

The experience of mothers of children with autism:

A hermeneutic phenomenological study

by

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Abstract

Mothers of children with autism experience their life as a never-ending struggle for their children. Whereas 'normal' children mature and grow out of the parental nest, autistic children remain under the care of their parents for as long as the parents are able to sustain them. The purpose of this study was to explore the experience of mothers of autistic children and gain new perspectives of how parents and professionals work together. Data consisted of transcripts from in-depth interviews with ten Icelandic mothers of children diagnosed with autism. The mothers all participated voluntarily and their age was from thirty four to forty nine years of age. The methodology used in the study was hermeneutic phenomenology building on Gadamer's philosophy and van Manen's description of thematic analysis. In the study the emerging themes of the transcribed interviews were grouped into five categories based on the discussions of the five overriding topics. These topics were; becoming a mother of a child with autism; coping and taking care of self; the father of the child; where to seek help; and the need for support from professionals. The results are described using quotations from the participants. The findings revealed that the participants experienced themselves as being alone in the period of the discovery of the child's handicap, because other people did not see the same as they did. Even though the participants saw their role as caretakers for their children as a never-ending responsibility they all saw the importance of taking care of themselves as well. The participants' experience of chronic sorrow, anger and empowerment is consistent with research literature. Outstanding in this study was the participants' descriptions of how their love for their children was rewarded in the way they learned and grew through the experience of having these special children. The participants use of humour became evident and was an important and spontaneous part in the dialogues. The study indicates that the participants experienced a difference in how themselves and the fathers' felt and responded

towards their autistic children. Based on the findings it is concluded that professionals working within the autism sector need to be more caring in their relationship with parents and to show more respect for the parents' expertise about their children and about autism. Collaboration built on mutual understanding and respect between parents and professionals is needed when forming intervention programmes.

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Chapter 1 Introduction

1.1 The background of the study

The phenomenon of interest in this study is how mothers experience their life with a child who has been diagnosed with autism. I first learned about autism when I as newly graduated psychiatric nurse worked (1977) at the Child and Adolescent Psychiatric Department of the University Hospital in Iceland. The autistic children fascinated me, with their peculiarities and unusual responses to their surroundings. They were hard to understand and they did not seem to understand what went on around them. They were like foreigners in their own country. To understand and to be able to help them was a real challenge.

Working with parents of children with autism I soon gained respect for their patience and how they seemed to enjoy every step forward in their child's development, however small it was. Furthermore, it was important for them to gain new understanding of their child's behaviour. Then as now the mothers were the professionals' primary contact with the families (Bristol, 1987; Milgram and Atzil, 1988). Since I first met these mothers I have wondered how they managed to cope inspite of the lack of support from the community and how they fought for the rights of their children. At that time people with autism were institutionalised but those mothers did not want their children in institutions.

Professionals and parents of children with autism have been working side by side for many years but not always as equals. Books written for parents and professionals that work with people with autism have to my knowledge, mostly been guidebooks, that show how to manage people with autism and to understand the condition. However, many professionals understand the importance of collaborating with parents. For instance Schopler (1995) who

emphasises the importance of taking into consideration parents perspective when formulating treatment programmes and research studies.

1.2 Purpose of this study

The purpose of my study is:

- 1) To gain a deeper understanding of mothers' life with a child with autism.
- 2) To explore mothers' experience with professionals, especially nurses that often are the first professionals' mothers turn to.

The reason for focusing on mothers as participants in this study is my own experience of them as the primary contact with professionals and the result of my literature search. Nevertheless, I am aware of the importance of understanding the feelings of both parents. In the process of literature search and in the interviews it became apparent that the parents experienced the situation differently. Although interesting, this phenomenon is not the subject of the current research project.

1.3 The research question

The research question: 'What is it like being a mother of a child with autism?' has been forming throughout my collaboration with mothers of children with autism, especially when working as a Home-visiting nurse. I am still (in the year 2002) working with mothers who have children with autism and I have many questions to ask. How are mothers coping? Is collaboration with professionals important? Is knowledge of autism important? Is it important for mothers to feel valued for their knowledge of their child? Parents of people with autism have to fight for their children's right in society. How does this fight influence mothers? These and other questions were the main issues in the interview guide used in this study and they show my prejudgement and assumptions of the phenomenon (Appendix 4). Other questions arose during the interviews with the mothers and by analysing the text.

1.4 Methodology

Hermeneutic phenomenology was the chosen approach in this study. Hermeneutic phenomenology gives the opportunity to gain understanding of an experience lived by another person by listening to that person in a dialogue and interpreting what the other person tells in a written text. Koch (1998) asked if telling a story could be research and she suggests that Gadamer's philosophical hermeneutics is a methodology that instead of telling the researcher what to do tells one to ask what is going on in the research. Then the researcher by listening reading and writing can give a new perspective of a lived experience. Gadamer (1998) claims that hermeneutic phenomenology gives the researcher an opportunity to discuss openly ones assumptions in the dialogue with the participants. Thus I was able to discuss my pre-conceptions of the phenomenon in the dialogue with the participants. Van Manen's (1997) approach to data collection and his description of analysing the data were used in this study and he explains data collection and data analysis in hermeneutic phenomenology as a way to gain understanding of others' experiences.

1.5 Significance of the study

The wellbeing of every child depends on how its parents adapt to their life situation. Having a child with developmental or physical difficulties is a strain on parents that influence the function of the whole family (Konstantareas and Homatidis, 1991; Teel, 1991). In my literature search I found more studies conducted on stress factors in parents' life than on parents' ways of adaptation and coping. This study will focus on gaining understanding of the emotional processes mothers go through from the time of their first worry about their child and what resources they use in their life with their autistic child. Furthermore, the aim is to explore parents reported experience of disrespect in the relationship between parents and professionals (Herman, et al., 1996). This study conducted by using hermeneutic phenomenology will give nurses and other professionals

insight into mothers' experience of having a child with autism. Furthermore, it can give a better understanding of what mothers of autistic children consider as the most important attitude from the nurses and other professionals they meet in their search for help and service for their child.

1.6 Limitations of the study

Turning only to mothers in this study is a limitation because a child has two parents, the mother and the father. Nevertheless, I have already explained the reason for this and that is my experience of the mothers' role in taking care of their child with autism. Another limitation is that the interviews were conducted in one language, Icelandic and later translated and presented in another, English and this could be considered as a limitation because of the danger of losing important meaning in the translation.

1.7 Definitions of concepts

The readers of this paper are asked to notice that;

**a child with autism and
an autistic child**

is used intermittently in this study. Although those two phrases should be taken to mean the same, the preferred use will be; 'a child with autism'. The reason for this is best worded by a participant in the study.

'I respect and love my child as a person and I want other people to do so as well, he is not and autistic child he is a child with autism, can you see the difference?'

Diane

1.8 Summary

In this chapter the background, my interest and pre-conceptions of what it is like to be a mother to a child with autism have been explained. This study is conducted to gain an understanding of the feelings the participants' experience in their situations as being a mother to a child diagnosed with autism. Furthermore, to explore how the participants experience their relationship with professionals. Such understanding can help nurses and other professionals to establish co-operation in the future. Using hermeneutic phenomenology in the study gives me an opportunity to reveal my preconceptions in the dialogue with the participants. My preconceptions are built on my clinical experience as psychiatric nurse and counsellor for parents and their children with autism for many years.

Chapter 2

Literature review

In this chapter I will explore the literature on autism and the experience of mothers/parents who have a child with autism or other chronic disabilities, by referring to studies that have been conducted on these phenomena. Then I will proceed to explore the phenomena chronic sorrow, coping and empowerment because those are phenomena that I have observed in my work with mothers who have children with autism and this review will be lead by my pre-understanding of those phenomena. I will, furthermore, explore studies of interactions between parents and professionals to gain a better understanding of parents' perception of co-operation between parents and professionals.

2.1 Autism

Autism is a fairly rare condition and to show how rare autism is Gresham et al. (1999) compared it to other difficulties and their study showed that learning disabilities are fifty times more common than autism and autism is five times more common than childhood cancer.

Autism is a developmental disability characterised by difficulties and abnormalities in several areas: communications skills, social relationship, cognitive functioning, sensory processing and behaviour. The guidelines published by the World Health Organization (WHO, 1992) for the diagnosis of autism include the following symptoms as the diagnostic criteria:

- The developmental abnormality is apparent before the age of three.
- There is always qualitative impairment in reciprocal social interaction as socio-emotional cues, lack of response to other people's emotions and lack of socio-emotional reciprocity.

- There is qualitative impairment in communication in form of use of the language skills they have and lack of social imitative play.

Autism is also characterised by restricted, repetitive and stereotyped behaviour (WHO, 1992). Numerous publications have been presented on autism. The first published study of autism was conducted by Kanner (1943). He stated: 'since 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits-and, I hope, will eventually receive-a detailed consideration of its fascinating peculiarities' (p.217). In the same report Kanner (1943) reported that his 11 'patients' came from intelligent and well-educated parents and furthermore he argued that 'one other fact stands out prominently. In the whole group, there are very few really warm-hearted fathers and mothers' (p.250). Initially autism was regarded as a psychopathological condition due to the relationship between child and parents. Later the focus shifted towards a developmental explanation due to the neurobiological function of the brain (Gilberg and Peeters, 1995). The prevalence of autism in Iceland is comparable to other countries and a study conducted by Magnússon and Sæmundsen (2001) showed that among children born in Iceland 1974-1983, there were 3,8 cases of autism per 10,000 children borne alive. Respective figures for 1984-1993 showed the prevalence to be 8,9 per 10,000 children borne alive. The consequences of this increase in number of children diagnosed with autism have been that the service in Iceland can not cope with the need of the children and their families (Magnússon and Sæmundsen, 2001).

2.2 Parents of children with chronical illness or other disability

Parents look forward to the expected birth of a child as an exciting event and plan for the future. When the child turns out to be disabled the parents experience a serious strain in the child-parent relationship by the energy

consuming demands of taking care of a new child and the recognition of the additional care that their child will need in the future. Furthermore, there will be the psychological strain in accepting a child that is not going to be the child the parents' had hoped for (Konstantareas and Homatidis, 1991; Teel, 1991; Krafft and Krafft, 1998). Krafft and Krafft (1998) furthermore, discuss the parents loss of opportunity to satisfy their own personal needs such as enough sleep, time for other children in the family and themselves or the couple together without their children. Furthermore, not having sufficient support, approval or reward for their hard work. Transition is a process in person's or a family life that occurs when ones life moves from one phase to another. This move can be followed, either by personal growth or the feeling of being stuck within the former norms of the family. Thus not being able to go on from one stage to another with new rules within the family. For instance a birth of a child changes the rules in the family (McCubbin, 1999). Mothers' and fathers' of children with mental illness have different needs for expressing feelings such as sorrow, in addition they have different views of how the illness affect the family-life. Furthermore, sorrow can change persons and hence the whole family situation is bound to change (MacGregor, 1994).

In Kristmundsdóttir's (1998) study of the experience of parents living with a child diagnosed with borderline personality it was indicated that parents felt that professionals and other people that were in contact with them and their child needed to be more familiar with the illness their child suffered from. Moreover, it came apparent that there is a need for professionals to be aware of and have understanding of the needs of their clients and their family members when forming the service. Researchers have shown more interest in the stress factors in the live of parents of disabled children than in how they cope. (Beresford, 1994). Researcher should focus on exploring how parents cope instead of only

exploring the stress in the upbringing of a disabled child and models and theories should give 'insight of the dynamics of family life and ways families react in times of stress' (Beresford, 1994, p.172). It has been indicated in several studies that mothers are the main caregiver of children with different disabilities (Bristol, 1987; Karlsdóttir et al., 2001). In a study conducted by Karlsdóttir et al. (2001) the mothers of adolescents with Crohn's disease were mainly responsible for the care of their children. Even though the fathers took relatively small part in the main care of the children the mothers' saw the fathers' being the strongest support. The mothers' worried about their child's future and that they would not be there to take care of their child. In addition they mention the need for more information and education about the disease in the beginning when the diagnosis was new to them (Karlsdóttir et al., 2001). Most of the mothers in Karlsdóttir et al. (2001) study were members of a patient organisation and felt supported by that, nevertheless, they felt sometimes the need to talk to a professional with knowledge about the disease and how it affects the patient and his whole family.

