Jihan Salem

Everyday life of families of children with special needs

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Oslo Metropolitan University
Faculty of Social Science

Abstract

This study is about the everyday life of families of children with special needs. It aims to investigate the everyday life of these families by looking at their own experiences of being a parent, their own perceptions and understanding of their children's special needs and how they meet them. Moreover, this study focuses on family relationships and how these relationships impact on the family's everyday life.

The thesis is based on data which was collected by qualitative research. The Family Map method was used in interviewing four mothers who have children of school age with special needs. The interviews were conducted in January 2020. The children have different kinds of diagnoses. The empirical material was analysed using systematic text condensation strategy. The data was sorted into meaning units, and then condensed into six code groups and 21 sub-groups and discussed in line with theoretical approaches of the concept of family, social construction, phenomenology and salutogenesis.

The findings of the study indicate the importance of support which is given to the families of children with special needs. The support can be emotional or practical and it might be given through interaction with the mother or with her child. Giving support to the family was a criterion for considering someone to be a member of a family and was a criterion for inclusion in one's own family. The findings revealed that the definition of family according to the mothers includes not only those with kinship relationships but also friends, neighbours and colleagues who are supportive to the mother and her child at the present time.

The study concludes with emphasizing the impact of having supportive people surrounding the families of children with special needs, to help them to cope with life's everyday challenges, empowering them to meet their children's special needs and making their everyday life more predictable and less challenging.

This study highlights the importance of considering the inclusion of people outside the kinship group in family therapy practice when thinking about providing help and support for families of children with special needs. The support which people give in addition to the support of one’s own kinship group would make a difference in the everyday life of these families and would enhance their well-being and their resilience. The effort families spend on bringing up their children is invisible and is taken for granted in some cases. This study highlights the efforts these families make in providing a sufficient, secure and predictable life for their children, according to the resources they have and the support they get from their families, friends, neighbours and colleagues.

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Sammendrag

Denne studien handler om hverdagslivet til fire forskjellige familier med barn som har spesielle behov. Hovedfokuset rettes mot hvordan foreldrene i disse familiene erfarer foreldrerollen, deres oppfatninger og forståelse av barnas behov, samt hvordan de imøtekommer disse. Videre tar studien for seg relasjonene innad familiene og går nærmere inn på hvordan disse relasjonene påvirker familienes hverdag. Informasjonen som fremkommer av undersøkelsene, er basert på opplysninger innhentet fra troverdige kilder.

«Familiekart-metoden» (direkte oversatt fra engelsk: *The Family Map Method*) ble benyttet under intervjuene av de fire mødrene, som alle har barn med spesielle behov i skolealder. Intervjuene ble gjennomført i januar inneværende år (2020). De aktuelle barna har ulike diagnoser. [...] Gjennom systematisk tekstforenkling ble teorien om den empiriske forskningen benyttet for å analysere informasjonen som ble oppnådd. [...] Informasjonen ble delt opp i 6 hovedkategorier og deretter 21 underkategorier, som alle er drøftet i samsvar med retningslinjer for teoretiske tilnærmingsbegreper som vedrører temaene familie, sosial konstruksjon, fenomenologi og salutogenesis.

Resultatene fra studien synliggjør viktigheten av den støtten som gis til familier med barn som har spesielle behov. Støtten kan være av følelsesmessig eller praktisk art, og det kan gjerne være at den gis gjennom samspillet med moren eller barnet hennes. Å gi støtte er et av kriteriene for å kunne anse noen som familie, og det er også et kriterium for å kunne inkluderes i familien. Resultatene avslørte i tillegg at definisjonen på familie, ifølge mødrene, ikke bare innebærer slektskapsforhold, men også venner, naboer og kollegaer som har vist seg støttende overfor mor og barn i hverdagen.

Studien avsluttes med å understreke virkningen av å ha gode støttespillere rundt familier med barn med spesielle behov. Et slikt hjelpeapparat vil hjelpe familiene med å kunne håndtere utfordringer i hverdagen. Det vil også bidra til å styrke og motivere foreldrene i møte med sine barn, slik at de bedre kan tilby barna det som de trenger. Støtten gjør hverdagslivet mer forutsigbart.

Denne studien har betydning for familieterapien, når det kommer til forslag om inkludering av utenforstående, altså familier utenfor slektskapet, for å hjelpe og støtte familiene.
Støtten fra disse menneskene, i tillegg til støtten eget slektskap gir, vil utgjøre en forskjell i familienes hverdag og vil styrke deres trivsel og pågangsmot.

Innsatsen som disse familiene legger i å oppdra sine barn er usynlig og tas for gitt i noen tilfeller. Denne studien har fremhevet innsatsen som disse familiene gjør for å gi et tilstrekkelig, sikkert og forutsigbart liv til barna sine, i henhold til ressursene de har og støtten de får fra sine familier, venner, naboer og kolleger.

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CHAPTER ONE: INTRODUCTION

During my clinical placement as a master's student in family therapy, I noticed that many of the families that seek help from family therapy services have a child with a diagnosis or a child with special needs. Some of these families have been referred by child protection services for professional support in dealing with their children and others came by their own initiative to find solutions and to learn about methods for tackling family problems. Regardless of the reasons behind their seeking help, the meetings with these families were characterised by various feelings among the parents: joy, positivity, acceptance, interest, love, hope, enthusiasm, disapproval, blame, helplessness and fear. Hearing the stories of these families and reflecting on their family situations, awoke my interest in their everyday life. Usually, a family is asked to take with them people who they think could be supportive in coping with the daily burden. I noticed that most of the focus is on family members such as grandparents, aunties and uncles. Rarely, a focus is given to other people such as friends or neighbours and their contribution to family life. I recall once during my clinical placement, a mother of two children, the eldest had an Asperger Syndrome diagnosis was asked, what could help her to cope with the stress she faces every afternoon? She replied: to have a cup of tea without any distractions after coming home from work, and before beginning any other daily tasks. Through my personal reflections as a social worker and as a student in family therapy, I realized that supporting these families is challenging especially when families have limited resources.

My own reflection on relations within families with children with special needs, have been informed by my private experience. From my sister, who lives in Jerusalem, I have heard much about her experience of having a child with special needs. We have regular contact by telephone, and I get the chance to talk to her and to my nephew who was diagnosed with autism. I know that my sister's family life has been changed since her child was born. Many things have had to change to cope with everyday challenges and to provide her child with adequate treatments, such as quitting her job. It has been important for my sister to maintain the contact with those who support her and make her feel better. My sister's story indeed inspired me to do this study and widen my knowledge about the phenomenon of rearing a child with special needs.

Everyday life experience of families with special needs is both interesting and important to investigate. My sister's own experience shows different aspects that are worthwhile to explore thoroughly such as family relationships, family perceptions of a child with special needs and family resources. These aspects influence family life and the ability to cope with life's challenges that may be encountered. I realized that there are many factors that influence family daily life which are worth investigating in an attempt to help families. At the same time, I noticed that differences in parenting methods impact on the child and the family's well-being.

Having a child with special needs has an apparent impact on the family system and the family's everyday life. The function of the family has been influenced and new family practices must be applied to cope with the change in the family. Understanding the new situation that emerged following the diagnosis of a child, is one of the challenges which a family confronts. Additionally, there is the lack of resources which a family has and uses when encountering these challenges especially when these children live in difficult socio-economic circumstances. Navigating difficult situations in families is one of the major tasks to be undertaken by professionals who are working with vulnerable families. Parents with children with special needs feel much uncertainty in dealing with their children and people act differently in uncertain situations. Relationships within the family are influenced by the emergence of new situations. Providing these families with appropriate support contributes to enabling the family to cope better with challenges arising from their children.

This study aims to explore the everyday life of parents of children with special needs through looking at their own experiences of being a parent, their own perceptions and understanding of the needs of their child arising from the diagnosis or impairments, their daily life with its challenges which are related to the child and how they cope with these challenges. Additionally, the study will focus on family relationships and to explore if these relationships are changed in relation to having a child with special needs.

This study will contribute to knowledge in the field of family studies, social work and it will enhance professionals' approaches to understanding individual family needs. It will help navigating possible family problems and in taking into account family resources when assessing how to support families and promote family and child welfare.

This study is an attempt to answer the following questions. How is the family, as a system, consisting of parents and children, is influenced by a change which happens to one of the family members? How might child impairment and/or disability lead to other changes in the family? What happens to the interrelationship between parents, other children (siblings) and the society around them (outside the household), when the parent become a parent of a child with special needs? How is everyday life in these families organized? What kind of challenges does the family encounter? How do they cope with life challenges which are related to the child's special needs? How might other family members, friends and practitioners influence the everyday life of a family and the parents' role in raising their child.

