participation in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Social worker's signature

Date

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ADDENDUM: C

INTERVIEW WITH RESPONDENT A

Researcher: Hi, thank you very much for seeing me this evening; I think you are really brave for doing this.

Respondent A: That's ok; I just reckoned that you need to hear the story from different parts of the family, as I know that my sister will be quite negative about my brother.

Researcher: OK, so could that mean that you are not negative towards your brother?

Respondent A: Yes, I am quite good friends with my brother and I feel that I understand him more.

Researcher: When you say you are friends, what does this mean for you?

Respondent A: I mean that I think that if my brother did not have autism, (Aspergers' Syndrome) he would not have so much to do with me. We do things together, which is fun sometimes. I like to do things with him, sometimes we go to the Avery Hill Park and watch some 24 years old play football and when they miss the ball we call them "gimps" and leg it (we quickly run away).

Researcher: It sounds like you ARE having fun with your brother.

Respondent A: Yes, I am and then during the summer we will go to the park, play outside and be adventurous but during the winter we will stay at home, play on the computer, games and with our animals. We will sometimes go to Sainsburys' supermarket and buy sweets and come back.

I find my brother's behaviour quite funny some times, he like to act as a prostitute which is quite a paradox, because he has the brain of a nine year old and he acts like someone who is doing something which you have to be much older to do.

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Researcher: It sounds like you are doing a lot of things with your brother?

Respondent A: Yes, I am but even though he is older than me he has the brain like of a nine year old boy, so I am sometimes taking the lead in some games.

Researcher: Does your brother mind you taking the lead in some games?

Respondent A: No, not really. He will hit me sometimes but I will just get out under his grip and just run away or go to the bathroom and lock myself in there and when I'm sure he is gone, I will go out.

Researcher: What do your parents do if they find out that your brother hits you?

Respondent A: I think we are sometimes split in the middle, my brother, me, mum and dad and then Elizabeth and the younger two

Researcher: What do you mean with this?

Respondent A: He doesn't get on or like Elizabeth at all and she always gets the worst part of his moods. He will tease her and will treat her really bad. I feel sorry for her sometimes and I try to make it better, but sometimes I will be nasty and horrible to her to as I think people should not treat my brother badly as he has a disability.

Researcher: Do you think your brother is treated differently then?

Respondent A: Yes and my brother does not want to be treated as if he has a disability. It is so mild that you would not even know he has it until he starts behaving badly or is in one of his Aspergers' moods again.

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Researcher: But it sounds that your brother is treating people, especially his family members differently, is that right?

Respondent A: Yes, my brother thinks the two younger siblings are demons and he really does not like them. He will sometimes be nice to our little 4 year old sister.

Researcher: So, when your brother is not nice, what happens?

Respondent A: When he is horrible and nasty, I try to make things better in the family, like if my brother is behaving badly I will try and cheer everybody up by being really lively and funny. I feel that I understand him more and sometimes have to be good even more to make up for his bad behaviour.

Researcher: Surely your parents don't expect you to make up for your brother's behaviour?

Respondent A: No they don't, but I have to explain to my family sometimes to give my brother time to calm down or make things right after he has been bad, they can't just go up to his room and immediately start screaming at him, they have to give him some time.

Researcher: It sounds like you know your brother really well?

Respondent A: Like I said, I know when my brother comes down for tea, a drink or to have a shower, that he is in a bad mood. But he will only like scream or say something and everyone will just be like quiet for a few seconds afterwards. Then mom or dad would say, right, that is how the day is going to be.

Researcher: OK. Could you tell me a bit more about yourself, what would you like to become one day?

Respondent A: Well, my dad is a neurologist and my mom a gastroenologist
I would like to become a neurosurgeon one day

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Researcher: That is very interesting.

Researcher: So, what do you do when you have some free time in the afternoon or during the weekends or holidays?

Respondent A: I sometimes go out with my friends but if I can't I stay at home and help out in the family. They've noticed tonight that I have been helping out more but that is because my brother was behaving so badly and I feel that I have to make up for it. Our au pair has given notice and we did not expect it. We are quiet anxious about it and that means that everyone should help out a little bit.