2.3 Mothers of children with autism

Being a parent of a child with autism was not easy in the time of Kanner's (1943) explanation of autism when parents were blamed for the child's condition. When the focus shifted towards a developmental explanation the parents felt that their sense of blame for their children's condition was somehow eased and those parents particularly welcomed this shift in focus. It is often difficult to understand the feelings of parents with a child with autism and this following quotation is one way to describe autism and a mother's feelings towards her child that is suffering from autism:

*Why does he never look me in the eyes
with love and affection? Why does he laugh when I cry,
instead of crying with me or asking why I am so sad?
Why is he so nice to me when I have a red ribbon in my
hair, and not when I am wearing a blue one? When he
cries and I want to comfort him and cuddle him in my lap,
it just makes everything worse'.*

(Gilberg and Peeters, 1995, p.2)

Our understanding of autism has changed and professionals' knowledge about the importance of co-operation has increased. Nevertheless, I ask myself whether this increased knowledge is helping professionals to show consideration to parents and their worries? When I began working with children with autism and their parents in 1977 Kanners' (1943) view of the parents of children with autism was a part of the professional attitude towards parents and still can be. A mother told me of a professional's attitude when she asked for help with her worries of her child's behaviour. The professionals answer was: 'You have to be firmer with your child', and that remark was followed by a pat on the parent's shoulder (A mother, personal conversation, 2000). In the book 'There is a boy in here' (Barron and Barron, 1997), Judy Barron, the mother of Sean Barron, a boy diagnosed with autism at the age of four, describes how professionals treated her and her husband with no respect and an arrogant attitude. Not giving them much hope for their boy's future when he was diagnosed with autism. They were told it would have been better if he had been blind. She goes on describing the emotions she and her husband experienced in the fight for their boy: anger,

disappointments, patience, aggressions, ignorance, fear, anxiety, helplessness and humour (Barron and Barron, 1997). Milgram and Atzil (1988) conducted a study on the stress that parents experience in raising children with autism. Their findings showed that clinicians' main aim was to help parents to do better with their child with autism and only secondarily and incidentally it was their aim to help parents to achieve personal satisfaction. However, there is a growing attention to the risk parents themselves run of suffering psychiatric and stress disorder. Parents of children with autism experience more stress than parents of children with other kinds of developmental disabilities (Bristol, 1987; Dunn et al., 2001). Furthermore, interaction between parent and a child with autism appears to be more stressful than between a child with Down's-syndrome and the parent (Kasari and Sigman, 1997). However, research and clinical evidence show that many families of children with autism and other handicapped children adapt successfully and function well (Bristol, 1987). It has great clinical significance to know what it is that helps the mothers to adapt successfully and in this study I intend to explore what helps mothers of children with autism to adapt successfully.

According to Bristol (1987) early diagnosis of autism, followed by parent education and information about autism and available service is important to minimise marital problems and parental difficulty in understanding their child's behaviour and for adaptation to the family situation. At the time of Bristol's (1987) study professionals seemed to be aware of the importance of adequate social support and information for parents of children with autism when trying to adapt to the strain of having a child with a handicap. Nevertheless, there seems to be little change in the last decade in the situation of families with children having autism. The only change is that the children are referred earlier and the diagnosis exists at an earlier age (Smith et al., 1994). Smith et al. found that parents had the same experience of little support and lack of appropriate help from professionals as parents had experienced ten years ago. When parents

searched for help they were told 'not to worry' and there seems to be the same danger of misdiagnosis. The burden of the care of disabled children is usually unequal between the mother and the father (Bristol et al. 1988; Miligram and Atzil, 1988) and is most often the responsibility of the mother. Miligram and Atzil (1988) argue that this is the accepted norm in most societies and I believe that is the perspective of the role of the mother in Iceland.

2.4 Chronic sorrow, coping and empowerment

To get a better understanding of mothers'/parents' feelings, that have a child with autism, these three following concepts will be explored, chronic sorrow, coping and empowerment. The reason for my interest in those concepts is relying on my experience in my work with mothers' of children with autism and my pre-judgement of the subject of mothers' experience of having a child with autism.

2.4.1 Chronic sorrow

Chronic sorrow, as described by Olshansky (1962) is a normal response to a painful experience such as learning about a child's chronic disability. This concept was used by Olshansky in a study of the experience of parents of retarded children and later it has been used to study other chronic disabilities (Phillips, 1991). Sorrow is a feeling of sadness experienced at the time when for instance parents receive the diagnosis of their child's difficulty. For the feeling to be chronic there has to be at least one relapse to this feeling of sorrow (Mallow and Bethel, 1999). In their study of chronic sorrow Mallow and Bethel, (1999) found a difference in how and when mothers and fathers of chronically ill children experienced the most painful feelings. It became apparent that the relapse, from the feeling of acceptance of the child's condition, to this feeling of sorrow was experienced at different moments in the life of the parents. The mother's experience was related to caring, seeking information about the condition of the child and when seeking help for her child. On the other hand the father's

moments of sorrow were more focused on the overall need of the family. Because of this difference there is a need to develop different strategies for mothers and fathers to help them to care for their disabled child (Mallow and Bechtel, 1999; Knafl and Zoeller, 2000).

Health care professionals and other professionals working within the health and social service need to be familiar with the natural process of the sorrow parents go through when their child is diagnosed with mental illness. It is important for parents to be able to start to rebuild and move forward in that process. This needs to be accepted and recognised by these professionals by offering co-operation and information of the treatment process (MacGregor, 1994; Eakes, 1995; Krafft and Krafft, 1998).

2.4.2 Coping

Coping is defined as cognitive and behavioural efforts to manage, reduce or tolerate both external and internal demands that are impeded on a person and the outcome is dependent on the persons ability to overcome the situation (Lazarus and Folkman, 1991). People use different methods to cope with a difficult situation. To explain how people react in painful situations Lazarus and Folkman (1991) use concepts such as positive reappraisal, confronting coping and escape avoiding. Dunn et al. (2001) explain positive reappraisal as personal growth and finding new faith, furthermore, it is the feeling of being creative and being able to find new important issues of life. Fighting for the child's rights, taking chances, expressing anger, finding ways to express feelings are a way of coping that is regarded as concepts of confrontive coping (Dunn et al., 2001). Such as a mother who can use her anger and express her feelings when she has to fight for her child's right to attend regular school classroom instead of being in special class for handicapped children (See 5.2.2). Different coping styles may lead to different results. For instance parents' use of escape avoidance and

distancing is correlated to increased depression and spousal difficulties. However, positive reappraisal, confronting coping and seeking social support increases well being (Dunn et al., 2001). Programmes have been developed to help parents to adapt to difficult situations, one is the COPE program (Creating Opportunities for Parent Empowerment) for hospitalised critically ill children and their parents. The programme emphasises how important it is for nurses to take into consideration the whole family circumstances and feelings. The aim of this individualised programme is to help parents to take an active part in the child's care and by that be better able to cope in a difficult situation (Melnik and Alpert-Gillis, 1998).

2.4.3 Empowerment

The process of empowerment is explained as the ability to adapt to one's situation and to have control over one's life (Gibson, 1995; Dunst and Trivette, 1996). Mothers of chronically ill children experience empowerment as a process of learning to assert themselves as an important link in the care for their children and to see themselves as advocates for their child in negotiation with the health care professionals. Parents need to see themselves as advocates for their child and to be recognised as the person that knows the child best even though the professionals have more knowledge of the diagnostic criteria. Most important for the mothers is to hold on, even though they recognise 'feelings of disappointment, frustration and anger' (Gibson, 1995, p.1207).

Relationship, co-operation, respect, personal and honest support and exchanging information is an important attitude from 'helpers' (nurses and other professionals) working by family-centred care. The way 'helpers' can improve their work with families is by constantly and critically reviewing their relationship with the families for the purpose of strengthening competency of the parents instead of confirming their role as dependent on professionals (Dunst and Trivette, 1996). Parents of handicapped and chronically ill children experience

empowerment by taking an active part in a support network with professionals, by co-operation, and by networking with other parents (Herman et al. 1996).

2.5 Parents relationship with professionals

Communication between professionals and parents is crucial for the acceptance of diagnosis for parents of severely handicapped or physically disabled children. It is important to give information of the child's diagnosis and show sympathy and understanding of the parents' situation. Meeting parents in such a way and building trust between parents and professionals can reduce the parents' anxiety. (Quine and Rutter, 1991). Parents' experience of the process of presentation of the diagnosis of severely handicapped children is likely to involve phenomena as grief, shock, denial, anger and chronic sorrow, followed by adaptation and adjustment (Quine and Rutter, 1991). In Kligour and Fleming's (2000) action research it became apparent that the parents experienced feelings of vulnerability because of self-blame and being blamed for the behaviour of their child. The parents in their study experienced a feeling of powerlessness in managing the child and of being degraded by professionals and other people they came in contact with, because of their child's disability. However, Kligour and Fleming's (2000) study showed that parents experienced other feelings as well and those were the feeling of power, reflection and autonomy. Kligour and Fleming (2000) indicated that when people (mothers) are given opportunity by support and information they can improve their everyday life with difficult children and parenting. Thus become aware of the influences and power structures that are affecting their life and then become empowered.

It is important to form a model of teamwork or network of parents and professionals that emphasises the concept of family centred ideas, with the locus of control being the parents instead of maintaining the parents dependency on the experts in the child's chronic disorder (McDowell and Klepper, 2000). For nurses and other professionals it is important to provide holistic care that builds

on the acceptance of the individuality and different needs of the parents. That could be achieved by family-based care and regular diagnostic referrals to follow up changes in the child's development (Mallow and Bechtel 1999). Furthermore, professionals should be aware of the possibility that parents may have different roles and needs in their care of their chronically ill child (Knafl and Zoller, 2000). In the nurse/patient (professional/client) relationship, the nurse/professional is a person that has a defined expertise that can meet the client's needs in a given situation. The working relationship between parents and professionals requires respect for the individual and need to include human considerations such as confidentiality, privacy, dignity and ethical issues. (Peplau, 1992). There are programmes for children with autism that emphasises the importance of co-operation between parents and professionals and it has been shown by research that such co-operation is helpful for parents and it is, furthermore, indicated that the co-operation makes the life with the child with autism less stressful for the mothers (Mesibow, 1997; Hastings and Johnson, 2001).

2.6 The gap between intervention programmes and parents' perception

Professionals are more and more taking into consideration parents feelings when planning intervention programmes. Nevertheless, parents still report the experience of disrespect in the relationship with professionals and thus Herman et al. (1996) recommend professionals to pay attention to this difference in theoretical framework of family support programmes, furthermore, pay attention to the perspective of the parents. It is important to tailor the service to the needs of each family and to give the parents information about the child's disability and available service for the family. Furthermore, establish a network between different services and the families (Herman et al., 1996). In their review of literature in their study Gilliss and Knafl (1999) did not find significant empirical evidence of nursing intervention programmes within the field of work with families and thus they advice nurses to be self evaluative in their review on nursing literature.

2.7 Summary

The literature review indicates that mothers' are the main provider of care for children with autism and children with other handicaps, such as children with chronic, mental or physical illnesses. Parents who have children with autism experience more strain in the parenting role than parents do with children who have other developmental disabilities. Mothers and fathers feel sorrow at different moments in their life with their handicapped child. Professionals working with these parents should be aware of these differences among the parents and respond accordingly in their co-operation with the family. It is important for the service systems to respect the parents as co-operators, and consider their strength instead of pathological findings. Professionals working with parents need to be familiar with concepts such as chronic sorrow and different coping styles. They need also to consider what it is that empowers parents in their struggle in taking care of a child with developmental condition or chronic illness. In the co-operation between parents and professional's information, support, respect and co-operation are important. Furthermore, parents see it as significant to form a network with professionals in the service. It is, furthermore, pointed out that there is often a difference in theoretical framework that guide the professionals and the parents perspective and professionals need to take these differences into consideration in their work with parents of handicapped children.

Chapter 3

Research design: methodology and method

In this chapter I will explain my choice of methodology and method as a way to gain an answer to my research question: What is it like to be a mother of a child with autism? My purpose is to add to the understanding of how mothers feel in such a situation. Furthermore, I intend to give new perspective to the co-operation between parents and professionals. In the following chapter I will discuss how the philosophy of nursing and phenomenology are coincided. Then I will discuss hermeneutic phenomenology as the chosen methodology and method in my study. Ethical issues will be discussed, furthermore data collection and data analysis. Finally I will explore rigour and trustworthiness in qualitative approach.

3.1 Phenomenology and nursing

I take a stand with Taylor (1993) and Rose et al. (1995) who argue that nursing and phenomenology are coincided. Taylor (1993) points out that nursing and phenomenology are coincided as both are concerned with viewing people as human beings and their objective and subjective experience as 'meaningful in terms of the context in which they find themselves' (p.175). By understanding people's experiences through a phenomenological perspective nurses can add to the theoretical base of nursing care (Taylor, 1993). Rose et al. (1995) claims that phenomenology is appropriate for the development of further knowledge in nursing and in the conduct of the development of nursing practice that builds on a humanistic worldview. Furthermore, I agree with Biering (2001) that nursing knowledge should be person oriented instead of being object oriented and nursing knowledge should be lead by empathy and the love for the human being. Phenomenology is a philosophy which asks the essential questions of ontology and epistemology, ontology being the nature of being and epistemology being

the nature of knowing, that is, not only what is known, rather how it is known and expressed (Thorne, 1991). Husserl (1857-1938) is generally seen as the father of phenomenology and for Husserl the aim of using phenomenology was 'to gain knowledge of invariant structures of consciousness' (Polkinghorn, 1983, p.203). Phenomenology used as research method is both a philosophy and methodology (Omery, 1983; van Manen, 1997; Beck, 1994; Halldórsdóttir, 2000) and there are many different ways of interpretations in phenomenology and all of them are concerned with understanding human experiences, one of those ways is hermeneutic phenomenology (Halldórsdóttir, 2000).