Many of the previous studies have focused on the implications of a child's diagnosis on family well-being, emphasizing how a child's mental and physical health could create changes in family life. Though, little literature has focused on the everyday life of these families and their own experiences. This study aims to explore the everyday life of families of children with special needs: to shed light on the family's own experience and their interaction as a family in relation to their child: how the family organizes it daily life to meet their child's needs. Whether family members in the nuclear and extended family have any role in helping the family? Are family relationships supportive/not supportive and do they have an impact on family well-being and coping? To investigate the unique experience of a family of children with special needs by listening to the parents' stories about how they perceive their child's diagnosis, how they experience everyday life and how it contributes to the changing of the cultural and social perceptions of a family's experiences. It encourages the (re)thinking of the child with special needs in line with the diversity of family presentations and family constructions in different contexts in the postmodern society. Moreover, it contributes to the identification of new methods in assisting the family and the child.

(World Health Organization [WHO], 2020) stresses that the term special needs can be accorded to a child who has an "impairment in body function or structure which prevents the passage of light and sending of form, shape and size of visual stimuli, limitation in activity , such as inability to read or move around , a restriction in participation, such as exclusion from school". The International Classification of Functioning, Disability and Health stressed that disability occurs as a result of a combination of biological, social, environmental and personal factors. The Convention on the Rights of Persons with Disabilities (CRPD) in line with The Convention on the Rights of the Child (CRC) article 23, highlights equality in rights with other children, as for example the right to social inclusion and protection. The right to suitable support enables an intervention which promotes their health and gives them the opportunity to develop according to their mental and physical function. The CRPD highlights the importance of the interaction between children's health conditions and the environmental and personal factors that have an impact on how the child experiences his/her disability. Meeting with numerous difficulties during interaction affects the integration and involvement of children in society and enhances or hinders their development.

According to the (UNICEF, 2020, 2. paragraph), children with special needs are vulnerable and they are subject to stigma and exclusion in society. Their rights are partially addressed by the decision makers in the government. Attitudes which encourage “fixing” the child, focusing on diagnosis and on medication are more likely, instead of changing attitudes and providing adequate support to secure mental and physical development.

Despite what UNICEF points to, the last decade has observed an obvious change in attitudes towards children with special needs and their families. New socio-cultural and political perceptions encourage implementing new policies which support children with special needs at home instead of in institutions. Such policies encourage including children with special needs in their communities and rearing children at home, which consequently requires providing families with adequate support (Duvdevany & Abboud, 2003, p. 264).

Parallel to change in perceptions of children with special needs, studies have demonstrated that the last three decades have seen many changes in family life. These changes are embedded in the diversity of the family structures such as one-parent families, step families and splitting the family to several households due to separation of the parents. Family changes have put children at high risks in some cases where the family’s social and economic resources are insufficient (Clarke & Joshi, 2003, pp. 17-24). Concentrating on family challenges and resources characterises the contemporary family therapy theories, aiming to empower family “functioning and resilience” instead of focusing on family “deficits and dysfunction” (Walsh, 2011, p. 29).

Making a family has been related to having children in family studies (Gillis, 2003, p. 150). However, the decision can be challenging when a family has a child with special needs. The family’s daily routines are influenced, and their everyday life seems to be different from other families of children who are developing more typically. The impact of having a child with special needs is larger than any other life challenges (Wilder & Granlund, 2015, p. 134).

In some societies children with special needs are still marginalized and their inclusion in society is challengeable. Studies of deaf children and children hard of hearing revealed that relatives withdraw from interacting with the children due to the difficulty of communicating with these children (Wilder & Granlund, 2015, p. 134). In Palestinian society, children with disabilities are stigmatized. Their families face different kinds of challenges in interacting with the society which affect their self-image and their state of mind. Consequently, social support provided to these families is associated with society’s perceptions of people with special needs. (Duvdevany & Abboud, 2003).

According to Tétreault et al. (2014, p. 272) having a child with special needs can affect both the “quality of life” and the “well-being” of family members. Family members can be subject to stressors which accompany everyday challenges. Burden appear in terms of financial problems, little support and lack of resources. Recognising the support which a family needs to cope with daily challenges is crucial in promoting the services provided to these families. “Family support”, “respite” and “child minding” are identified as vital in assessing family need. Lack of individual, social and economic resources have an impact on engaging the child in leisure activities that are important for his/her development. The experience of having a child with special needs influences the parents’ mental and physical health in the long term (Tétreault et al., 2014).

Duvdevany and Abboud (2003) discuss the importance of social support on the well-being of mothers of children with special needs. In their study of Arab mothers, they differentiate between two types of social support, the formal and informal. Formal support is described as the help provided by welfare services. While informal support is that provided by social networks and family members in the extended family or by friends, and which can be both in terms of material and emotional support. Classifying the support in this way, relates to the sources of the support and not to the fundamental nature of the support. There are distinctions in defining the concept of support and there is no agreement on how it should be defined (Tétreault et al., 2014).

Following the previous definition, informal support is rooted in help that family receives from family members and their social network. This help comes in terms of *emotional support and practical support*. Emotional support is experienced through giving love and care to the family which help to lower tension in tough situations; love and care enhance family well-being (Tétreault et al., 2014, p. 274). According to Wilder and Granlund (2015, p. 134) emotional and instrumental support which are provided by social networks are “resilient resources” for families of children with special needs. Quality interaction between individuals in the social network and the family or the child through everyday life routines is beneficial. It provides the family and the child with numerous examples of help and in different arenas. This emphasizes the importance of family and social network support alongside the formal support which is offered by professionals.

Practical support is defined as "whatever support or intervention" is provided by the parents, family members and their social network to enable the child to be included in any activities. When practical support is given by persons other than the parents, the parents experience having free time (Tétreault et al., 2014). Other types of support have been recognized as crucial for the family and they are classified as formal support such as: educational support that assist in helping the family to adopt adequate methods to teach their child. Psychosocial support focuses on family relationships and securing good interactions which prevents conflicts and tensions. It also gives support in attending leisure activities and sport which integrate the child into society and ensure child development. Respite care which allows the parents to have free time for carrying out tasks that they are supposed to do. This kind of care proved to be very beneficial for the family and the child. Respite care is mostly known as a formal service, and some define it as a paid service. Several studies point to the positive effects of short breaks which provide the caregivers with time for themselves and promote family health (Tétreault et al., 2014).

According to several studies, the mothers are the main caregivers for the child in most cases. Consequently, mothers are exposed to high stress every day and this can cause mental illness such as depression and anxiety (Duvdevany & Abboud, 2003; Tétreault et al., 2014).

In Arab culture for example, mothers of children with special needs depend on the social support they get from "family members, neighbours, friends, social organizations, professionals and formal services" Though, the support which they receive from family and their social network increase their feeling of well-being. According to cultural norms and values in Arab culture, family is considered "the main source for security, self- esteem and self-identity of the individual and without family support, there is an increase in the level of anxiety and stress" (Duvdevany & Abboud, 2003, p. 267).

CHAPTER TWO: THEORETICAL APPROACH:

The Concept of Family

Many of the social studies in the twentieth century have articulated the concept of a nuclear family which consisted of a small group: married parents and children. Household and economic group were synonyms for family in the sense that the group shared both a household and an economy. This image of family was however, influenced by different types of cultures and traditions. For example, a nuclear family is less favoured than an extended family in some cultures (Cheal, 2002, p. 55).

The concept of family has been subject to debate in social studies and it has been difficult to give one definition of the concept due to the changes that have occurred in family structure in the last decades. In addition to other social and cultural factors that have contributed to increasing family diversity and in complicating the definition of family in modern and postmodern society (Cheal, 2002, p. 55). Levin (1994, p. 95) has addressed this problem, she stressed that the concept of family is a unique one that can bring different meanings in different contexts. She refers to three different approaches to the concept. One of them and which is most relevant for this research, is the individuals' own perception of family and how the individual comprehends and understands concept of family. Individuals decide who their family is, how to form it, who to include in it. So, family can be a group of people that consists of sisters, brothers and neighbours and friends.

Stepfamilies are a popular image of the modern family, for example, and consist of stepparents and stepsiblings that can either be regarded as family members or not. Family is seen as a *"self-identified group of two or more individuals whose association is characterized by special terms, who may or may not be related by bloodlines or law, but who function in such a way that they consider themselves to be a family".* A family is a kind of single system that consists of individuals. This system is subject to continual changes and it can be affected if one of its parts (individual) becomes incapacitated. Family health has been a concern of several studies that focus on enhancing the well-being and the health of the family members. The complexity of analysing family health is embedded in family relationships and their function as one system in relation to the sickness and impairment of one of the family members (Moen, Hall-Lord, & Hedelin, 2014, p. 3167).