Researcher: Your parents must be really proud of you? So, when you've finished helping out in the house, what do you do next?

Respondent A: Well, I like basically the same things as my brother, like computer games, video games, watching telly or movies and keeping myself busy with things. I like to read and listen to music too. If I have a bad day, I would be horrible to my sister or anyone but will just go to my bedroom until I feel better.

Researcher: That sounds like you know what to do to control you bad or angry feelings.

Respondent A: I feel that I have to keep the balance in the family and I feel that it is my role to make sure that people don't treat my brother horrible because he has Aspergers' and does not understand why people might treat him differently.

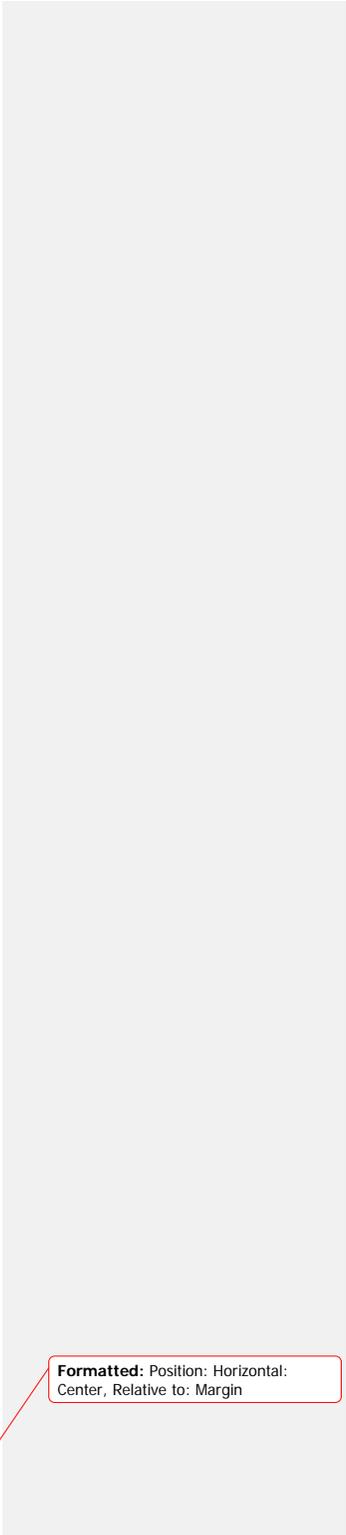
Researcher: Can you remember when any Social Workers visited your family or helped your family?

Respondent A: No, but my brother was once offered a ticket to go to Thorpe Park from Mencap but did not want to go as he does not like to be around other people with disabilities as he does not think that he has a disability.

Researcher: Let's talk about the different roles you play in you family

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Respondent A: When my brother is horrible to Elizabeth I will sometimes be nice to her to make her feel better; I suppose I am sometimes the healer.



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ADDENDUM: D

INTERVIEW WITH RESPONDENT 3

Researcher: Hello, thank you for seeing me this afternoon.

Respondent three: Good to see you Cindy and my pleasure.

Researcher: As you can remember when I asked you for this interview, I would like to gain a better understanding into the social worker's experience of working with sibling of Autistic Spectrum Disorder (ASD) children. Can you please tell me more of your experience?

Respondent three: Yes.

Researcher: Thank you. I understand that you have had a lot of involvement with families where there is an ASD child and where the families were in need of support?

Respondent three: Yes, I have carried out quite a number of core assessments on families where support was needed.

Researcher: Can you tell me more about the core assessments you referred to?

Respondent three: Yes, basically, the core assessment is a problem focused assessment where there is a problem, a diagnosis, and then support . When the local authority receives a referral requesting support for a family, it is the local authority's duty to assess the situation and make appropriate recommendations.

Researcher: Ok, so can you explain to me how you, personally, carry out these assessments?

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Respondent three: I would arrange to meet with the whole family and might spend 2 or 3 visits to obtain information, which will help the assessment. I will get consent from the parents to contact all parties – normally support agencies - in order to gain more information about this family.