3.2 Hermeneutic phenomenology

Hermeneutic phenomenology is the choice of methodology in this study because I believe it will be the best way to gain an understanding of the experience of mothers who have a child with autism. Hermeneutic phenomenology is a way to understand the meaning of an experience as lived by another person and the aim of the researcher is to interpret a meaning that could be concealed when using the natural science methods (Omery, 1983). When understanding is gained in human science the researchers have to translate the meaning they have grasped and form it into concepts that can be told to others in a truly understandable way (Polkinhorne, 1983). Thiselton (1988) argues that hermeneutic phenomenology is more than an interpretation of the text, it is an interpretation of communication in any form, written, verbal or non-verbal (Thiselton, 1988, cited in Halldórsdóttir, 1999).

Two important concepts in hermeneutic phenomenology are the hermeneutic circle and the fusion of horizons. Gadamer had the hermeneutic circle of understanding affirmed and he did so by the notion of conversation between two persons, a dialogue that is open to other's point of view and by that the researcher can understand the participant's experience (Reeder, 1988).

Gadamer (1998) claims that when a person is trying to understand and interpret a text that person is always projecting. When some initial meaning emerges to the text that person begins to project meaning to the whole. The person reads the text with certain expectations and the initial meaning emerges from the text because of that certain expectations that builds on that person's fore-structures and for-judgement. 'Working out this fore-projections, which is constantly revised in terms of what emerges as he penetrates into the meaning, is understanding what is there' (Gadamer, 1998, p.267). Heidegger and Gadamer explain the hermeneutic circle as a way to clarify prejudgement and prejudice in understanding, that is, being aware of one's prejudgement instead of 'bracketing' them, and this are called by Heidegger and Gadamer the horizon or the structure of the interpreter (Reeder, 1988).

Experiences have a meaningful horizon of before and after that fuses in a motion of what comes before and after the experience and creates a constant flow of experience (Gadamer, 1998). Understanding happens when the horizon of one person fuses with the horizon of another in an inquiry (Thompson, 1990). Interpretation happens in all the steps of the researchers' work, in the dialogue and when listening, writing and reading the text and this makes the language a way of understanding (Gadamer,1998). I agree with Annells, (1996) who claims that Gadamer emphasised hermeneutic phenomenology as being practical. In accordance to this I view hermeneutic phenomenology as an appropriate approach to gain understanding of the experience of mothers that have children with autism. This view builds, furthermore, on my nursing practice as a clinical nurse working with children with autism and their parents, thus by my pre-knowledge of the phenomenon.

3.3 Ethical issues

In qualitative research unexpected ideas can become apparent in the dialogue between the interviewer and the participants' and this is possible because of the flexible nature of the method and methodology that gives the permission to see different perspectives in the ongoing process in the dialogue (Holloway and Wheeler, 1995). This requires that the participants are ensured confidentiality and given a promise of respecting the participant's wishes to withdraw from participating in the research and by ensuring that no harm will be done. Burns (1989) claims that failing to obtain consent from the participants and failing to inform participants of their rights as well as the right to withdraw from the study is a treat to ethical rigour. Fontana and Frey (1998) stresses that this should be more than words on paper or orally. They further point out the need to have genuine respect and concern for the participants even though the researcher desire to learn about people and their experience. The researcher should be well aware of how personal and sensitive the experience is that the participants are describing (Fontana and Frey, 1998).

3.4 Data collection

The method of data collection in this study was face-to-face in-depth interviews with ten mothers who have children with autism. A researcher needs to accomplish and develop an atmosphere of relationship and trust in a face-to-face interview and by establishing trust the researcher will be the main instrument in the collection of data (Beck, 1994). Trust in the dialogue between the researcher and the participant is not always easy to establish and maintain. There must be trust in the dialogue and the researcher needs to be able to see the situation from the view of the respondent. Furthermore, at the same time be aware of one's own pre-conceptions, furthermore, be careful not to impose them on the participant (Fontana and Frey, 1998; Fontana and Frey, 2000). Nevertheless, the researcher can use own experience as a perceptual lens to a better

understanding (Benner, 1994). The path of in-depth-interviews has been increasingly in the direction of negotiative interaction between the participant and the interviewer with the interviewer participating in a dialogue instead of trying to be neutral (Fontana and Frey, 2000). In a hermeneutic phenomenological interview the true dialogue is achieved when the researcher reveals own biases and prejudgements to the participant and is open to the questions from the participant and accepts that the interview can take another direction than the one the interviewer had expected (Benner, 1994). I agree with Halldórsdóttir (1996) when she claims that there are two experts taking part in the dialogue, the researcher being the professional and the participant being the expert in the lived experience that is discussed. Van Manen (1997) claims that when the researcher openly discusses the theme that appears during the interview, in the light of the research question, it will turn the dialogue into an interpretative conversation.

In this study I draw from van Manen's (1997) way of data collection and analysis that underpins hermeneutic phenomenological research as a dynamic interplay in six steps (See chapter 4):

- '1) turning to a phenomenon which seriously interests us and commits us to the world;
- 2) investigating experience as we live it rather than as we conceptualize it;
- 3) reflecting on the essential themes which characterize the phenomenon;
- 4) describing the phenomenon through the art of writing and rewriting;
- 5) maintaining a strong and oriented pedagogical relation to the phenomenon;
- 6) balancing the research context by considering parts and whole' (pp.30-31).

3.4.1 The method for selection of participants

A purposive, theoretical design is a design that is by Polit and Hungler (1995) regarded as suitable for in-depth- interviews. Where the aim is to get the best description or full nature of the phenomenon of interest and the criteria is subjects that have particular knowledge about the phenomenon (Polit and Hungler, 1995, see 4.3.3). This can be accomplished by contacting a person that is knowable about the subject of interest and that person could assist the researcher to contact possible participants (Morse, 1997). Sample size depends on the judgement of the researcher and should be judged enough, according to Sandelowski (1995) when 'new and richly textured understanding of experience' is gained. Thus the sample size that have been projected in the proposal often needs to be changed depending on the quality of the text and the shape the inquiry takes (Benner, 1994; Polit and Hungler, 1995) and this can be done by finding more participants if needed.

3.4.2 Interview and interview guide

An in-depth-interview regarded as an research method consists of method, structure, purpose and the relationship between the researcher and the participant and the researcher should be personal enough to give the participant the feeling of trust without imposing the interviewers pre-conceptions in the interview (Seidman, 1998). The interview serves two specific purposes in hermeneutic phenomenology. One is to gather and explore experiential narrative and by gaining a deeper understanding in human phenomena. The other is that the interview can be used as an instrument to develop a conversational relation with a participant about a meaning of an experience (van Manen, 1997). Van Manen (1997) stresses the need for the researcher to be oriented and aware of what is the aim of the study and he suggests that the interview questions should be worded, for instance with a 'why' and 'how' beginning. In addition he points out that silence, patience, repeating, body language and facial expression is

important procedures in communication. An interview guide can be useful as a reminder for the researcher and can be formed in the beginning stage of the preparations of the research. It can be a product from the researcher's prejudgement of the phenomenon and is often reformed in the dialogues with the participants (Biering 2001).

3.5 Data analysis

Both the researcher and the participants have their life and social situation before the interview and Denzin and Lincoln (1998) discuss that the reader learn about the researcher and the researched in the study and they argue that the reader should consider the role of the interviewer. The interpretation of text is the comparison of the understanding of separate parts of the text and understanding of the whole text. Furthermore, the explanation of this movement between the parts and the whole are the hermeneutic circle and happens when the horizon of the participant fuses with the horizon of the researcher. (Kvale 1983; Thompson, 1990). Thematic analysis is explained by Van Manen (1997) as recovering theme or themes that are characteristic for the emerging meaning in the text and are relevant in the work of analysing. Van Manen (1997) further explains themes in many aspects, such as an experience of focus, experience of meaning and a point and the wanting to make sense. He sees work done by hermeneutic phenomenology as being pedagogic in itself by being in the world with others as someone who ask questions, selects data and describes and interpret text in a research.

3.6 Rigour and trustworthiness

In qualitative research the researcher aims at understanding the participants' social and personal experience and by inquiry aim to give that experience a new meaning and understanding (Denzin and Lincoln, 1998). Furthermore, in qualitative research in order to ensure the methodological rigour the researcher

is obliged to present all the steps applied in the selected method conducted in the study, furthermore, to present the data as recorded individually and as a whole (Burns, 1989; Sandelowski, 1986, Sandelowski, 1995). According to Polit and Hungler (1997) four criteria have been suggested for establishing trustworthiness in qualitative research and these are; credibility, dependability, confirmability and transferability. Credibility is the truth of the data. Dependability is the stability of the data in time and changing conditions. Confirmability is focusing on the characteristics of the data. Inquiry audit is a technique within dependability and audit trail is a technique within confirmability and is a process enabling other investigators' to come to their conclusion of the data. Furthermore, there is the transferability and that is giving enough information of the studied phenomenon for others' to make their judgement (Polit and Hungler, 1997). If the researcher succeeds to see new perspectives in the data, she/he will be able to present the phenomenon of interest in a new perspective (Sandelowski, 1995).

Fontana and Frey (2000), discuss the interview as a research method and point out that the spoken or written word can give different people a different understanding of the phenomenon no matter how carefully the researcher goes about interviewing and reporting her understanding of the phenomenon. The interview method has been questioned and even not regarded as scientific due to the non-statistic underpinnings of the interview in qualitative approaches (Morse, 1997). However, the freedom and variations of interviews provided in a hermeneutic phenomenological inquiry gives a richer picture of the themes. What is important is to lead the participant towards certain themes in their life without being leading in a specific direction (Kvale, 1983). Koch and Harrington (1998) discuss the ongoing debate about rigour in research guided by the philosophy of hermeneutics. They consider the research work as plausible and believable when it is engaged and logical by being detailed and reflective on each interpretation and they point out that the researcher should be aware of the reality that this work is done in a changing social, political world. Thus the

researcher needs to have a critical insight when presenting the product of the research.

3.7 Summary

The philosophy of nursing and phenomenology are coincided as both are based on human respect and the thought that every person is a whole human being in relation with the social settings that person lives in. My purpose of this study is to gain a deeper understanding of mother's experience of having a child with autism, and the hermeneutic phenomenology was my choice of approach. Gadamer's philosophy accepts the researcher's prejudgement of the phenomenon to be openly discussed in the dialogue between the researcher and the participant. In the dialogue the researcher is trying to understand the participants' viewpoints of life in a horizon of before and after when the understanding of the researcher fuses with the understanding of the participant in an inquiry. What underpins my choice of research approach are Gadamer's (1998) philosophy and his explanation of the hermeneutic circle and of the fusion of horizons. My work was guided by van Manen's (1997) explanation of the interpretation of lived experience or a text with thematic work being the structure of that experience. My fore-judgement and my experience in my co-work with mothers of children with autism underpin this choice of methodology and method.

Chapter 4

Data collection and analysis

In this study the data was collected with face-to-face in-depth interviews with ten mothers. The in-depth- question was; what is it like to be a mother of a child with autism? In this chapter I will describe how the access to the participants was obtained and give a description of the participants. Furthermore, ethical considerations, data collection, data analysis, trustworthiness and rigour are discussed. The methodology used in this study was hermeneutic phenomenology.

4.1 Access to the participants

The target population for this study were mothers who had a child with autism. The criteria for participation in the study were being a mother of a child with autism at the age from six to sixteen. There were two reasons for this age range. Firstly, to have some time from the diagnostic process (in Iceland children with autism are usually diagnosed at the age of three to four). Secondly, it was regarded as important to span the pre-and regular school age to adolescence in regard to different milestones in the child's development and in the life of the family according to that. I turned to two mothers, who were active in work in the Icelandic Autism Society and asked them to participate in the study and they willingly participated. Furthermore, I asked them to recruit eight other mothers that were willing to participate. The eight mothers they contacted showed interest in participating in the study. I first contacted those other mothers by phone and then I sent a letter of presentation (**Appendix 1**) and a written consent (**Appendix 2**). The signed consent forms were either sent back by post or handed in at the interview site.