The concept of family has been discussed extensively in family literature. The structure of the family had been subject to questioning. What are the characteristics of a family and who should be included in a family was *the* question? Is a concept of family confined to a specific space and time? Such an issue has been discussed thoroughly in social sciences that articulated the concept of modern families. Such questions invite extending the circle of defining families and suggest an invitation to modify, adjust, or confirm perspectives on the concept of family. Levin and Trost (1992, pp. 8-11) refer to a variety of elements that individuals have taken into consideration when they include persons in their family: parents inside and out the household, children and adult children who left the household and also pets. Inclusion of people in the family is also influenced by "Family boundaries" in which consist of barriers that determine family perceptions on inclusion. Barriers are embedded in family relationships to others and their interaction in wider society (Cheal, 2002, p. 33). Family members engage in several activities to supply material and emotional needs to each other and these activities illustrate what family members do as a social group (Cheal, 2002, p. 77). Morgan (cited in Finch, 2007, p. 66) emphasises the importance of understanding family through an individual's activities in everyday life. Morgan called these activities "family practices" that are integrated into everyday family life and their daily routines and by which individuals are *doing family*. Finch (2007, p. 66) added the action *displaying family* to emphasize the importance of family practices. By displaying family, she emphasized "the fundamentally social nature of family practices, where the meaning of one's actions are to be both conveyed to and understood by relevant others if those actions are to be effective as constituting family practices".

Children are considered important family members in the modern family. The shift in the perception of children and childhood goes back to the 19th century in Europe and in North America when children were seen in different ways and have been accorded different positions in society and in the family. Trost found that family definition is connected to having a child, "a married or cohabiting couple with a child" (Levin, 1994, p. 95). This assumption was highlighted also by Gillis in relating the concept of family to having children as mentioned previously. Children were considered the spirit of the family and spending time with them was imperative for parents. Furthermore, the quality of time spent with children was important in terms of reinforcing family relationships, making them meaningful and solid. Therefore, parents organised their time by following their children's timetables on a daily basis and especially during holidays. Gillis put it this way " we no longer live with children, we insist on living through them" and children became a part of parent's identity throughout life (Gillis, 2003, pp. 149-150).

In the beginning of the 21st century many changes have occurred and influenced the traditional family. The family began to be constituted in a different shape: the divorce rate is higher, and more children were born to unmarried parents. The continuity and the stability of family were influenced by individualization and this had an impact on family, personal and economic relationships. New arrangements of welfare states emerged such as economic support for education and different types of benefits. Gender differences, women's rights and individual choices and interests were highlighted by feminists: women sought education and jobs and became relatively autonomous. These developments impacted on family relationships and consequently on everyday family life which has been subject to change. Everyday family life has been characterized by many choices that should be considered in relation to family members' interests and personal conditions (Beck & Beck-Gernsheim, 2002, pp. 104-110).

Salutogenic approach

A basic concept in the salutogenic approach is the concept "Sense of Coherence" SOC that is related and could be understood through the sub-concepts: comprehensibility, manageability and meaningfulness. Aron Antonovsky who was the pioneer of this theory in 1979, wanted to draw our attention to the importance of thinking about promoting health by asking ourselves about the factors that make people stay well in difficult and demanding circumstances instead of focusing on the diseases that impair people. To shift attention from pathogenesis which deals with the reasons for the disease to the factors that make one feel better. To ask a person about the reason for being well although he/she has been confronted with stressful circumstances, instead of asking about the reason for being unwell. This is the essence of the Salutogenic approach (Hansson & Cederblad, 2012, p. 245).

The "Sense of Coherence" SOC is clarified by "generalized resistance resources" (GRRs). Antonovsky talked about individual resources that make people cope with pressure in stressful life situations, and in which it makes sense and meaning for them by acting with this attitude. These GRRs comprised the "Sense of Coherence" (SOC) which is defined by Antonovsky as: "generalized orientation toward the world which perceives it, on a continuum, as comprehensible, manageable and meaningful". A strong (SOC) leads to health and entails that he/she perceives a specific situation as demanding and intends to deal with its *"meaningfulness";* he/she is aware that the situation is not ordinary one *"comprehensibility"*;

and he/she thinks of solutions using an available resources repertoire to cope with the situation and to take action *"manageability"* (Eriksson & Lindström, 2006, p. 376).

In family therapy, a salutogenic approach provides a method or instrument to predict good health in both children and adults (Eriksson & Lindström, 2006, p. 378). Relevant to this research, is to look at the coping strategies in families of children with special needs. Previous research showed that these families encounter life stressors as caregivers, and they react by adopting uncertain practices (Solem, 2011, p. 58). Their practices are embedded in their lifestyles that are shaped by socio-economic and cultural conditions (Antonovsky, 1996, p. 12). By helping parents to comprehend their child's problem differently, providing social support, increasing parents' resources, they could think of new practices that help them to tackle daily stress and improve their and the child's health (Solem, 2011, p. 61).

The salutogenic approach has a holistic character which means that it considers all the factors that influence the individuals and does not focus on only one aspects of life. Therefore, it is crucial, in family therapy practice, to throw light on the individual's everyday life by considering the different actors with whom they interact. Families' everyday life is structured by daily routines and plans that are made by parents and which are affected by family living conditions. To increase parents' social and economic resources, living conditions should be improved and thereby increasing SOC in families. Appropriate interventions, suitable support can improve both physical and mental health as well as improve resilience in families (Eriksson & Lindström, 2006; Solem, 2011). High SOC has been associated with better health and low SOC has been associated with both physical and mental health problems (Eriksson & Lindström, 2006, p. 378).

Antonovsky stressed that SOC could be affected by culture and context, but it is mostly affected by an individual's previous experiences that have permeated the process of tackling difficult situations and what resources one should use to tackle situations. It is imperative to understand strong or weak SOC as a procedure that combines perceiving a specific stress situation, thinking which meaningful action to apply in such a situation to best cope with, and using suitable resources to manage the situation. The likelihood of succeeding or failing in this procedure depends on how strong the SOC an individual has, and in any aces individuals learn from each experience and their SOC becomes stronger (Antonovsky, 1996, p. 15).

Social construction approach

The concepts of family and children with special needs can be understood through the social construction approach. According to constructivists, scientific concepts are developed through a process that is impacted by social, political and cultural factors. To comprehend the scientific concepts, one should look at how these concepts have been constructed historically and culturally, and to explore the elements that influenced the constructing of these concepts. To elaborate this point, one should understand the terms *real kinds and social kind and looping effect*. Real kinds are natural, and they have the characteristics of enabling us to generalize about them, such as gold. It has a specific property that enables making conclusions about it. Social kinds refer to different kinds of institutions and phenomena in society such as marriage, language, taboo, kinship, forced marriage and so on. Social kinds from an interpretivist standpoint can be observed and understood differently in different times and contexts. Social kinds are characterized by subjectivity and they are in continuous development. They are socially constructed: they depend on how people conceive them, interact with them, modify them and reconstruct them over time and space. Social kinds have a role in social sciences in terms of making causal generalizations about "social groups' values, beliefs, meanings, norms and actions", which turned out to be problematic from a radical anti-realism constructivist's perspective (Risjord, 2014, pp. 47-53). A moderate constructionism stream implied the complexity in revealing what is real but indicated the intentionality and meaning-making process that are embedded in identifying a real kind as a social one. Gergen (1999, p. 48) stressed the importance of meaning-making through individuals engaging in relationships that entitled interaction, dealing with, and talking and making agreements. By relationships new knowledge about different kinds among people are generated. Root suggested these three characteristics of a "real social kind": A. common sense understandings are people implemented by communities to make distinctions and classifications and thereby prescribe different treatments: B. those who are classified and who identify themselves (or not) with the classification, so the concept becomes a part of their self-image: C. specific rules are imposed to the interaction with those who are classified. If these three characteristics are permeated into the social kind, then social kind could be "real" and causal generalization can be applied (cited in Risjord, 2014, p. 50). However, this idea is subject to discussion and articulation and does not promise that all the real kinds could be considered as social kinds and vice versa.

Looping effects indicate the process by which changes happen in specific classifications of "social kinds". Social changes influence the descriptions of the classified group and consequently, the group behave in accordance to the description. New behaviours are followed by new self-perceptions about the classification and about the identity of those who are classified (Risjord, 2014, pp. 51-52).

Hacking explained the debate on real or constructed in his book the *social construction of what?* By discussing different types of social kinds such as child abuse and autism. He discussed child abuse as social kind that had been revealed in 1961 and had gone through a quick change that shaped its current form and gave it the title social kind. This change had been related to social, political and cultural factors. Philippe Ariès in *Centuries of childhood* introduced the challenge of thinking of childhood as socially constructed. Social scientists discuss childhood and children in different ways by looking at different conditions and behaviours that interact with the idea of childhood and children. The interaction consequently caused change in children and the idea about childhood, which invited scientists to think about problems in childhood. Knowledge of child abuse was started by American pediatricians in Denver in 1961 who got attention to injuries in small children, until then it was called cruelty to children. The knowledge that came out about child abuse at that time attracted the attention of many different actors in the society who consequently made future predictions about child abuse. These predictions had an impact on the children themselves and on their family and the environment they belonged to. What Hacking stressed was that the truth (knowledge) and the moral position on child abuse that the pediatricians initiated, influenced the work of many different actors in such areas as social services, media, law and family. Future predictions could assist the thinking about treatment affected children and alternatives for families where the abuse had occurred. Additionally, it could be used to explore other kinds of child abuse such as sexual abuse, incest and sibling abuse and emotional abuse (1999, pp. 101-103).