When I visit the family, I will firstly look at the family composition, the roles and relationships within each family and how this family function on a daily basis.

Researcher: What is the reason for doing this?

Respondent three: By looking at how the particular family functions, you gain better understanding on the different relationships parents have with their children, sibling relationships and the relationships this family has with agencies and other people outside the family. I used the Ecomap, which is a social work tool to identify internal and external relationships. This will show how the family works in partnership with different agencies and organisations, whether they need support or guidance and how they can become it.

Researcher: Could you elaborate a little more about external support?

Respondent three: Yes, it is support from agencies outside the family in the community. This might be the health agencies, education department, benefits agencies, housing department and community charities. During the process of conducting the core assessment, I look at how these families access local support and how integrated the family is in their community.

Researcher: Is that important?

Respondent three: Yes, it is very important.

Researcher: Can you tell me why?

Respondent three: It is important to identify whether the parents are meeting the needs of the child, whether the child is disabled or not. The basic needs of the child will be health, care, developmental and educational needs ,it is important that parents take responsibility in ensuring that these needs are

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met, if needed with necessary support. From the recommendations, it will not always be social services or children's services providing the support to the family but rather a charity, which might be able to support family better.

Researcher: Do you spend time with each family member when you complete these assessments?

Respondent three: No, even though I will ask the parents to ensure that their children are present when I visit as it is a prerequisite to see them, the siblings of the ASD child do not always make themselves available. I will try and engage them in the conversation, but it will never be to the extent where I can establish their perspectives, views and feelings extensively.

They will often be advocated for by their parents, who really just want support with their disabled child or a break from the caring for their disabled child.

Researcher: What kind of information will the parents then give with regards to the siblings?

Respondent three: They will give you basic information such as how the child is doing in school, whether the child helps with caring for his or her disabled sibling and how they think the child is coping. Most of the time, the parents' focus is on the disabled child.

Researcher: Can I then assume that not enough time is spent on the sibling of the ASD child?

Respondent three: Yes that is often the case.

Researcher: What do you think is the biggest struggle for the sibling of the ASD child?

Respondent three: I think that the sibling is often being made "disabled" by not having the opportunity to develop their social skills and relationships as a child without a disabled sibling would be able to do.

Researcher: What do you mean by this?

Respondent three: It is often the sibling who helps out with the care of the ASD brother or sister and, in doing so, they become young carers and will then lose the opportunity to develop social

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relationships, which will affect their social communication and development. Their free time will be used to help care for their disabled sibling whereas the child who does not have a disabled sibling and their age, will be accessing community activities, building friendships and relationships and will therefore develop their social skills.

Researcher: Do you sometimes feel that these families were supported appropriately and the right support was offered to the families?

Respondent three: Well, no, not always, as it is not always possible to fund and ensure the support they need. Equally, there are not always enough local resources available, if the local authority is not able to fund certain services.

Researcher: Knowing this, how does this affect you?

Respondent three: I feel frustrated at times. It feels at times like a conveyor belt service where the assessment is completed, if needed, presented to a funding panel to get support for the family. If not, referrals are made to community services or charities and the case is closed and then only reviewed 6 months down the line.

Researcher: You have already identified some struggles and difficulties you have as a social worker. Can I ask you to think of what makes it difficult for you carry out your work to the standard in which you would like to be able to do? And what do you think could possibly help to change this?

Respondent three: Working for the local authority, there is targets to be reached, such as timescales to complete these assessments, timescales to ensure that a support package is presented to a funding panel and then of course there is the local authority's computer system and data base which requires a lot of paperwork and computer forms are processed which will be used as performance indicators.

Parents must be focused on not only their disabled child's needs, but also the singling of their disabled child's needs. Parents' understanding of how the sibling of the ASD child's life is affected.

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Social workers must know their resources available and know how to link the families with the community resources.

More time to complete these assessments carefully, more time must be spent with the whole family in order to produce a detailed assessment.

Researcher: Thank you for this very valuable information. I appreciate your time and willingness to allow me to interview you.

Respondent three: My pleasure Cindy.

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