4.1.1 Description of the participants

This study was undertaken in Iceland and all the participants' were Icelandic. All the mothers showed interest to participate in the study. The mothers that participated were ten, the two I turned to in the beginning of my work and other eight they recruited. Eight of the mothers were living with the child's father; two were divorced and lived with the autistic child and siblings. The age range of the participants' was from thirty four to forty nine years of age. To ascertain the rights of the participants and confidentiality all the mothers were sent letters of presentation of the purposed study (Appendix 1) and a letter of informed consent (Appendix 2) and they were given pseudonyms in the presentation of the findings. In order to preserve the anonymity of the children they will be referred to as males. This decision relies on the population in Iceland being small (<290.000) and the gender differences is considered to be that autism is approximately three times more common in boys than girls (Gilberg and Peeters, 1995).

4.1.2 The interviews and the interview guide

The research question: What is it like to be a mother of a child with autism is the product of my pre-conceptions and interest in the phenomenon of concern. This question was the in-depth-question in the interview and each participant was told that she could tell her story in any way she wanted. Furthermore, an interview guide was used in the interviews and it consisted of few questions to emphasise the in depth- question of the study. In the proposal of this study the interview guide consisted of seven questions. After the two first interviews I realised that two of the questions could be intertwined in the other questions. After that the interview guide consisted of five supplementary questions. The interview guide (Appendix 4) was initially written in English (in the proposal) and later translated by myself into Icelandic to be used in the interview process. The interview guide was intended, as a reminder for myself to cover all the topics needed to answer the research question.

4.2 Ethical issues

In a study where the participant is asked to describe her personal and painful experience of being a mother to a child with autism the question of trust in the interviewer is significant. It is also important that the researcher ensures the participants confidentiality and respect (Fontana and Frey, 1998; Fontana and Frey, 2000). Therefore all relevant ethical issues such as anonymity and confidentiality was revealed in the letter of presentation (Appendix 1) and the informed consent (Appendix 2). In the informed consent the participant was, furthermore, told about the process of collecting and analysing the data and at what point the data would be destroyed. In addition, the participants were told of the gain it could be for them to participate in the study and that would be the opportunity to discuss their experience with a professional with experience in working with children who have autism and their parents. In the interview the participant needs to feel that she can trust the interviewer to respect the promise of confidentiality. That trust was built throughout the interviews and each participant was reminded of her right to withdraw from the study and I assured her that her dignity and privacy would not at any time be abused. The participants' were, furthermore, told how the material, which would be gained from the interviews, were kept secured and that they were granted pseudonyms in the presentation of the study. Two ethical committees were contacted, and sent letters of presentation of the study and its purpose. The Data Protection Commission granted its consent (Appendix 3) and it was the only consent I needed.

4.3 Data collection

The data in this study was collected with face-to-face in-depth interviews. A face-to-face interview based on hermeneutic phenomenology is both an inquiry and a dialogue between the participant and the researcher. In my study I used non-standardised interview, which allowed the participants to tell their story in any way they wanted, after they had heard the research question: What is it like to be

a mother of a child with autism? The research question could also be put forward like that: 'can you tell me in your own words about your experience as a mother of a child with autism?' Data was collected either in the participant's home or at my private office, depending on each participant's wish or preference. The interviews lasted from one to two hours, depending on the feeling of saturation, when there did not seem to be any more to discuss. The participants were, furthermore, asked to contact me if they afterwards came to think of something important that had not been discussed in the interview. In accordance with hermeneutic phenomenology the participant was asked to describe an experience and in the dialogue we reflect on that experience. Van Manen's (1997) six steps of 'methodological structure of human science research' (p.30) underpinned my study:

1) Turn to phenomena of interest, which commits us to the world:

In this study it was the world of mothers who have children with autism. Ten mothers that were willing to revile their life story and trust me with their thoughts and feelings in their life with their autistic children. According to van Manen (1997) a phenomenological study is a study of individual human experience in the light of its context in social and historical settings and there is only one interpretation of the phenomena, the researcher's.

2) Investigate experience as it is lived rather than conceptualise

The practical wisdom in doing phenomenological research is to understand the nature of the lived experience. Hermeneutic phenomenology allows the researcher to make visible owns pre-conceptions and pre-understanding of the phenomenon. Therefore, in the dialogue the participants and I could discuss what it was like to have a child with autism, furthermore, laugh together when the participants told their funny stories about their children (See chapter 5). As argued by Halldórsdóttir (1996) there are two experts in the dialogue the researcher and the participant and both bring their experience into the dialogue. For me, being

an expert in autism it was important to be able to reveal my prejudgement and pre-conceptions openly without imposing my views upon the participant and then afterwards it was my role to interpret and present the result in an understandable way for the reader. Steps three to six (van Manen, 1997) will be discussed in section 4.4.

4.3.1 The reflective diary

In accordance to Burnard (1991) I kept a reflective diary in the form of a tape-recorder and later I wrote my reflective thoughts in a written diary. By listening to, writing and reading my own reflections from my diary I was able to reflect upon and critique my participation in the dialogue. I learned by this work and made use of that experience in coming interviews. This diary was an important part of my study helping me to reconsider my role in the interviews. Then I did reread van Manen's (1997) advice of how to go about asking other people to reveal their own experience. Thus remind myself of the use of patience and silent moments or repeating the sentence and by that help the participants to continue.

4.3.2 Sample size and saturation

Purposeful, theoretical sampling design with snowball or network sampling was used in this study (Polit and Hungler, 1995). The sample size in a qualitative research depends on when theoretical saturation and the qualitative information in the collected data is considered achieved (Sandelowski, 1995). In this study the sample size was considered enough when the same pattern began to repeat itself in the interviews. After listening to the tape-recorder, transcribing, reading and rereading the transcripts I concluded saturation was achieved. Though not until I had contacted the participants by phone and asked for clarification and discussed unclear points from the interviews. When we both had the feeling that there was no more to say or ask the saturation in data collection was considered achieved.

4.4 Data analysis

Data analysis begins formally when the researcher accepts the transcript as raw data that is ready to be analysed and in that process the researcher tries to understand each transcript as a whole and then 'develop a consistent approach to accounting for the data' (Sandelowsky, 1995, p.373). Following are the steps three to six of the data collection and data analysing of van Manen's (1997) six steps of doing phenomenological research and how I processed through those steps, the first two steps were discussed in section 4.3.

3) Reflecting on the essential themes which are characteristic for the phenomenon

My main purpose in the process of analysing the data is to gain an understanding of the phenomenon. Through reflection I wanted to be able to bring into nearness the experience of mothers who have children with autism and I did so by listening and re-listening to the audio-tapes, to get a grasp of parts and the whole of the mothers description of their experience.

4) Describing the phenomenon through the art of writing and rewriting

I transcribed the interviews, word by word, When doing so I felt empathy and respect for the perseverance that the participants' had shown in their life with their children and themes began to emerge from the topics discussed in the dialogues. When transcribing each interview I realised that I was learning something useful for my work with parents of children with autism. My hope is that I will be able to give my learning to others in my findings and conclusions chapters.

5) Keeping an oriented, pedagogic relation to the phenomenon

Even though I was able to let my pre-judgement be visible in the dialogue I needed to remember that the main aim was to use my pre-judgement helping me

to a better understanding of the participants experience, thus not to impose my preconceptions upon the participant.

6) Considering the parts and the whole and by that balancing the context of the research

In order to get an understanding of a phenomenon one has to have some organised thought of the comparison of the parts in each interview and the whole text and then consider how the parts contribute to the whole. To gain understanding of the whole I read and reread every transcript, finding topics and themes until seeing some pattern in the participants experiences (See chapter 5). I agree with Appleton and King (1997) when they insist that this comparison of understanding begin in the interview with the participants and goes on in the analysing process and when the researcher turns back to the text or the participant for verification. This constant comparison 'is the hallmark of any research inquiry as researchers are constantly comparing data sets' (p. 20). The thought of going back to the participants for verification of the researcher's interpretation is an act that not all hermeneutic experts agree with. Nevertheless, by having the verification from the participants the validation is evident when the participants can identify the metaphor and agrees with it (Smith, 1999).

4.4.1 The exact step in my analysis and interpretation of the data

Burnard (1991) points out fourteen stages in the analysing process. I did not go directly through those fourteen stages; rather some of them were intertwined in my work in analysing the data. Furthermore, in the process of collecting and analysing data the six steps of methodological structure van Manen (1997) presents are intertwined in my work. Van Manen further argues that in the actual research process various aspects are related simultaneously or intermittently and that was how I proceeded. I will now present the process in my work of analysing and interpreting of data:

- 1) I listened and re-listened to the audiotapes of the interviews, to get the grasp of the parts and the whole of the text.
- 1) I transcribed the interviews, word by word.
- 2) I read and reread every transcript, highlighting with different colours the emerging themes that seemed to have bearing on the phenomenon under study.
- 3) I identified discussion topics and gave them names. Furthermore, I identified themes within each topic and gave them names. (See chapter 5).
- 4) I found typical quotations from the dialogues with the participants that were characteristic for the different themes.
- 5) In this process I was able to turn back to the transcript to verify my understanding, furthermore, I went back to the participants for verification of my understanding of the essence of the phenomenon. Two of the participants (the participants I had turned to in the beginning process) read the findings chapter for verification.

4.5 Rigour and trustworthiness

Rigour or confirmability in qualitative research relies on the way evidence is used, the techniques in collecting data, the purpose and techniques in the analytical process (Sandelowsky, 1986). I will now explain how trustworthiness was accomplished in this study by using Polit and Hungler's (1997) explanation of the concepts; credibility; dependability; confirmability and transferability.

Credibility was accomplished by openly discussing my interest and connection to the phenomenon. Polit and Hungler (1997) discuss how the researcher's

credibility is relying on the researcher as an instrument in the analysing process. One of my abilities as a researcher in this study relies on my education as an autism counsellor and many years of working with children that have autism and their parents. Furthermore, credibility was gained by giving sufficient time and building trust in the dialogues.

Dependability and confirmability in my study was accomplished by documenting all the steps and decisions in the research process such as in the collection of data and data analysis and is according to Polit and Hungler (1997).

In my study *transferability* was accomplished by clearly describing the research procedure, methodology and method, furthermore, by describing how the understanding between me and the participants' grew from the fusion of our horizons. My aim is to deliver this study in writing in such a way that the reader can follow the audit trail and by that, gain new perspectives.

4.5 Summary

In this chapter I have explained the process of gaining access, collecting and analysing data in my research in accordance to Gadamer's philosophy and van Manen's way of doing hermeneutic phenomenological research. In this study chapter three and four are intertwined. Chapter three is a discussion of the methodology and method used in this study and the fourth is an explanation of how I used this methodology and method as the structure of the process in my work. In this study I did my best to create an atmosphere of trust, by telling about my interest in the phenomenon and referring to the letter of presentation. I asked the research question somehow like this: 'Will you tell me about your experience of being a mother of a child with autism'. In the dialogues I used my preconceptions to interpret and ask questions.

Chapter 5

Findings and discussion

In this chapter the findings of the study will be presented and discussed in the perspective of the literature. For the sake of clarity the themes that emerged from the interpretation of the transcribed interviews were grouped according to five main discussions topics. These topics were: (1) **becoming a mother of a child with autism**, (2) **coping and taking care of self**, (3) **the father of the child**, (4) **where to seek help**, (5) **the need for support from professionals**. Within the first topic, **becoming a mother of a child with autism**, five themes were identified, (1) being alone with a discovery, (2) the recurring sorrow, (3) milestones becoming obstacles, (4) a never ending responsibility, (5) rewarded love and learning from the child. Within the second topic, **coping and taking care of self**, four themes were identified, (1) breaking out of the isolation, (2) using anger to fight for the child, (3) coping by the means of humour, (4) becoming empowered. Within the third topic, **the father of the child** two themes were identified (1) the difference between the father and the mother, (2) support from the father of the child. Within the fourth topic, **where to seek help**, two themes emerged, (1) nobody wants him, (2) parents to parents. Within the fifth topic, **the need for support from professionals**, four themes emerged, (1) support and lack of support in the diagnostic process, (2) I know better, (3) when the subject is money, (4) giving advice to professionals. The findings will be discussed in relation to relevant literature, which will be interwoven in the text. Finally in the summary the main findings will be drawn together in relation with reviewed literature.

The participants in this study were all mothers and therefore the term **participants** and **mothers** will be used intermittently in this chapter.

Furthermore, the gender prevalence is considered to be one girl against three

boys (See 4.1.2). Therefore the child will be referred to as a **he** regardless of the child's sex.

5.1 Becoming a mother of a child with autism

The birth of a child is most often supposed to be a happy event. Parents expect a healthy child with all the best characteristics from both parents. The birth of a child with autism is also expected to be a happy event. The mothers that participated in this study did at first experience the birth of this particular child as the expected healthy child. Yet it differed at what moment in the child's life the mothers began to wonder if the child was not quite as healthy as was first assumed. Something seemed to be strange with the child. The mothers began to ask themselves what it was exactly. The mothers feeling of being alone in the discovery period, experiencing sorrow, a never ending responsibility and finding something positive in this experience will be discussed in this section.