Another example of real or social kind is the psychopathology instanced in childhood autism that was first diagnosed in 1949. Autism is a diagnosis that had been through continuous development since autism existed before and after the identification of the concept and the diagnosis in 1949. But, should autism be articulated by biological or social explanations? Hacking stressed the importance of understanding these kinds in terms of biology and social construction and not only by either one or the other. Autism was initially intersected with schizophrenias to refer to some symptoms such as the absence of interacting with others and/ or engaging in social relationships. In psychiatry, the child's autism was explained by having a mother who did not react emotionally to the child. Autism had been linked to communication impairments since the child could not speak. Others also attributed autism to a lack of "theory of mind”. The contemporary literature about autism described autism as “the way people are” instead of “a thing people have”. To theorize autistic children in terms of social or real kinds, might seem problematic as it is characterized by communication difficulties. These difficulties do not mean that they cannot interact with their classification as autistic children. On the contrary, they interact with people in their family and their environment in an aware and reflective manner in accordance with their classification. Their interaction bears consequences for the whole environment they belong to and on those who are classified as autistic children. As a result, changes happen in the environment around the child such as the changes in the family’s perceptions of an autistic child. This change makes the classification of autism to be socially constructed due to the social that is embedded in the kind. But also, autism is real due to all the truth and knowledge that is integrated in the definition of the kind (Hacking, 1999, pp. 108-115).

For example, the status of a family is one type of social kind and the meaning of family is socially constructed. There is no one universal understanding of the institution of the family and the definition has several dimensions. The function of family varies widely from one place to another and this is due to its cultural, social, political, and economical aspects (Levin, 1994). Here in this research the concept of family with all its dimensions will be one social kind to be looked at through a social construction point of view. A child with special needs or disabilities is another social kind that will be studied through a constructivist standpoint as well.

Phenomenology approach

The idea of phenomenology is attributed to Edmund Husserl 1859-1938. It grew out of the need to have new theories to understand human experiences. Phenomenology as “an anti-traditional style of philosophy” aims to find the reality of things that describe a phenomenon in the way it exists, without involving any other social, religious, political or scientific factors that could blur the description and understanding of a phenomenon (Moran, 2000, p. 55).

Phenomenology can be applied as both theory and method in understanding a phenomenon and in seeking new knowledge about people’s experience of a specific phenomenon in their *life world* (Giorgi, 2008, p. 36). Svenaeus and Nilsen (2005, pp. 43-44) indicate three traditions in using phenomenology in research: the first one is to highlight people’s experience of living with specific conditions such as illness. The second one is an empirical phenomenology method that is applied to the medicine sector. The researcher looks for a “meaningful structure” that reflects upon a patient’s own experiences of being ill, hearing their stories on living with sickness, and how they understand their own experience. This is regardless of any current knowledge or theories put forward about the illness. The third use is about applying phenomenology as philosophical theory where one can acquire new knowledge about subjects and objects by asking ontological questions about a specific phenomenon. What is family? What is friendship? What is love and care? Seeking knowledge was start of phenomenology.

Giorgi (2008, p. 35) stressed its first use application by distinguishing between phenomenological method and case study to emphasize the essence of phenomenology as Husserl developed it in the first place and which deals with the truth as it is perceived by individuals experiencing a specific phenomenon as they are living in the world. However, the three applications of phenomenology mentioned above overlap each other in terms of the knowledge they generate about phenomena.

Knowledge in phenomenology is “a qualitative change in a person’s way of seeing, experiencing, understanding, conceptualizing something in the real world, rather than a change in the amount of knowledge which someone possesses”. The way an individual comprehends and understands phenomena creates different conceptions of the reality of the world. Individual conceptions are influenced by the principles the individual has, the social contexts and the different experiences one has. Conceptions have similarities and distinctions. The similarities contribute to create common conceptions among people that give them the feeling of belonging to a specific group and assist in rejecting contradicting conceptions and the distinctions might cause distance between individuals (Barnard, McCosker, & Gerber, 1999, p. 218).

People’s own reflections on their experiences of phenomena are at the heart of the phenomenological study. Husserl wanted to find out how meanings are produced by our experiences. Therefore, he stressed the crucial importance of studying the lived world away from the current knowledge or theory that researchers have. He suggested phenomenological reduction as a systematic method to study individuals’ experiences by focusing on what constructs these experiences regardless of the world where they displayed. Reduction is about looking at individuals’ conscious actions that target specific objects or phenomena. These actions/experiences are intentional, and they influence the identity of the individuals who also decided the conditions in which these actions should take place. Individuals’ own perceptions are consequently crucial in displaying world objects. At the same time, by individuals’ interactions and experiences, meanings of world objects continue to be produced (Svenaeus & Nilsen, 2005, pp. 46-47). In other words, reduction enables researchers to collect reliable information from the subjects about their own experiences in the way they are presented, understood and perceived by them. Additionally, it assists in finding out how new knowledge has been constructed and how meaning-making is made through continual interrelations in the life world (Giorgi, 2008, p. 41).

Life world is about people's authentic experiences of the world while living in it. It's not about how the world became as objects or about what the world consisted of, it's not either about how individuals became how they are, it is rather about the processes whereby people interact in the world and make/give meanings to objects. Meaning making is produced through people's conscious interactions with other objects. Interactions create different life world experiences, which are described as intentional processes (Svenaeus & Nilsen, 2005, pp. 46-47). Consciousness is a basic term in understanding phenomenology. It indicates that human beings' actions in the world are driven by consciousness. Consciousness reflects the intentional actions of individuals that prove their existence in the world (Giorgi, 2005, p. 76).

To elaborate, the interrelation between the individuals and the objects or "phenomenon experienced" is illustrated through individual acting. The variety of interaction between subjects and objects in the world create different experiences and subsequently different understandings of the same one world, which is constituted of the same objects/ phenomena and subjects. "There is only one world, which is understood and experienced in various ways by people; this world is both objective and subjective at the same time" (Barnard et al., 1999, p. 216).

CHAPTER THREE: METHODOLOGY AND DATA COLLECTION

Selection of sample

Since I wanted to investigate how the parents of a child with special needs live their daily life and to write about their experience, the first criterion for the sample was parents who are caregivers and who live with their child in the same household. In accordance with my experience from clinical practice, mothers are the main caregivers in families with children with special needs. They have an important role in rearing their children and making decisions for and with them especially when parents are separated, so I thought I will recruit mothers, but I did not have a problem to recruit fathers also.

The second criterion was related to the diagnosis the child has been given. I was interested to find parents of children with different diagnoses because it will give different kinds of knowledge. Moreover, different diagnoses might result in different kinds of behaviour among the children and consequently affect family life in different ways.

The third criterion was children (girls and boys) attending school. This would enable the capturing of a holistic experience of parenting in different life arenas and to explore their daily life in different contexts. Interaction with different people in society creates different experiences, such as school teachers and other professionals in social and public health sectors. Through their daily interactions in society, parents might have a variety of experiences of the phenomenon of being a parent of a child with special needs and it is important to highlight their experiences.

Problems in recruiting informants

I started the recruiting procedure in October 2019. In order to recruit the sample according to the criteria presented above, I had to contact friends and colleagues of mine who worked in the social and education sectors. I thought this would save me time in finding informants since they have daily contact with parents of children with special needs. I discussed with them the objectives of my project and the sample I was looking for. I recruited one informant by this means. I repeated this procedure one more time and my friends recommended contacting schools for special education and schools which have a class for special education and ask if I could recruit informants there. They provided me with names and emails of the schools, and I made contact later. This process resulted in two potential informants/mothers. For me it was a good start and I thought that the potential informants could help me to recruit others, so I prepared myself to use snowball recruiting.

A mother was recruited in the beginning and she agreed to participate in the research but withdrew because she became sick. She was asked to give names of other potential informants, but she did not respond. Another mother who had agreed to participate in the research, did not answer the text messages I sent to her. The key informant tried to contact her, but she did not respond.

I sent an email to a school that has special education classes where one of the key informants works, but the request was rejected. I sent another email to a centre for the treatment of children, following a recommendation by one of the key informants, but I did not get a response from them either.

Recruiting informants was both a challenging and time-consuming procedure. In December, I thought of other possibilities to recruit informants, so I contacted a mother who I met during my placement period and asked her if she was willing to participate in my research. She answered me and agreed to meet me when she was well because she was sick. In January, I made contact with another mother who I know has a child with special needs and she also agreed to meet me.

Sample

According to the sampling criteria presented above, and during four months working on recruiting informants, I managed to recruit four mothers of children with special needs. Their education levels varied between high school and master’s level. They all worked as teachers, social workers, freelance artists, and shop attendants. Some were single mothers and others were married or cohabiting with the fathers of their children.