5.1.1 Being alone with a discovery

What was it exactly that was strange with the child? This was a question the mothers asked themselves and other people they turned to. In all cases but two the mothers were the first to notice that something was strange in the child's responses and behaviour. The mothers 'sensed' that something was wrong while other people did not initially see anything wrong. The mothers' feeling of something being wrong is consistent with Benner's and Tanner's (1987) concept of intuition. In their study of how nurses use intuition Benner and Tanner (1987) define intuition as 'understanding without rationale' (p.23). They furthermore discuss similarity recognition and intuition building on know-how and experience. In considering similarity recognition and intuition building on experience, all the participants in my study but one had older children and this could have contributed to the mothers' feeling of something being wrong. Nevertheless, it was difficult for the mothers to point to something specific because autism can

not be seen at first sight. The child looks like every other child. The diagnostic criteria of autism says that autism appears in lack of communication and in lack of any form of reciprocal social interaction, thus people with autism seem not to be able to understand other people's emotional responses and do not show emotional reciprocity (WHO, 1992). The first specific symptoms the mothers were able to point to had to do with the child's lack of ability to communicate and two mothers describe this in the following words:

'At first it was the look in his eyes, his eye contact was somehow strange.... I felt from the beginning that something was wrong'.

Sara

'He did not have any interest in other people.....he was one and a half years old and seemed to develop normally, even said a few words.....yet he never did ask for help or have the initiative to communicate with people. Something was not as it should be'.

Martha

The way Martha and Sara describe their children is consistent with the diagnostic guidelines of autism (WHO, 1992). The mothers said that they had the feeling that there was something wrong with the child even though they were not able to point to anything particular. Gilberg and Peters (1995) draw attention to the lack of affection and love in the child's eyes and the paradox reactions to laughter and crying.

After discovering that something was peculiar about the child the participants turned to other people for support. They turned to the child's father, other family members or friends. The first reaction of the fathers was to try to calm their wife's and tell them 'not to worry so much'. Two participants had friends that encouraged them to have the child examined. One mother said that the first

people she turned to were the nurse and the doctor at the Health Care Centre when she was taking the child to routine eighteen months referral. The nurse at the Health Care Centre reassured the mother that nothing was wrong and the child might only be a little late in its development. Even doctors that were child specialists often misdiagnosed the children as having deficits in attention, motor control and perception or being hyperactive. Delaney and Engels-Scianna (1996) reported similar experiences in their study where the parents of children with emotional illness felt the mental health service had failed them when they asked for help. One mother in my study described her experience of going from one specialist to another because the specialists' explanation did not fit how she herself perceived the child's behaviour. She describes her experience in the following words:

'I was beginning to think that there was something wrong with me. That people thought it was my wish that something was wrong with my child. Then I said to one child specialist, just when I went out of the door with my child: 'Will you please take him in your arms and then I looked him in the eyes and asked him 'Is this right?' Then the wheels started turning'.

Ann

The participants did, furthermore, discuss how hard it was to accept that their children had autism. This is consistent with MacGregor (1994) who claims the diagnosis of a child with mental illness is a terrifying experience for parents who are already filled with fear of bad outcomes. The parents thinking of mental illness as being a personal and social loss for the child, afraid that their child will not be able to enjoy pleasure in life such as joyful play and participating in the family and peers activity. This description of MacGregor's (1994) of parents fear of the consequences of the diagnosis is consistent with the description of one of the mothers in my study. This mother described her despair in the period after

her child was diagnosed and then what it was that helped her change her mind, she said:

'I wanted to take our lives (my son's and mine). Then I thought of my husband and other children and I decided that this was selfish and took on the task to take care of a child with autism'.

Martha

Although this fear of the consequences of the diagnosis became apparent in my study the participants described mixed feelings of sorrow and relief when given the diagnosis of autism. At least they then had something to help them to go on in the upbringing of this special child, they could seek information and study autism and learn how to make a better life for their children. As Martha said, 'I took on the task to take care of a child with autism'.

5.1.2 The recurring sorrow

Sorrow was an important part of the participants' description of their life with their autistic child. They described the sorrow returning again and again and one mother described it as follows:

'It is like a slap in the face, you fall down, everything falls apart, and all our existence falls apart. Then you start building up again. Still the blows come regularly after the first one'.

Martha

The mothers whose children were adolescents described the process of sorrow being less painful as time went by. The first shock and sorrow was experienced when their child was diagnosed. Then the sorrow was re-woken almost at every milestone and change in the child's life as for instance when realising that their child would not be able to have their own family. Nevertheless, the returning

sorrow was somehow different or less devastating with time. The change in this returning sorrow is described by one of the participants:

'It is less now, in the beginning there was terrible sorrow. I needed to cry and I had a need to read about autism. I always began crying before I was able to start reading. Then this feeling of sorrow changes and the rough times grows farther apart, it is like quitting smoking. There are now other things that brings about and are the source of the sorrow'.

Diane

Olshansky (1962) first defined sorrow that comes again and again as chronic sorrow and as being a normal response to a painful experience that comes in periodically. It was initially used in a study of the emotions experienced by parents of severely retarded children and Olshansky built this description on his own personal and professional experience (Phillips, 1991). Krafft and Krafft (1998) in their study of parents of severely retarded adult children describe this ongoing sorrow as an emotion that is experienced episodically and has no predictable end for the one who experiences it. Krafft and Krafft (1998) describe those periods of sorrow as losses comparable to the death of a loved one. First comes the loss of the healthy child the parents expected followed by other losses such as not being able to see one's child grow or him not being able to take care of himself.

Other things in life can bring sorrow and these experiences will get intertwined with the sorrow of knowing that the child has autism. Four of the participants had other devastating experiences at the same time as realising that their child had a handicap, such as the death of a loved one, being sick themselves or divorce. One participant who had experienced sickness and other family problems at the same time as her child was diagnosed described this in the following words:

'You do not have your autistic child in a vacuum, there are other things in life that happen at the same time and then the feelings get intertwined'.

Diane

Two of the participants had lost their mothers at the same time as their children were diagnosed with autism and the sorrow due to that loss intensified the shock and the pain they felt associated with their children. Furthermore, they felt that they had lost the person that would have given them the most support in taking care of their child. One participant described the intensification of this loss in this way:

'A month later my mother died suddenly, she was my best friend. This was a two-fold blow, I did not have time to deal with the sorrow for my child, it drowned in the sorrow for my mother. It was so much to deal with at the same time'.

Sara Jane

5.1.3 Milestones becoming obstacles

All but one of the participants described how they were ready to fight for the rights of their child. This fighting was associated with particular milestones in the child's life. Often it was when changes took place in the child's education such as when the child was going from pre-school to regular or special classes. One mother described how she had to fight for the appropriate service when her son began regular classes at school:

'When he attended pre-school we had 'top' service and the program was good for him and we expected the same when he began going to regular school. Then I had to fight for everything. I had to fight with the principal to get the support in the classroom that my child needed. This was new to me; I am not the fighting type'.

Dora

Another participant told how badly she felt in the period after her son finished primary school at the age of sixteen. She did not have any offers for her son to continue his education. Then she described her relief when he was at last offered a placement in special class in a High school and she said:

'There is a special class in a High school in which he is with other young people with autism and the teachers are knowledgeable about autism. They have a long experience in working with children and young people with autism, and the best thing is that he is happy there'.

Rose

Two mothers of adolescents described how they felt when their young adolescent boys discussed their wishes to have their own families and to have drivers' licences. The mothers felt hurt and aggrieved for their boys that they would never be able to have many of the things other young people do. One of the mothers described this with these words:

'He is so terribly worried about not being able to have drivers licence and he talks about getting himself a wife who can drive and I know he will never drive or have a wife'.

Rose

5.1.4 A never ending responsibility

All the participants talked about the feeling of being responsible for their children for the rest of their lives. They would always need to be there for them. This was a feeling they all experienced very early in their children's lives. Then they all pushed the thought away, in order to cope with their everyday responsibility. All the participants experienced being worried about the future and deciding where their children would be after leaving home and having to decide at what point this should happen. The four participants that were mothers of children that were in

early adolescence were especially worried about their children's further education and work placement. These mothers were able to discuss their worries with their husbands. Nevertheless, it was the mother's responsibility to make all arrangements. They had to follow up on school placement and other important arrangements concerning their children's future. One adolescent's mother described how tired she was of having to fight again and again for what was her child's right according to Icelandic law:

'He has been in special class for some years and has had an excellent teaching service. He is now able to do things we did not dream of. Suddenly last winter they (the politicians) decided to cut down the services. Then suddenly I felt very tired. Again to fight for service we fought for years ago. I do not feel up to this. Nevertheless, I will go on fighting as long as it takes. This is a lifelong job'.

Jane

Two participants whose children were adolescents felt it was important to be aware of the danger of becoming dependent on the role of being a mother of a child with autism. They also emphasised how important it was to be able to trust other people with their child. To be able to trust other people was a part of being able to consider the child's placement in the future. These two mothers in my study described what had helped them to accept that some day their children needed to grow away from them. They had heard of, or met, two older mothers who had not been able to take this step to decide for their children's future. One of those two older mothers had ended up by becoming mentally ill and the other one was totally preoccupied with her child and had no life without him.

The participants talked about how difficult it had been to accept the fact that the child and they themselves needed the various social supports that were offered to them. When they did accept the need, the service was not always available immediately and they sometimes had to wait for years. Furthermore, the study

found that it was difficult for the participants whose children were adolescents to take decisions about when and how much social support was needed, as the children grew older. They worried about what was to become of their children when they themselves died. One mother described how tremendously difficult it was to think about her son's future after she died or became too old to take care of him. She described those difficulties and the steps she took as follows:

'I have three older children and now he is an adolescent and I asked them to take care of him when we died (she and her husband). Then I met this lady from the social office and she scolded me for asking them. That helped me to see that this was not the right thing to do and now I have applied for a Supported Home for him and I know that this is what he himself wants'.

Rose

Another mother described how she had responded towards the problem of deciding a home placement for her son:

'We were so fortunate to be able to get a placement for him in a Supported Home where he will have all the service he needs. Now I am at a point where I am too tired to be able to care for him the way I was able to before. I trust those people and thus I will be able to be with him in another way, and be less tired'.

Diane

5.1.5 Rewarded love and learning from the child

All the participants discussed their love for their children and this love was evident in what ever was discussed. In the dialogue this love overshadowed other issues such as their own needs. This love was a constant theme throughout the dialogues. It was, furthermore, important for the mothers to accept the reality of life for their children with autism, in particular that their children

would not be able to live an ordinary life. The mothers found that their love for their children was rewarded in many ways, for instance how they were able to learn and grow from their experiences. The mothers enjoyed and were proud of every step forward in the child's development and experienced them as victories. One participant described her pride like this:

'He is now doing things we had not dreamed of such as riding a bike without being in danger and is able to stay home alone. This makes us proud of him even though he will always need someone to take care of him and will not be able to play football like the boy next door'.

Jane

The participants described experiencing pride in their children's achievements and saw them as theirs own and the children's victories. One child being able to walk alone to school was described by one of the mothers as her own and her son's victory:

'He was ten and I still walked him to school. Then he asked why I did this; smaller kids went by themselves. I was scared to let him go by himself to begin with. Then we both were happy and proud'.

Alice

Of the ten participants there was one mother that was especially occupied with the thought of her child being respected as a person and not spoken of as a handicap. She compared calling her child autistic with calling a child with cancer cancerous and said that she had not thought about how important this was until she herself had a child with a handicap. This was really important for her and those were her exact words:

'I respect and love my child as a person and I want other people to do so as well, he is not an autistic child, he is a child with autism, can you see the difference?'

Diane

All the participants' spoke of how having a child diagnosed with autism had changed their views in a positive way, such as being more understanding when they saw parents having trouble with controlling their children in public places. These three quotations tell in what way:

'I have changed a lot. I have more tolerance for other people. Now I almost never let people irritate me the way they did before. Still, I often think, I did not need this, I was good enough as I was before (she laughs). I feel older'.

Ann

'To have a child with autism has made me more mature. The autism was unexpected, it was not meant to be. Life has been difficult. Because of this experience I do not judge other people and he has given me more than he has taken from me'.

Sara Jane

'To have a child with autism changes everything, one has to reconsider everything. The whole life of the family changes, it has taken some time for us all. My boy has taught me so much – about himself, autism and not at least about myself'.

Alice

5.2 Coping and taking care of self

All the participants in the study were more occupied with thoughts of their children and their futures than they were of their own wellbeing. One mother

described how her own wellbeing was intertwined with her son's wellbeing and said:

'If he is unhappy and angry and I am not able to calm him down I feel terrible and unhappy because he is not able to tell me what he wants. If he is content then I can relax. My concern is his wellbeing both day and night. I am sometimes very tired and often forget my own needs and this is how my life is now. I can even forget to comb my hair'.