The children were aged between six and fourteen and they had different diagnoses such as: Attention deficit hyperactivity disorder (ADHD), Autism spectrum disorder (ASD), Asperger Syndrome, Syndrome, Hearing impairment and developmental delay.

My aim was to recruit a minimum of six parents of children with special needs. Finlay recommends three to six informants in order to get enough data. According to Finlay, three informants are sufficient for master’s degree research because every interview demands deep analysis (Finlay, 2011, p. 141). Additionally, an adequate number of informants will supply enough data for research analysis (Malterud, 2012).

Data collection process

a) The key informants are supposed to ask potential informants if they are willing to participate in a master's study and to be interviewed by a master's student. Those who agreed to participate in the study, were asked to give their mobile number to the master's student for further contact.

b) Establishing initial contact with the informants was launched in October 2109 and time for interviews was arranged for January 2020, due to Christmas holidays. One of the informants was recruited in January. I initiated contact with potential informants by sending them text messages where we agreed on the time for a telephone conversation. The potential informants who answered the messages suggested a time when to call them. I called the potential informants and briefly explained the objectives of the research and the interview process.

c) I sent the informants a letter which explained the purpose of the study, the process of conducting the interview and the conditions of participating in the investigation after the telephone conversation. In addition, I sent a letter giving details of informed consent to be read and signed (Kvale, 1996).

d) I conducted the interviews in January 2020 following the informants' request.

e) A time and place were arranged for interviews. The mothers decided where we should meet. Some of them invited me to their houses during the morning time and others to their workplaces. The interview lasted between 90 -120 minutes and they were audio recorded.

Method

I read the book *Stefamilien-variasjon og mangfold* written by Irene Levin in the beginning of doing this research. Levin used the method family map in her research to collect data about families she met in relation to her research and family relationships. I was inspired by this method and I thought since no one has used it before, I will use it in my research. This method was new for me and after counselling from my academic supervisor, Professor Levin, I decided to apply the family map method in collecting data because I considered it to be a holistic method that enables me to obtain knowledge about family relationships in relation to special situations in family life.

As a point of departure, I needed to get more information about the method and how to apply it in research. I asked Professor Levin to give me both an introduction and training in applying the method and she was willing to do so. I suggested that we could meet in Familia AS where I had had a placement during master clinic course in family therapy, and she agreed. After discussing the idea with my previous supervisor in Fri-Familia AS, who agreed to it, we arranged a seminar about family map methods. In February 2019 Professor Levin visited Fri-Familia AS, and presented the method to the students on a Master's in Family Therapy programme and their supervisor who attended the seminar. The seminar lasted for three hours. The students participated in the demonstration of the method and I observed and took notes. The seminar was important in the sense of introducing the method, discussing it and giving reflections covering the whole process. This emphasized and supported my wish to use the method in my research. As I would have to put this training into practice several times later on, I practiced it by interviewing my partner. In January 2020 I took a second training session with my academic supervisor prior to conducting the interviews to refresh my memory about the method and to prepare myself for collecting data.

About family map

The family map method consists of three parts: a family list, a family map and a conversation. The family list deals with the question about family members whom the informant thinks about and considers as a family. The informant is provided with a blank paper 4 A and pen and asked the following question: *"When do you think of your family, who you think about? can you write a list of those who are family for you?"* (Levin, 1994, p. 128). The informant is asked to write names of those who she considers as family and write relationships beside these names, such as son, brother and so on. Also, she is asked whether she can think of others who she has not included in the family list. The family list illustrates how the informant thinks about her family, and the reasons behind the inclusion of those people in the list. It is a departure point for asking questions about relationships and positions of family members (Levin, 1994, p. 128).

The informants in this research stated that writing a family list was "a kind of a weird task" to do. They said that one never thinks about who is or is not a family member for them. Writing a family list helped them to think about relationships to those who were included and not included in the family list. In some cases, they added or erased people from family lists after they reflected upon their relationships to them.

The family map is the second part of the method (illustrated in chapter four). To accomplish this task, the informant should use small pieces of papers that are provided in good numbers. These pieces of papers have been cut out in two different shapes and two different colours. Red triangle shapes are to symbolise male and pink circles to symbolise female. Moreover, a white paper, 60 cm x 60 cm is used to place the pieces on it. The informant is asked the following question: *"can you place your family members on the white paper as they experience the situation today?"* (Levin, 1994, p. 129). The informant should write her family members (people she writes on her family list) on the small pieces including herself. She should write names and relationships to those people and place them on the white paper in accordance with how near or distant they are to herself. Family map was a tool that has been used in the interview. The informants took time to place the pieces on the paper and reflect thoroughly about their relationships to those who are included. The fact that they are asked to place the pieces in accordance with closeness and distance brings up many reflections and feelings among the mothers. Especially when they reflected upon the changes that characterized their relationships to others. Some of them talked about how their perspectives on relationships have changed over time and how they perceived relationships now. In the end of the interview the informants are asked to stick the pieces on the paper with glue. I recalled that one mother sent me a text message late in the evening and asked me to move her father further away than her mother, because she is definitely closer to her mother.

The family map is a visual picture of family relationships from the informant's point of view. It consists of people the informant defines as a family such as: kinship relationships, friends, neighbours and pets. Family map provides "a concrete expression of an informant's (*inner image*) of relationships to family members" (Levin, 1994, p. 131).

The last part of this method is conversation. Conversation with informants enables an investigation into how informants make meaning by their specific actions by explaining to the researcher how and why she acts in such a way. Discussing the everyday life practices of a family, provides rich information about how parents' meaning construction is established by their agency as actors (Ulvik, 2007, pp. 73-75). My aim was to talk with parents about different themes in their everyday life through focusing on their subjective experiences and their authentic voices as parents of children with special needs. I integrated the life world interview principles into the conversation. Life world interview is a qualitative method that is basically used to explore informants' deep understanding and explanation of specific actions in their everyday life. This has been discussed thoroughly by Husserl in his phenomenological approach. Husserl described life world as a phenomenon that consisted of different kinds of patterns that people follow in their daily interaction with each other. These patterns (life world) are consciously composed and it makes a very vital part of individuals daily acting with each other (Svenaeus & Nilsen, 2005, pp. 50-52).

The conversations are based on Marianne Gullestad's articulation of everyday life as "a diffuse concept that has many dimensions. The most important two dimensions are: "the daily organization of tasks and businesses and everyday life as experience and the world of life" (cited in Gulbrandsen, 2014, p. 44). However, I prepared an interview guide with short questions to help me to hold the focus on everyday concrete situations in family life that I was interested in investigating. The interview guide consisted of a. "Introducing questions", b. "follow-up questions" and c. "probing questions (Kvale, 1996, p. 133).

I started the conversations by asking about yesterday's practices from the minute the child woke up until he/she slept. Questions regarding bedtime routines, school, mealtimes and activities were included in the conversation. By recalling yesterday's events, information about the interaction between the informants and their children emerged. Also, the family's relationships with others were discussed. The study's main objective is to shed light on the holistic experience of having a child with special needs in everyday life. This entails that one looks on *how* mothers make meaning through their daily experiences by interactions with their child, and not only on how they organize their life (Gulbrandsen, 2014).

I used probing questions when I wanted to get more information about specific situations involving the child. Listening and reflecting over the conversation created a comfortable interview atmosphere and encouraged the informants to unlock their experiences. The topics that were elaborated in the interview were related to the everyday practices of the family. Kvale explains that interview questions should be assessed through their relevance to the study of *thematic dimension* and the interaction in keeping the flow of the conversation going and motivating the subjects to talk about their experience and feelings" (1996, p. 130).

Reflections about the method

Talking about everyday life practices enabled the informants to discuss the themes which are high priority for them. Their elaborations of their own experiences and how they comprehend these experiences, helped me to understand how they act in specific cases and how their acting creates meaning for them. Thinking of family members and who to include in family list, was a strange task, some of the informants said. They are not used to reflecting upon their family, so they had to think about it and they asked me to elaborate my question about writing a list. This might have implications on the answers they gave me and their family lists, and I was aware that asking this question would be both interesting and challenging to the mothers.

A criticism of the method might be that the family map method could not satisfy an informant who wanted to include people with whom she has close relationships and were important for her in her everyday life, but who she wanted to present separately from family members. The method does not satisfy/provide an alternative in this situation. I solved this problem by asking the informant to present her suggestion on the family map. There she drew different levels of relationships to friends and neighbours as it was worthy to mention their contribution to her life and her child's life

As a researcher I am fully aware that I could have received other answer, if I had asked them another day, or during another period of their life. Perhaps if they entered the interview just after they had an unpleasant experience, then their answers to my questions might have been different and their family map would look different. Family maps could indeed provide an image of family relationships in different periods of an individual's life as Levin found out in her research *Stefamilien - variasjon og mangfold*. In this research however, understanding the current situation was the aim of the investigation and which informants reflected upon.