Margaret

This description is consistent with Walters (1995) in his hermeneutic study of the experience of relatives of critically ill patients and he argues that the relatives see themselves mirrored in the ill family-member'.

Even though the participants all described how time consuming their roles as caretakers were, they all mentioned the need to take care of themselves. First after the child was diagnosed they were completely occupied with thoughts about the child. Later they realised that they had become isolated in the role of being a caretaker for a child with autism and tried to find ways to fulfil their personal needs and break that isolation. Furthermore, they discovered new coping mechanism to strengthen themselves and used their anger to become stronger in the fight for their child's rights in society. The use of humour was also important in coping with the difficulties of taking care of their autistic child. The mothers were able to see the humour in their child's peculiar behaviour and were able to share that humour with other people. Furthermore, the participants described how having this particular child made them stronger and helped them to be more tolerant of other people.

5.2.1 Breaking out of the isolation

All the participants talked about how isolated they and their families became because of the child's behaviour, friends stopped coming and they gave up visiting other people. They talked about the need to take care of themselves and to take steps to break the isolation and they used different ways to do so. Some of the participants broke the isolation by finding a job outside the home or by socialising in some other way. Two of the participants used further education and one participant made a career in her profession. One participant described how she broke her isolation by beginning to work outside her home:

'I have been isolated and alone, especially since my husband is away most of the time. Now I am able to start working outside the home and I am looking forward to being with other people more'.

Sara

Another participant sought professional help to break the isolation and she described how she was unable to do anything for herself until she found professional help:

'I have at times felt up to my neck and terribly tired. I shut out those feelings, I felt numb, and I was very sad and closed myself off from other people, then I decided to seek professional help for myself and now I feel much better'.

Dora

5.2.2 Using anger to fight for the child

All the participants described how they had at one time or other been angry because of their child's handicap or how people treated their children. All but one said at some moment or other in the dialogue 'I felt angry and then...' and told of some incident where the anger had helped them in the fight for the child's rights in society. The participants' descriptions indicate that it depended on their

personality and the circumstances how and when they reacted with anger. They often were not aware of their use of anger until afterwards. One mother described how she realised after the fight that she had used her anger and become stronger by that:

'I had never had a quarrel with anyone before, but I was angry on his behalf and therefore I was able to fight for his rights. This fight made me stronger, before I had always been the quiet type'.

Dora

This is consistent with Dunn et al. (2001) who argue that fighting and expressing anger is confronting coping and claims that the result of confronting coping is increased wellbeing. My study showed that the participants experienced that fighting for their child made them stronger. This study indicates that anger is a feeling that comes again and again in the life of the participants but for different reasons and at different times. Sometimes they became angry with those who responded towards them with ignorance or for example as one of the mothers that felt the need to be angry alongside other angry parents in her worst moments of anger after her child was diagnosed. At that time she did not feel able to be grateful for having a child with autism, as the other parents seemed to be. The other parents discussed this role as a way to grow and get personal strength. This mother said that she was not ready to attend the parents' meetings at the State Diagnostic and Counselling Centre at that time in her life because she felt so differently from the other parents:

'I wanted to be at meetings with parents that were as angry as I was. People that felt as terribly angry as I did. I believe it would have done me good but I did not find such people, the parents at those meetings all looked at me with surprise'.

Ann

5.2.3 Coping by the means of humour

The use of humour appeared to have great impact on the wellbeing of all the participants but one. As described by the participants humour seemed to be empowering and helpful in coping with their circumstance. The participants were able to see their children's peculiar behaviour as a source of humour. In the dialogues in my study the participants told how this peculiarity often makes people laugh and how they were able to share their laughter. Some told humorous stories such as this one:

'Once the whole family was abroad on a vacation and having a picnic in a forest. We suddenly realised that he was not with us. Everybody panicked and we ran and called his name. We called and called, then suddenly I saw him sitting under a tree like a little Buddha, smiling and pointing one finger down at his head without saying anything. We all sat down and cried with laughter'.

Diane

One of the characteristics of autism is repetitive, stereotyped behaviour (WHO, 1992) and this stereotyped behaviour of autism can often be difficult to handle, nevertheless, sometimes it can be funny. One mother describes such behaviour as being 'tragic-comic' and this view of hers is best told in her own words:

'He is funny in a sad way. He is sometimes so funny; even when he is stuck on something I can see how funny it is. His newest habit is saying; "every women dances and says hi, hi" and I have to dance with him until I am exhausted'

Dora

These descriptions of how the participants use humour is consistent with Beck (1997) who argues that humour helps to reduce anxiety in stressful situations and gives an opportunity for expression of emotions when being with people that understand and enjoy the same humour. The use of the child's peculiarities and

the sometimes 'tragic-comic' nature of the humour are understandable when considering Kanner's (1943) description of the uniqueness of autism as interesting and peculiar. It seems that this uniqueness inspire the mothers' in this study to tell humorous stories about their children. Even though the mothers' sadness of the children condition became apparent in some of the stories in this study, nevertheless, the sadness could be a source of humour and thus being 'tragic-comic'.

When the participants told these humorous stories we laughed together and it gave a feeling of togetherness and mutual trust. These humorous stories told by the participants in my study became a spontaneous and important part of the dialogue. The trust was the same kind of trust that is developed in the relationship between a professional and a client where the use of humour can be therapeutic. This is consistent with Buxman (2000) who stresses the importance of using humour therapeutically. However, it is necessary to ensure that all participating enjoy the humour and to ensure the right circumstance and moment (Buxman, 2000). One participant described the use of humour in the relationship with other parents. She talked about how parents at parents meetings used what she called the Pollyanna play (The story of Pollyanna is about a young girl who could always find something good no matter how bad things seemed to be, by Eleanor Parker, 1945). The Pollyanna play was used at those meetings to help the parents to see the brighter side of having a child with autism and this participant said:

'When we parents meet we are very good at playing Pollyanna. Someone says: 'Let us play Pollyanna' and we start telling funny stories and jokes about our children and we laugh and laugh because they can do so many funny things and it is never on purpose'.

Diane

5.2.4 Becoming empowered

The study showed that the mothers' used many ways to make them stronger. Being knowledgeable about autism gave some of the participants a feeling of being able to have a say in what was best for their children and that gave them a feeling of empowerment. This is consistent with Dunst and Trivett (1996) whose model of empowerment suggests that empowerment ideology is the belief that people have strength and ability to become competent. Other important issues in the mothers' lives with their autistic children that made them stronger and apparently empowered them have already been mentioned in this chapter. The most outstanding of those issues is gaining personal growth through the experience of being a mother to this special child and how they learned through their children and thus became more tolerant and understanding towards other peoples sufferings. The mothers' experience of personal growth is consistent with Dunn et al. (2001) who describes such personal growth as positive reappraisal. The participants were able to express anger in the fight for the child's rights in society and thus discovered their own strength. An important empowering factor was how the mothers used humour to help them to see the brighter side of their role as the main caretaker for their children. It has been mentioned before how proud the mothers were of the victories of their children when they were able to do things the mothers had not expected such as being able to ride a bicycle or walk alone to school. The importance of being able to take care of themselves was shown in the study. One way they used to do so was breaking out of the isolation that was the consequence of being a mother of a child with autism. One of the mothers that broke out of the isolation by pursuing her own career described how this made her stronger, nevertheless, at the same time feeling humble:

'Being a mother of a child with autism I see it as a privilege to be able to think about my own career and myself'.

Jane

5.3 The father of the child

The study showed that the fathers' living with the family are important as caretakers of the child with autism, nevertheless, their role was different from the mothers. In Iceland people have long working hours and in families with handicapped children the fathers mostly have the role of supporting the families need. This difference in fathers and mothers role as caretakers as best described in the words of one of the participants:

'I have taken responsibility for the care of our child; my husband has placed himself in the background from the beginning. My husband has to support our family needs and bring food on the table and he works until late'.

Diane

5.3.1 The difference between the father and the mother

The participants that lived with the child's father described how they and their husbands often had different views about how to meet the responsibilities of being a parent of a child with autism. It has already been mentioned how the fathers tried to calm their wives in their worries about the child. In the first phase of the search for help and diagnosis the fathers did not seem to be as worried as their wives was. This is consistent with Mallow and Bechtel, (1999) who in their study on parents of children with developmental disabilities point out a difference in mothers and fathers feelings of sorrow and the sorrow showing at different moments. It was shown in their study that the worst moments of the mothers' sorrow was in the process of searching for the right diagnosis and in the relationship with health care service. The fathers experienced their sorrow directed towards social norms (Mallow and Bechtel, 1999). One participant experienced this difference sometimes being obstacles in the process of coming

to terms with the fact that their child had autism and in accepting available service and she described this like a struggle:

'This has taken me some time and I had to break down some walls, and open doors. First my own walls, then my husband's. It took me some time to break down my own walls and then I had to break down my husband's walls'.

Alice

5.3.2 Support from the father of the child

All the participating mothers had the main responsibility for taking care of the special needs of the child with autism. They also took on the extra work concerning the child such as meetings with the people from the school and other organisations connected with the services for children with autism. All the participants talked about their responsibility and extra work in the care of their child as a matter of fact and none of them complained about their husbands taking less responsibility than they did themselves. Regardless of the described difference the eight mothers that were living with the child's father felt supported by their husbands and as couple they were able to talk about their child and what they were going through. Following is how a mother in this study experienced this difference as being supportive:

'I always want my husband besides me when I am somewhere discussing our child. He sits there and I do all the talking and ask all the questions. Then afterwards we discuss what we have been told and he often heard something I did not. He takes life as it comes and that helps me. I have a tendency to worry about the future'.

Ann

The mothers accepted the relationship of father and child being different from theirs relationship with the child. One mother described this difference and at the same time she saw them (the couple) giving mutual support:

'We have been the strongest support for each other, even though we experience this differently and meet him (the child) differently. He (the husband) does not go quite by the book, nevertheless, my husband understands him very well and I respect their relationship'.

Jane

5.4 Where to seek help

All the mothers described their need for support and that they did not always get the support they hoped for and needed such as from family and friends. In the dialogue we wondered about the reason of this lack of support. Was it possibly the strange, peculiar behaviour of a child with autism that made people hesitant to take on the responsibility, even for as short while? We were not able to find the answer to that question. The participants found other ways of support such as from other parents.

5.4.1 Nobody wants him

There were differences in how the participants experienced support from their nearest family in many different ways. All of them seemed to experience more support from their own parents than from their in-laws. As mentioned before it is not apparent at first sight that there is something the matter with a child with autism. Until the child begins to show its peculiar behaviour people do not notice that something is wrong. Why was the mother not able to control the child's behaviour? The mothers felt this question in the air even though it was not directly voiced and they talked about how they experienced this attitude from both relatives and strangers. One mother found friends and family not as willing to help with the care of her child with autism as her other children. Her

experience was that no one wanted him and she felt hurt for his sake. This is how she experienced the attitude from family and friends when she asked for help:

'There was suddenly an opportunity for me to go abroad with my husband. The Short Time Home could not take him, and no one in the family was ready to take him, but everyone could take his sister. He is not that difficult to handle'.

Jane

5.4.2 Parents to parents

The participants mentioned the importance of support and mutual understanding from other parents who had a child with autism. Even though the autism showed in many different ways and its seriousness was different among the participants' children they all described how important support from other parents was. The mutual understanding of each other situation was important. The participants also found the Icelandic Autism Society an important support especially those participants that have been active members and gone to meetings and conferences in Iceland and abroad. They considered the participation in parent's network both important and empowering. One participant described this support in this way:

'It is a good feeling to be with other parents and talk about autism and ones own child, go to meetings and congresses with parents and professionals and discuss autism and nothing else'.

Diane

5.5 The need for support from professionals

This study showed that the participants want more professional support. However, the participants were seldom offered support and some of them did experience being put down by professionals and officials. The dialogues' left me with some advice from the participants that will later in this section be presented in the participants' own words.

5.5.1 Support and lack of support in the diagnostic process

All the participants had mixed experience with professionals. All but two had gone from one professional to another to get answers for their worries about their children. The participants that first turned to nurses and doctors at the Health Care Centres experienced disbelief from the professionals about what they were saying and were reassured that all would soon be better. One participant described how she experienced rejection from the staff at the Health Care Centre because of her feeling of something wrong with her happy smiling child of 18 months. When the child was 22 months old his mother took him to the family physician and finally felt that there was someone who was listening to her. She described her experience in the following words:

'He did not let us leave until he had contacted a child specialist with know-how of autism and then the wheels started turning and we ended with the diagnosis of autism'.

Sara Jane

Seeking support from professionals is not always an easy task. One participant in my study described how proud she was of herself when she asked for help from the professionals at the State Diagnostic and Counselling Centre and she said to them:

'Now that you have finished your work, can we turn to you in the future and ask for counselling and advice when we need to?' I put a heavy emphasis on the word 'counselling' and would you believe it they said 'Yes'. This made me feel proud of myself

Ann

This mother, however unsure she was of the result, indicated the need for support from professionals. Her experience is consistent with Hanlon and Hanlon (1996) that undertook a survey among parents of children with autism (in Ireland). They came to the conclusion that the participants in their survey were not content with the service of the health care system. They also found that the parents in their study needed more support and information than were available to them (Hanlon and Hanlon, 1996).

My study showed how important it is for professionals to be careful in the relationship with parents, not at least in the time parents and child are going through the process of diagnosis. One participant described her negative feelings about the diagnostic process and the anger she experienced towards those who told her and her husband about their child's diagnosis. She described the situation when receiving the diagnosis, furthermore, as an awkward situation:

'It was the social worker that by accident was the person that told us that our son had autism. She thought that we had already been told and talked to us like we knew. I was very angry; nevertheless, I pitied her in those circumstances. It was a real mess'.

Diane

This shows how important it is for professionals to be aware of parents' feelings in the diagnostic process and furthermore, for each professional to have clear roles in that process. All the participants told about incidents in connection with

professionals, which made them angry. They had experienced professionals that had not listened to what they had to say. However, they also described their experience of respect and willing co-operation from professionals at one time or another. They described the relief they had experienced when they felt they were able to trust professionals and when professionals showed respect and support. One mother said:

'This was the part of the diagnostic process that we had been warned about as being difficult but it was this part that I experienced as the easiest because he was the only professional that we could ask questions. He explained and really listened to what we needed to say about our child'.

Martha

5.5.2 I know better

Two participants in my study described professionals that gave the impression that only they knew what was best for the child in a given situation and the professionals did not listen to the parent's opinion. One of those two participants described this feeling of rejection and how she took the matters in her own hands and she described this in the following way:

'After he was at last diagnosed with autism they told us it would be best for him to change pre-school and at that point we trusted them (the professionals) to know what was best for him. In this new place he was met with impersonal attitudes. After he had been there some time, I thought that this was not right for my child. I did not stop until he was back in his old place where we both met love and empathy and I was able to cry on their shoulders when I felt bad'.

Ann

The other participant described how she experienced uncomfortable pressure from professionals when offered services she did not feel ready to accept. She said:

'I understand that they were trying to help but I was not ready at that time. Later I went to see the place and now I am ready to let him go and that process has already begun'.

Dora

These two examples are consistent with Coulter (1999) who describes such an 'I know better' attitude as being an effort to keep distance between a professional and a client which only serves to make the client dependent on the professional.

5.5.3 When the subject is money

One participant described it as being more difficult and degrading to deal with officials than professional's when seeking support for their child. These officials were the people responsible for the money and the services their child with autism had right to according to law. Such services as driving handicapped children from their home-village to where they did have an educational offer that suited them. When she applied for this service for her son the officials she encountered had a 'we will see' attitude and she had to start fighting for the child's rights in society all over again. The mother said:

'Whenever it means money, or a service that will cost more we have to start fighting all over again again, without any support, and we are reminded of the cost. It is hard enough to admit that he needs extra service. We should not have to beg on our knees for what is rightfully his'.

Sara

The participants described themselves as advocates for their children and had to follow up on the service that was rightfully theirs and their children. The participants recalled incidents where it had been their opinion that the services should reconsider their decisions. One participant was determined to have her child's entitlement from the State Social Security Institute re-evaluated. She was convinced that her child should have the same financial support from the State as physically handicapped children. She saw their assessment unjust towards her child and his family circumstances. She described this incident in these words:

'We went through all the procedures and they explained to us how it should be, as if we were children. I did not agree and decided to try again. I wrote a diary about him. One has to do everything for him even though he is not in a wheelchair. I sent a new letter, accompanied with the diary to the State Social Security Institute and got back a 'Yes'. I am very proud of myself, I think I made a difference and an example for other parents'.

Ann

5.5.4 Giving advice to professionals

The importance of how professionals respond towards parents that turn to them for help has become evident in this study. Such as when they do so in their doubts about their child being 'normal' as well as in other crucial moments such as making decisions of the child's future. The participants said that they would have appreciated having some professionals to turn to when they really felt they needed help and did not know where else to turn. The following is some advice to professionals from two of the participants:

'I think that you (the professionals) know what you are doing. Yet, you could listen to us, and I often have the feeling that sometimes I know better and it

seems to me that parents should take part in every discussion about their child's future placement such as school, work and home'.

Alice

'I felt that I knew what was best for her, but the professionals made me unsure about myself, so I accepted their opinion. It became apparent later that I was right, they should have listened to what I said about my child'.

Ann

These two quotations show the need for respect and co-operation from professionals. This is consistent with Halldórsdóttir (2002) who discusses the empowering possibility for a client that meets a professional who shows competence and caring as well as trust, respect and commitment to the problem when a client asks for help. The findings in this study indicate how delicate the line is between being a 'good' professional that shows consideration and respect for the client and being paternalistic by having the attitude 'I know best'. Coulter (1999) stresses the importance of partnership instead of paternalism in the relationship between doctors and patients. I argue that it should be the same in all relationship between professionals and their clients and all the participants in this study wished to be respected and accepted as co-workers in the planning for their child's future.

5.6 Summary

The findings of this study indicate that all the participants with the exception of two were the first to notice that something was wrong with their child. Furthermore, they experienced themselves as being alone with the discovery, seeking support from family, friends and professionals. The mothers sensed that something was wrong when other people were not able to see anything wrong with their seemingly happy smiling child. It became apparent that meeting

professionals that did not show respect and understanding was an especially painful experience. This is consistent with Delaney and Engels-Scianna (1996) and Halon and Hanlon (1996) who reported similar findings of professionals failing parents by not giving support. The participants described the never ending responsibility for the child's future because the child would not be able to take decisions about his own future. The participants all described the returning sorrow usually with every milestone and change in the child's life and the mothers of adolescents described this sorrow as changing with time and becoming periodic. This is consistent with the explanation of chronic sorrow by Olshansky (1962) and Krafft and Krafft (1998) as a periodical feeling with no predictable end. The participants used their anger when fighting for their child and the fight and the anger that prompted the fight made them stronger. This is consistent with Dunn et al. (2001) explanation of confronting coping. In my literature search I was not able to find anything similar to the beautiful descriptions from the participants of rewarded love and how they learned from their children and this was an outstanding part of the study. Neither was I able to find comparison to the participants' use of autism peculiarities in a humorous way by sharing their experiences with other people and telling stories about their children. Nevertheless, Beck (1997) points out that humour helps people to express emotions and reduce anxiety. The described difference between mothers and fathers feelings regarding the child's handicap is consistent with Mallow and Bechtel (1999) who found in their study that the feeling of sorrow was at different moments in the life of parents of developmentally disabled children. In Karlsdóttir et al. (2001) study the mothers of adolescence with Chrohn's disease experienced their husband's role different from their own, nevertheless, the fathers were supportive. This is consistent with the experiences of the mothers in my study. All the participants made efforts to live their own life in spite of their role as caregivers for their child. They did this either by further education, or by working outside home. It became evident in the study that participants had both good and bad experiences with professionals and most of them told of at least

one incident where a professional had made a difference and shown respect and understanding. However it became apparent that they wanted more professional support and co-operation.

Chapter 6

Conclusions, implications and recommendations

The purpose of my study was to gain an understanding of the experience of mothers of children with autism. Furthermore, through that understanding I wanted to gain insight into how the participating mothers view their relationship with professionals. My interest in this phenomenon is built on my work as a nurse and counsellor for parents of children with autism. My hope is to increase my understanding of the phenomenon and hence to promote professionals to renovate their relationship with parents of children with autism and other kind of handicaps. In my choice of hermeneutic phenomenology I agree with Koch (1998) who argues that in a hermeneutic dialogue the researcher can gain a insight that builds on reciprocal trust and by revealing that understanding the researcher can make a difference in how to approach their clients in their work. The study revealed both expected and unexpected findings. Expected because of my pre-understanding of the phenomenon what is consistent with Gadamer (1998) that argues that the researcher can not be free of his/her pre-understanding. Unexpected because I gained a new understanding of how mothers cope with being mothers of children with autism. I also gained new understanding of what the mothers consider important in their relationship with professionals. In this chapter I will discuss the findings reported in chapter five. I will especially emphasise findings that I consider being important for clinical nursing. I will, furthermore, reveal my own learning experience when doing this study and discuss implication for nursing practice, nursing education and further research.

6.1 Conclusions

The findings of the study indicated that the participants experienced themselves being alone with the discovery of their child's handicap because other people failed to notice the handicap. The child's father, family, friends and professionals often rejected the mother's feeling of there being something wrong in how the child responded to the world. The participants' experience of the repeated sorrow is consistent with Olshansky (1962) and Krafft and Krafft's (1998) explanation of chronic sorrow as being a normal response to a repeated suffering that has no predictable end. The never ending responsibility of having to fight for the child's rights in society often at every milestone and changes in the child's life was outstanding in the study. The participants experienced deep love for their children and they described how having this particular child helped them become stronger as persons and being more tolerant and understanding towards other people's suffering. Even though the participants were occupied with the role of being a caregiver for the child with autism they all took steps towards taking care of themselves. They used different ways to break the isolation they experienced by having a child with autism. Their use of anger, humour and pride helped them to cope with their responsibility. The participants' use of anger is consistent with the definition of Dunn et al. (2001) of confronting coping as the ability to express anger and to use anger in fighting. Furthermore, the participants found that this fight made them stronger. The participants' use of humour as a way to cope became a discovery for me and in my literature search I was not able to find studies that supported this finding. Nevertheless, the use of humour between professionals and clients have been reported such as by for example Beck (1997) and Buxman (2000) who stresses the importance of the use of humour as one way to build trust between professionals and clients. The mothers' description of how they learned from being a mother to a child with autism and how they gained personal growth from that learning was an outstanding description in the study.

The findings showed that the mothers thought the fathers' met the role of caretaker differently from themselves, nevertheless, the participants that lived with the child's father experienced them as supportive and they respected this difference in roles. Furthermore, the participants described the fathers' emotional responses such as anger and sorrow being different from their own. The difference in recurrent sorrow is consistent with the study of Mallow and Bechtel (1999) who reported that mothers relapse to sorrow were related to co-operation with the health care systems whereas fathers experienced repeated sorrow was in relation to social norms.

The findings in my study indicate that support and respect from professionals is important for mothers of children with autism. The need for more support was described differently by the participants. The mothers of the younger children described need for more support, respect and understanding in the diagnostic process. On the other hand mothers of adolescents described the feeling of being alone with decision making for their children's future and wanted support from professionals.

I therefore conclude that, nurses and other professionals, officials and politicians need to reconsider the service, relationship and co-operation with parents of children with autism and children with other handicaps. Mallow and Bechtel (1999) point out that the way to provide holistic care for parents and their chronically disabled children should be by regular referrals and family based programs. Herman et al. (1996) insisted on the importance of establishing a network of parents and professionals. The findings in my study support the need for holistic care and network of professionals and parents. Such co-operation should build on mutual respect. The professionals should respect the parents' knowledge of their child and the deficit the child suffers from and parents should respect the professionals for what they stand for.

6.2 Implications for nursing practice

This study was conducted using a hermeneutic phenomenological approach and I argue that phenomenological research approaches are the best fitted for inquiry into peoples lived experiences. Although there is a considerable disagreement in the literature I agree with Taylor (1993) who argues that phenomenology and nursing are coincided because both are concerned with human beings. By listening to the participants in this study and reflecting on their experience with them I gained a new perspective of parents' situation with handicapped children. Already in the dialogues I began to see myself as a nurse and counsellor in a new light. I had always thought of myself as a 'good nurse' and co-worker, understanding and respectful in my co-operation with parents of the children in my service. I can see now that I have still much to learn from the parents themselves to improve my work. I reveal my learning experience here in the hope that it will be beneficial for other nurses and professionals working with children and their parents within different disciplines. One important point is how we nurses can show respect and listen to what parents have to say about our work. The participants described such an attitude as having considerably positive impact on their wellbeing and as being both helpful and empowering. Here I refer to nurses and other professionals that come in contact with parents of children who suffer from autism or other deficits that makes it necessary for the parents to be in contact with professionals.