Ethical consideration:

Research ethics refer to issues to be taken into consideration during the data collection procedure. Dealing with these issues is mainly based on familiar ethical codes, well-known in conducting human research. Ethical codes are considered to be a work tool to assist the researcher to make choices in the research process from the start of the research to the last stage (Kvale, 1996, p. 110).

Informed consent. A letter of consent was sent via email to the potential informants to read and sign. The informants must receive information about the objective of the study, its features and how it will be conducted. Furthermore, the informants must know that their participation in the study is voluntary and they can withdraw from the research at any point (Kvale, 1996, pp. 112-113). Information about recording was detailed in the letter of consent. I decided to inform the informants about recording, in our initial telephone conversation. I wanted to be sure that they were comfortable with recording and to establish trust between us. The informants gave permission to recording and the interviews were audio-recorded. In one case, the informant asked me to stop recording for a few minutes because she wanted to talk about a sensitive subject that she did not want recorded. I collected the letters of consent on the same day prior to each interview.

Confidentiality

As a start point, I filled out an application for the Norwegian Centre for Research Data, and the project was approved in November 2019. I used the university's audio-recorder to secure a good quality recording. The interviews were transferred to Universal Serial Bus (USB) and were encrypted after each interview. The interviews were deleted immediately after transferring it to USB from the recorder. The data was copied to an additional USB as a backup and it has been encrypted and stored at my home.

Analysis of data

I transcribed the data verbatim into two languages: English and Norwegian. All the sensitive information such as names were anonymised. Systematic text condensation strategy was applied in analysing data. Together with my academic supervisor, I sorted the data into preliminary themes which are related to the research objectives. Preliminary themes were arranged in a table and were highlighted as meaning units. We have reviewed the meanings units several times and then condensed them into six code groups and 21 sub-groups. Sub-groups have been discussed in line with the theoretical approaches and previous studies. “STC aims for thematic analysis of meaning and content of data across cases” (Malterud, 2012, p. 802).

Validity and reliability

Reliability refers to producing consistent results in research. Therefore, the research results rely on several stages in conducting research. Reliability in interviewing relies on the interview guide that has been used. The interviews started with asking the informants to write a list of family members and then to make a family map. The conversation that followed has questions about the everyday life of the informants. I heard what the informants wanted to tell me and then elaborated the conversation to discuss topics that I was interested to know more about. In some cases, I just followed what the informants wanted to tell and it was obvious that each one of them has something that was a high priority for her to share with me. Some of them started to talk about family relationships and family practices during writing about their family and doing the family map. These reflections about family have enriched the data because they were told by the informants without asking them about it, and on their own initiative. These reflections have produced subjective data which enabled the categorization of similarities and differences.

Validity is about quality control throughout the stages of knowledge production. This is where the "craftsmanship and credibility of researchers becomes essential". Quality of craftsmanship refers to the communication and actions in the whole research procedure which requires constant checking, questioning and thinking theory. By validating, knowledge about specific phenomena is gained (Kvale & Brinkmann, 2015, pp. 277-282).

Validation is profound in terms of asking theoretical questions related to the method that has been applied to investigate the phenomenon of being a parent of a child with special needs. Additionally, validation is also important in terms of asking whether the informants are telling the truth. In the phenomenological approach, the subjects are the experts in their life, and they tell own their stories. This leaves the question about truth in the margin since truth in human science is always challengeable. Informants tell their stories from their own point of view and they believe that their stories are valid within the context of their life. Validation of life experience relies on the interpretation of the researcher. Additionally, transcription belongs and is a product of a specific context where the data was produced. This context should be integrated into the interpretation of the written data. For example, one of the mothers talked about how seasons affect their leisure activities. Both transcription and interpretation should assure validity when she says, "*in summertime it's different"*.

CHAPTER FOUR: PRESENTATION OF DATA AND FINDINGS

The following table illustrates the code groups and the subgroups discussed in this research.

Code groups	Subgroups
1. Family list	Mother's own kin, partner's own kin, former partner's kin Household Supportive kinship and network Geographic distance pets
2. Family map	Relationship to persons who are included in family list
3. Daily routines	Mealtimes Bedtime routines Stimuli/leisure activities
4. Hectic every day	Time as stress factor Siblings and friends/ importance of socializing Daily routines Child health related appointments Leisure activities
5. Relation to professionals	Public health Social services School
6. Challenges and support	Language/culture Civil status and mother's health Communication between parents Religion and faith

1. Who is my family?

All the interviews started with a short introduction of what we should do in the interview, and then by asking the question: When you think of your family, who do you think about? can you write a list of those who are family for you?" as described previously in chapter three. The mothers wrote lists of their family members, who they considered as family at the current time and they reflected over reasons for including them. The lists varied in their length and content. Writing the family list took time in some cases because the mothers wanted to share personal details about those who they noted down on the list. In some cases, the mothers explained and elaborated the reasons behind the inclusion of those people in their family. Criteria for inclusion in family lists were the mother's own kinship, partner's own kinship, household, support for the mother/the child, geographic distance, and pets.

Kinship was a common criterion which all the mothers took into consideration in the inclusion of family members. All the family lists included, on different levels, grandparents to the child, uncles, aunties, siblings. A partner's own kin were included differently in this research according to the mother's own experiences of her partner's kin and her contact with them in the current time. Former partners were included in the list and their children with a new wife/cohabitant. Their former partner's kin were partially included in some the cases of lone-parent families.

The household was another criterion for inclusion in the family and all the people who live in the household were included: mother, father, and children. In this research, there were no step families, but were lone-parent families.

Support for the mother and the child, was a basic criterion that has many dimensions. Supportive people were friends, neighbours, colleagues. They are people who the mothers experience as supporting her in everyday life and supporting her child. To be supportive is a basic principle for inclusion in the family lists as this research results revealed. Being supportive intersects with the other criteria of inclusion in family lists.

The mothers included their own kin, their partners, children, parents, stepparents, brothers, sisters, aunties, uncles, cousins, nephews, and nieces. They said that there are many people in the family, but they would write only those who they have contact with and who mean something for them. Those who support them continuously.

> *"We are many in the family but those who mean something for me and who are most supportive for me in everyday life are here (pointing to the list)".*

Their contact with those from their own kinship group varied from regular to occasional contact. Kinship seemed to be a determinant factor in inclusion of the mother's family lists, and in some cases, it was taken for granted and seen away from the support context.

> *“This is my brother (while she is writing the list), we are not so close to each other, we have different personalities and different approaches to life, he is very organized and has little empathy, unlike me”.*

A former partner's own kin were included in the family lists. The mothers have little contact with them at the present time, but they included them because they had a good experience of them in the past, and they said that a former partner’s kin are their children’s relatives.

> *“They are the family of my children, we had a contact when I was married, they were sad when we got divorced and were angry of my ex-husband. Now I don’t have much contact with them because they moved to another country, but we are kind to each other, I don’t tell them my private things, but we give gifts to each other and we like each other”.*

Partners and children who live in the same household were included in the first instance. Adult children who live outside of the household and former partners were included as well in family lists despite how often they have contact with the mother and the child. A mother explained how divorce has influenced her life. She had to change homes and her children had to change schools. She recalled this experience as sad and difficult for the whole family.

The mothers have also included their own kin who live away from them. The geographical dimension did not pose a problem for communication with the family. The mothers reported that through online calls such as Skype, WhatsApp, and Facebook, they have preserved relationships with their family. The mothers get much emotional support and encouragement through these online calls. For them, moral support was valuable.

> *I call her often, she is always available for me, I ask for her advice, she makes me feel that I’m a good mother. She encourages me and assures me that I can tackle challenges and things will be better. She motivates me to be strong and patient.*

Some of the mothers said that relations in the family can be challenging because they have a child with special needs. Some of their family members criticised their way of rearing their children instead of supporting them. They felt that they often have to explain their children's behaviour and why the children behave like this and why they (the mothers) reacted in such a way. They said that they felt that their family did not understand their situation and could not give them the support they needed in consequence. For them, kinship did not necessarily mean that family members would be supportive, and sometimes were even an extra burden.

> *"They don't understand my situation or my children's situation nor do they have any empathy, and so I don't feel that I'm so close to them. My brother can come out with such sentences like, you should do that, or it's like that".*

Another mother said that her mother and her stepfather who used to support her when her child was little/small, became sick and they could not offer as much help as before. She elaborated that their health situation makes them dependant on others and although they offer help, she could not rely on them.

Most of the mothers included persons such as neighbours, friends, and colleagues in their family lists. In explaining the reasons behind including them, they emphasized the support they receive from them. Their support is both moral and material. These are persons which the mothers meet often in their daily life and with whom they share much of their private life situations. They are persons who offer help in different ways. Such as conversations, fetching, making dinners and child minding.