6.3 Implications for nursing research and education

I was not able to find studies conducted by nurses in the field of autism but several studies of the relationship of nurses and parents of chronically ill children and hospitalised children were found. For example, Karlsdóttir et al. (2001) describes the mothers as the main caretakers of children with Crohn's disease and they found that the mothers worried about their child's future and they had the need to be able to turn to professionals that listened to them. Those findings

are similar to the findings in my study. Less attention has been given to fathers in these situations and it would have both theoretical and clinical implications to explore the difference of feelings of the mothers and fathers and their responses toward their autistic child. Furthermore, research could be conducted to gain a deeper understanding of how mothers use their anger and humour to empower themselves as well as being proud of their child and themselves. Carpenter (1995) has argued that research concerning those who care and those who are cared for should be conducted in communication between them. This argument does certainly apply to the parents of children who needs nurses as caretakers and the story of their relationships with professionals should be conducted by qualitative approaches such as hermeneutic phenomenology. Furthermore, I agree with Rose (1996) and Kendall (1997) who stress that the gap in understanding parents' responses and feelings when taking care of a handicapped child could be bridged by qualitative researches. My study gives information about the participants' feelings, what they use to cope in the role of being a caregiver for a child with autism and in the relationship with professionals. It is my hope that this study will encourage further research and be incorporated into nursing education. I myself have learned how I can improve my relationship with parents by more carefully listening and respecting the parents views.

6.4 Recommendations

The participants in this study gave some recommendations for the future relationship between parents of autistic children and professionals. Those recommendations can best be said with the words of one participant also cited in chapter five.

'I think that you (the professionals) know what you are doing. Yet, you could listen to us, and I often have the feeling that sometimes I know better and it

seems to me that parents should take part in every discussion about their child's future placement such as school, work and home'.

Alice

My hope is that my study will contribute to further research and thus I will draw together what I see and recommend as implications for nursing research and my hope is for the result of such research to have implications for nursing practice.

- This study has opened the door to the understanding of how mothers of children with autism experience themselves as being alone in the discovery period as well as experiencing anger and sorrow at almost every milestone in the child life and developmental process. Furthermore, this study has given insight into the mothers' use of anger, humour and pride in their life with their autistic children as a means to cope. To replicate this study with mothers of children with other chronic illnesses could give nurses and other professionals a new perspective of how mothers respond towards their children being chronically disabled.
- This study has raised the issue of the difference in how mothers and fathers meet the strain it is to have a child diagnosed with autism or other chronic condition. By further research professionals would be more conscious of parents' different needs in such situations and be able to use that knowledge when implementing intervention programmes.
- One significant question this study has raised concerns the relationship between parents of children with chronic illnesses and professionals. Further research is needed in the field of co-work and co-operation between parents and professionals. Such research should concentrate on parents' perspective of the co-operation.

6.5 Strengths and limitations of the study

The strength of this study is the way it was conducted, by a hermeneutic phenomenological approach. This allows the researcher to gain information of the phenomenon of interest by listening, interpreting and asking questions for clarification of his/her interpretation of what the participant is telling, both in the dialogue and afterwards when analysing and writing the findings. The methodology and method allowed my pre-conceptions and pre-knowledge of the phenomenon to become evident in the dialogue. The study was limited by the fact that it was conducted in one language, Icelandic that is my native language and written in another, English and sometimes it was difficult to make sure that the importance of what the participants were communicating was not lost in the translation. To avoid misinterpretation on that ground a colleague that is equally competent in writing in both languages went through the findings with me and then I turned to the participants for verification of my interpretation of their descriptions from the dialogues. Another limitation was not studying the experience of the fathers as well as the mothers and my study shows the need for such a research.

Epilogue

My hope is that the findings in this study will be useful in further research and nursing practice and thus improve the relationship of parents and professionals. I myself have drawn learning that I already use in my work with parents. I have learned to be more respectful and to listen more carefully to what parents say. My hope is for nurses to be in the forefront in research that concerns peoples' perspective of the health services in hospitals and out in the society. Nurses are often the persons that are in closest contact with clients of the health and social service and the first parents turn to. Thus it should be in our interest to gain a better understanding of our clients' perspective.

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Appendices

Fylgiskjöl

APPENDIX 1

Introductionary letter to possible participants in the study of: The experience of mothers of children with autism.

Dear receiver

My name is Sólveig Guðlaugsdóttir. I am a psychiatric nurse and a family counselor. I am employed at the Child and Adolescent Psychiatric Department of the National University Hospital (Landspítalinn) and as a Home visiting nurse. This research is my final assignment for my Masters degree in nursing from the University of Manchester in Britain, through the University of Akureyri, Iceland.

This is a qualitative research based upon mothers' voluntary participation in a study of their own experiences of being a mother to a child with autism.

The purpose of this study is to gain a deeper understanding of the experience of parents of autistic children and their relationship with the services offered. In this study only mothers will be asked to participate.

Your participation will consist of interviews, one or more, lasting ca. one hour at the time. Together we will choose a convenient location, provided that privacy will be guaranteed during the interview.

The interviews will be recorded and later transcribed by me. All personal identifications will be erased and then the data will be processed. While not being processed the data will be conserved in a private safety deposit box at my bank. The Data Protection Commission has sanctified this research and all their requirements have been met in order to ensure total confidence and anonymity.

I also wish to clarify that should you decide to participate and then reconsider, you will be perfectly free to do so, without any complications from my behalf. Should this situation arise all data received from you will be erased completely.

Enclosed you will find a document (Informed Consent) which I ask you to sign if you decide to participate. Please send it to me in the enclosed, stamped envelope.

Further information will be given by me through telephone: 5530153, GSM: 8623053
E-mail: solveigg@islandia.is

My best regards,

Sólveig Guðlaugsdóttir
Ljósaland 2

**Kynning rannsóknar á:
Reynslu mæðra af að eiga barn með einhverfu.**

Til mæðra sem leitað hefur verið til um þáttöku í þessari rannsókn:

Nafn mitt er Sólveig Guðlaugsdóttir, ég er geðhjúkrunarfræðingur og fjölskylduráðgjafi. Ég starfa annarsvegar á Barna-og unglingageðdeild Landspítans og hins vegar við heimahjúkrun. Rannsókn þessi verður lokaverkefni mitt í mastersnámi í hjúkrun við Háskólann í Manchester í Bretlandi sem tengt er Háskólanum á Akureyri.

Rannsóknin sem byggir á eigindlegri (qualitative) aðferðarfræði fer fram með viðtölum sem byggast á frjálsri frásögn móður af reynslu og upplifun sinni sem móðir barns með einhverfu.

Markmiðið með þessari rannsókn er að öðlast dýpri skilning á aðstæðum foreldra barna með einhverfu og samskiptum þeirra við þau þjónustukerfi sem leitað er til. Í þessari rannsókn verður eingöngu rætt við mæður og skoðuð upplifun þeirra í þessum aðstæðum.

Þáttur þinn í rannsókninni verður ca. einnar stundar viðtal í senn eitt eða fleiri. Valdar verða aðstæður sem henta þér. Þó þarf að vera öruggt næði til samræðna.

Viðtölin verða hljóðrituð og síðan skráð af mér, öll persónueinkenni afmáð og síðan unnið úr upplýsingunum. Á meðan á rannsókn stendur og ekki er verið að vinna beint úr gögnum verða þau varðveitt í bankahólfu mínu. Leitað hefur verið til Persónuverndar og öllum skilyrðum hennar fullnægt í því skyni að fyllsta trúnaðar og nafnleyndar sé gætt.

Tekið skal fram að þó svo að þú ákveðir að taka þátt en breytir síðan um skoðun, hefur þú fullan rétt til þess, án nokkurs eftirmála af minni hendi og munu öll gögn sem þegar hafa verið unnin afmáð á viðeigandi hátt.

Fylgiskjal 1 (Fh)

Meðfylgjandi er bréf (upplýst samþykki) sem ég bið þig að fylla út ef þú ert tilbúin að taka þátt í þessari vinnu með mér og senda mér síðan í meðfylgjandi frímerktu umslagi.

Allar nánari upplýsingar gef ég í síma: 5530153, GSM: 8623053

Netfang: solveigg@islandia.is.

Með bestu kveðju;

Sólveig Guðlaugsdóttir
Ljósaland 2
108, Reykjavík

APPENDIX 2

Informed Consent

Name of Research: 'The experience of mother's who have a child with autism.'

I, the undersigned, am aware of the purpose of this research. It is to add to professionals', and others', understanding of the situation of mothers' (parents') of autistic children.

My participation in the research will consist of approximately 1 hrs. interviews, one or more. The interviews will be recorded and transcribed by Sólveig Guðlaugsdóttir and she will personally process the information received. The strictest regulation concerning privacy and anonymity, set forth by the Data Protection Commission, will be followed.

The data will be numerically classified, as opposed to alphabetically, while being processed. The data will be stored in Sólveig's personal safety deposit box at her bank. All the data will be destroyed when the research has been completed and evaluated. I am free to withdraw from the research at any point of time at which time all data concerning me will be destroyed.

My gain from participating in this research will be an opportunity to discuss my experience with a professional who has a long experience in working with autistic children and their parents. The results might add to professionals' understanding as well as others' who are involved in the affairs of children with autism and their families.

By signing this paper I confirm my participation in this research and also my awareness of what it involves as well as my right to withdraw at any point.

I declare that I am willing to participate in this study as a volunteer.

Date: _____

Tel: _____

Upplýst samþykki

Heiti Rannsóknar: Reynsla mæðra af að eiga barn með einhverfu.

Mér undirritaðri er ljóst að markmið þessarar rannsóknar er að auka skilning fagfólks og annarra á aðstæðum mæðra barna með einhverfu.

Um verður að ræða c.a. einnar stundar viðtal eitt eða fleiri þar sem reynt verður að öðlast dýpri skilning á aðstæðum og upplifun mæðra barna með einhverfu. Viðtölin verða hljóðrituð og skráð af Sólveigu Guðlaugsdóttur og mun hún sjálf vinna úr efninu. Mér er ljóst að fylgt verður fyllstu reglum um trúnað og nafnleynd samkvæmt kröfum Persónuverndar. Gögn verða auðkennd með númerum en ekki nöfnum þann tíma sem verið er að vinna úr þeim. Gögnin verða geymd í bankahólfi Sólveigar og þeim síðan eytt að lokinni rannsókn og mati prófdómara. Ég get dregið mig til baka úr rannsókninni á hvaða stigi sem er og mun þá öllum gögnum þar um verða eytt.

Ávinningur minn með þátttöku í þessari rannsókn verður sá að fá tækifæri til að ræða reynslu mína við fagaðila sem hefur langa reynslu af vinnu með börnum með einhverfu og foreldrum þeirra. Niðurstöður geta bætt skilning fagfólks og annarra sem koma að málefnum barna með einhverfu og fjölskyldna þeirra.

Með undirskrift minni staðfesti ég þátttöku mína í þessari rannsókn og einnig að mér er ljóst hvað í þátttöku felst ásamt rétti mínum til að draga mig til baka á hvaða stigi sem er.

Ég undirrituð

Lýsi hér með yfir því að ég er reiðubúin til að taka þátt í þeirri rannsókn sem hér um ræðir sem sjálfboðaliði.

Dagsetning: _____

Sími minn er: _____

APPENDIX 3

Sólveig Guðlaugsdóttir

Ljósalandi 2
108 Reykjavík

Data Protection Commission

Rauðarárstigur 10 105 Reykjavík

Tel: 510 9600 Fax: 510 9600

E-mail: postur@personuvernd.is

Web site: personuvernd.is

The Data Protection Commission has received your announcement concerning the processing of personal data. The announcement has been numbered 163/2001 and a copy of it is included. Protection Authority finds no faults with the concerns of the announcement and it has therefore been published on the institution's web site.

Respectfully

Hörður H. Helgason
Lawyer

Sólveig Guðlaugsdóttir

Ljósalandi 2
108 Reykjavík



Persónuvernd

Rauðarárstíg 10 105 Reykjavík
sími: 510 9600 bréfasími: 510 9606
netfang: postur@personuvernd.is
vefning: personuvernd.is

Reykjavík 17. apríl 2001
Tilvísun: 163/2001/ HHH/--

Persónuvernd hefur móttengið tilkynningu í yðar nafni um vinnslu persónuupplýsinga. Tilkynningin er nr. 163/2001 og fylgir afrit hennar hjálagt. Af hálfu Persónuverndar eru ekki gerðar athugasemdir við efni tilkynningarinnar og hefur hún því verið birt á heimasíðu stofnunarinnar.

Virðingarfyllst,

Hörður H Helgason
lögfræðingur

Hjál:

- Tilkynning nr. 163/2001 um vinnslu persónuupplýsinga.

The interview guide

The in-depth question:

What is it like to be a mother of a child with autism?

Supplementary questions:

1. Does having a child with autism affect you and your family life? If so, how?
2. What has been most helpful in your life with your child?
3. What are the most prevalent feelings you have experienced in connection with having a child with autism such as disappointment, anger, patience, ignorance, fear, humour, anxiety or aggression?
4. Has having a child with autism influenced your personal growth?
5. What is your experience of professionals?