> *"What I do when I have problems with my son is to contact my friend and she always has time for a cup of coffee with me".*

It is relatively common that mothers of a child with special needs have to explain their child's behaviour, or they are asked about the child's impairments, diagnosis and its implications. Such situations expose the mother to additional stress. The mothers reported that having a relationship with families who have a child with special needs (like them), spared the mothers explaining their child's situation or dealing with unnecessary questions. They felt that such relationships are equal and harmonious. In addition, those families when they offered help, they meant it, unlike others, who say: "*let us know if you need help"*, in Norway people often say "si ifra hvis du trenger hjelp". The mothers felt that not all those who say this, really mean it.

> *"This couple has a child with special needs who takes a taxi with our daughter. It is actually an invitation for friendship. One is spared explaining and excusing because everyone knows how it is. It's easy to have relationship with them"*

Pets were included in some of the family lists and family maps. They were regarded as a family member and the live in the household. One of the family lists and family maps included pets. A mother described her cat as an important family member because she is a common interest for her and her son. She and her son often chat about their cat. How is the cat doing and what does she need and who will take care of her? The mother explained her child's care for the cat and how he feels proud when that cat prefers to sit on his lap and not on the mother's.

> *"So, our cat (pointing to the family list), who is important for my son and for me, because she is our mutual interest. We love her and we talk about her, he sends me pictures of her, and he is so proud that she sits on his lap, she also has permission to go upstairs to him".*

2. Family maps

The mothers copied the names of the persons who they have on their family list and who they considered as a family in order to make family map. I provided the mothers with a big sheet of paper and small pieces of papers and I asked them to write the names in their family lists on these pieces and then to arrange them on the paper in accordance with closeness and distance to themselves. The mothers started by putting themselves and their child's details on the map. The mothers arranged family maps according to the relationships they have to the persons in their family lists. Emotional and practical support in relation to their child were two criteria which they considered when making a family map. Persons who they have kinship to and who are supportive to the mother/her child were placed close to the mother on the family map. For example, an adult child who assists the mother in collecting his/her brother or sister, a grandparent who follows the child in leisure activities, encouraging the mother and showing sympathy. Grandparents support in daily life was very essential for the mothers. They gave practical help with the child or with his/her siblings. In some cases, the mothers moved to live near their parents.

> *My mother helps one day a week. She can take care of my daughter after school; they eat together and so, I can work a little bit longer. My father in law takes care of my daughter also and gives her food until we come back home at four o'clock.*

However, those who were not supportive were placed far from the mother and the child on the family map. The distance from the mother and the child reflected the nature of these relationships. Grandparents who have supported the mother and her child in the past, were placed close to them on the family map. They have become older and they are not in a state of good or normal health, therefore, the mothers would not ask them for help, on the contrary, they helped them, as the mothers said.

The family map reflected an image of the relationships of how the mothers saw their family at the present time. For example, an adult child who moved from the household and did not have constant contact with his mother or his brother with a special need, was placed far from the mother and the brother on the map. The mother described a cold and not strong relationship between the siblings since they were children. This relationship did not get better when her children became older. To the contrary, it has become less significant because the eldest child did not acknowledge his brother's special needs. The eldest son was however included in the family map.

> *"It is really interesting to think about it, because my oldest son comes very far here (points to the map), it's difficult to get in contact with him, he is 24 years old and he has no time for me. The two brothers don't like each other, and they are very different".*

Mothers reported that family relations changed over time due to changes in the family situation. Though, they included their former partners and their new partners and children in their family map, they emphasized that they are important persons in their children's lives and so they were important also for them.

One of the mothers talked about the difficulties that she met during her integration phase in Norway as an immigrant. She considered her husband's family as her family and described her relationship to her mother-in-law as close. Her mother-in-law helps her with daily routines, collecting the child, taking care of him, and hosting him. Moreover, she helps the mother by joining her in meetings that are related to the child where she translates conversations to her.

> *I have a close relationship with my mother in law, I call her mom, she helps me, she never says no, she suggests that he (the child) stays overnight at their home. We understand each other, she understands the system and the regulations here (in Norway) and explains them to me.*

Family map of a mother of a child with a diagnosis of ADHD, online contact with mother’s own family

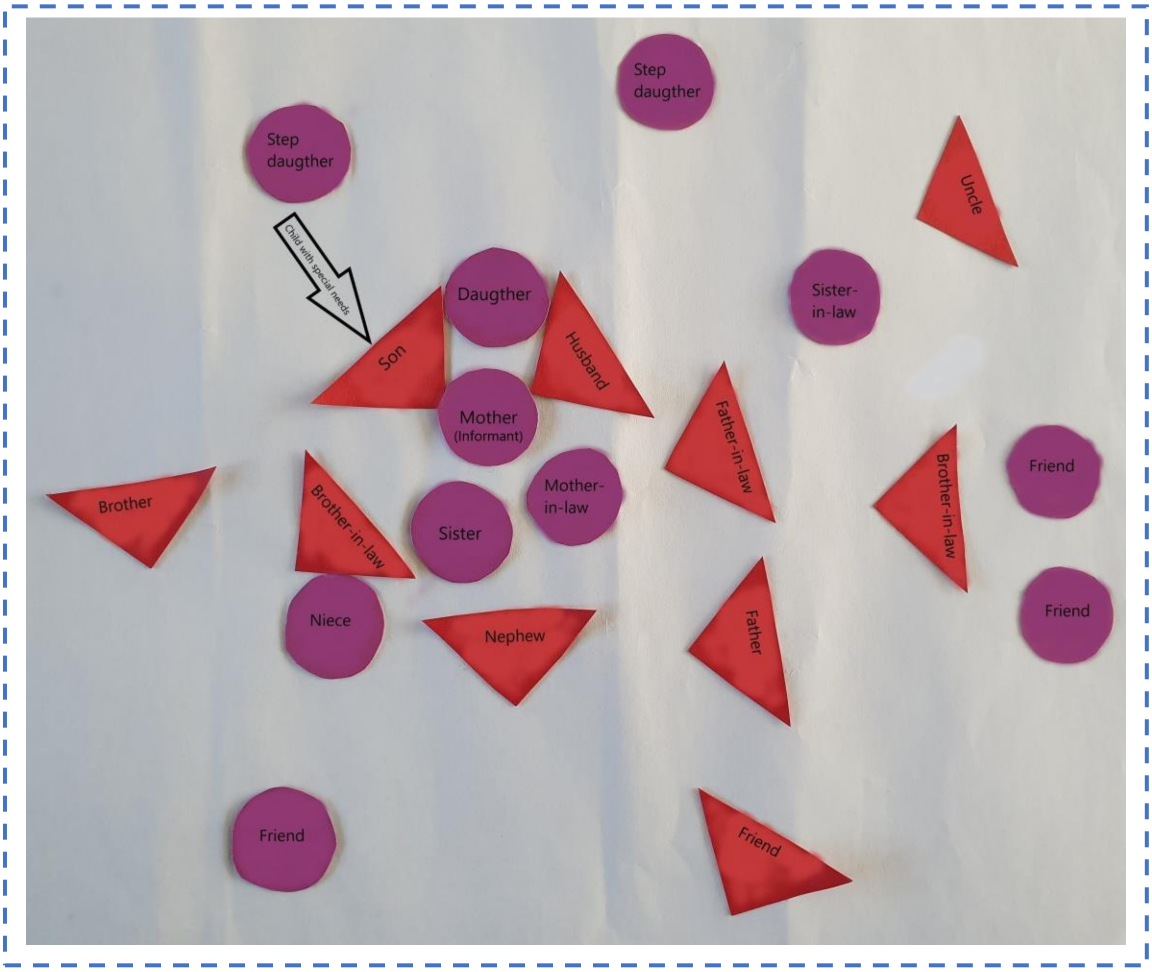

Figure 1

Figure number one illustrates a family map which includes: the mother, her son (the child with special needs), her family who live abroad (sister, brother, daughter, nephew, father , niece) and her husband’s family in Norway (husband, two step daughters who don’t live in the same household, mother-in-law, father-in-law, brother-in-law, uncle, sister-in-law) and friends. This family map demonstrated both close and distant relationships of persons who were considered as a family. Contact with family members via internet and social media applications helped the mother to maintain relationships with her family. She received emotional support and advice from her family, and she could maintain a relationship with her daughter. Moreover, her son could have regular contact with his half-sister.

When it comes to mothers' relationships to neighbours, friends, and colleagues, it is imperative to mention that all the mothers included those who support them in the present time. The mothers reported that they get emotional and practical support from their acquaintances. Friends and colleagues know a lot about everyday situations for the mothers and they offered different kinds of support. A mother described her close friend by saying: *"She is a mother and she helped many children in her job, and she was always here for me. She knows everything about me and about my life".*

Family map of a mother of a child with a diagnosis of Asperger syndrome

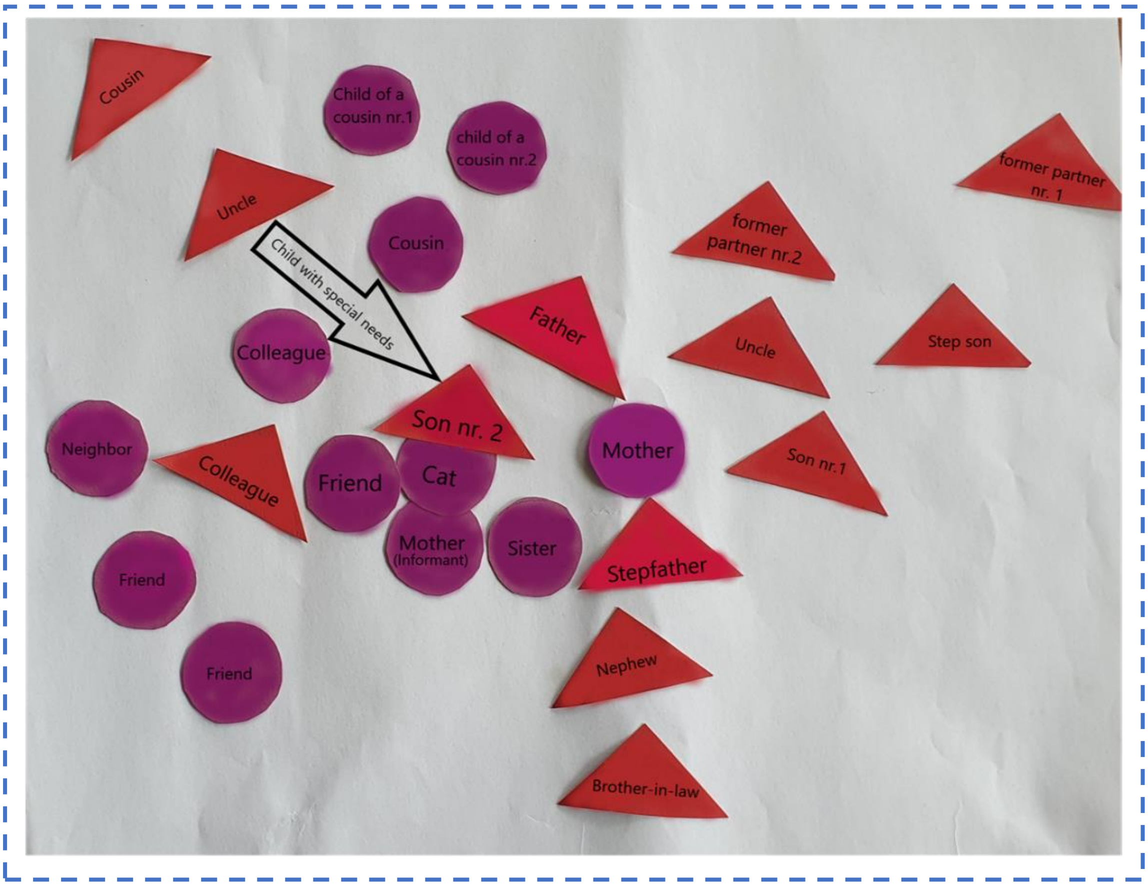

Figure 2

Figure number two illustrates family map which includes: the mother, her youngest son (the child with special needs), her eldest son who lives outside the household, her first former partner, the father of her eldest son, her second former partner the father of her youngest son, her mother, her father, her stepfather, sister, uncle, cousins and their children, brother-in-law, friends, neighbours, colleagues and cat.

3. Daily routines

The mothers reported worries about whether the child got enough food and the right food. Nutrition was a problem for them. Some of them talked about difficulties in supplying balanced meals to their children. The mother's supportive role was to establish a mealtime routine which might guarantee that their children get enough nutrition by the end of the day, though establishing fixed meal times was a challenge, as the mothers stated. In some cases, having good nutrition was crucial not only for establishing a mealtime routine, but also in treating the impairments that child has.

> *All the children who have this syndrome have a bottom in their stomach, but we know that food is so important, and we tried to create a normal food environment so she could eat by herself. We do not change mealtimes to eat all together. We do not wait until her siblings come back. When dinner is ready, we eat. It is she who is important.*

Most of the mothers felt that they must work harder to establish a mealtime routine and supply well balanced nutrition. Either the child would not eat enough, eat only specific types of food, eat unhealthy food, or would not eat what the mother offers to him/her. In the case of small children, planning meals and giving adequate nutrition was easier for the mothers. Children with the diagnosis of Autism and Asperger Syndrome have more difficulties regarding food. They were selective and they did not eat as the mothers wished. In the case of the older children, the mothers said that they have continual discussions with their children over mealtimes, food types and drinks. In some cases, discussions escalated to conflicts.

> *"Meals are difficult. I want him to eat vegetables, fish, and to get some vitamins. He is not interested in improving his nutrition or his lifestyle".*

The mothers reported a distinctive bedtime. Some of them said that their child has steadfast bedtime routines, while others reported variations due to the child's state of mind, age, and health. They emphasized that if the child went to sleep early, it would be easier for them to wake him/her up the next morning and their day would be different, but this was difficult to achieve at times. The responsibility of carrying out the task of waking up the child and putting him/her to bed was divided between the parents in the families where they have two parents in the household, which make establishing bedtime routines possible.

> *She is awake by herself; she sleeps in her room. Her father helps to get her clothes and she puts them on by herself. She goes to the toilet and then to the kitchen with her father and they eat breakfast with her brother. Her bag is ready with her lunch box in, we leave the house to take the tram that goes at 7 o'clock.*

In the cases of single mothers' families, the responsibility of organizing bedtimes is left to the mother alone, or to mother, and child. In the case of teenagers, the mother needed to remind the child of bedtime and to confirm that he/she is in bed. Sometimes it sounds as the mother is "nagging" and it could be problematic because the children do not like "nagging" as the mothers reported, but it is difficult for their children to follow bedtime routines. Moreover, bedtime routines can be disturbed during vacations and illness. In some cases, surfing on the internet and gaming were also obstacles that influenced establishing and maintaining regular bedtime routine. A mother described bedtime situation:

> *"It was half past ten in the evening, so it's quiet up there, but I know that he probably has one or two screens with him in the bed: mobile and laptop. Other children can have rules, but with him, NO".*

The mothers talked about leisure activity routines. Most of the mothers reported that they either arranged leisure activities for their children, or they engaged in their children's activities. They said that their children liked to play together with them and they (mothers) liked to play with them. They felt that they got more knowledge about their children´s world through playing with them or even by being an audience. Although mothers reported lack of time, still they played with their children and they experienced these activities as quality time.

> *"I ask him if he wants to finish playing Mario and Dizzy (a game) because we started playing yesterday, so he came downstairs. He plays and I watch him, we have a nice time together and we talk about our day also".*

Some of the mothers integrated playing into their daily routines and emphasized that playing was crucial for the child. A mother explained that they stimulate their child by engaging her in daily activities in the household. They described this experience as stimuli for their child.

> *She likes to cut up vegetables or mix food or set up the table and she is very clever to do these things without us asking her, and this is not a help for us but a stimulation for her and learning. She is happy to be with others and never in her room, playing in the living room.*

The mothers reported they felt a responsibility to involve their children in playing with other children and friends. They enabled and maintained such activities by inviting other children to their home or arranging different outdoors activities. *"His friend is here most of the time. They talk and play with PlayStation together, when the weather is good, they play football outside".*

All the mothers reported that their children used at least one device of the new technologies for communication; tablet, PlayStation, memory planner, mobile and computer. These devices were integrated into children's everyday life. The mothers reported various implications of the use of these devices for their children. On one hand, they described using tablets and PlayStation as interesting, amusing and learning activities for their children. They said that their children learn and entertain themselves at the same time. A mother described her experience of surfing a website *Salaby* with her child and finding maths exercises that her daughter liked to do. Another mother stressed that using a memory-planner to organize a plan for the day was beneficial for her and her daughter. On the other hand, mothers stressed the difficulty of limiting the use of these devices by their children especially when the child becomes used to it.

4. Hectic every day

The mothers described their everyday life as hectic. They said that their day is busy, and they did not have enough time to complete all their daily chores. Besides their job, they must deal with several issues related to their children, during the day. They said that they have to pay attention to all their children and not only the child with special needs. They also described siblings as both helpful and demanding. Adult siblings assisted parents in giving care, collecting the child from school and child minding. A mother described a daily situation for her family.

> *"One of us has to be home when she is back from school, my husband or her siblings or her grandparents, she can't be alone, so that's when we think family, its nagging and distressing and knowing one should come home and you look at the time and check subway times, so it's more time consuming than ordinary family and it is stressful".*

Siblings likewise need help from their parents on a daily basis. Some of the mothers described siblings' relationships that are characterized by jealousy, competition, or ignorance of the child's subject matter. In these situations, the mothers could spend more time with the other siblings to create a balance between their children. A mother portrayed their everyday life as surrealistic and parents must be practical.

> *It's surrealistic for us to go from an acute situation [with my child] to selling waffles in a football camp. I have gone right from the hospital to football camp with her brother. It's very surrealistic to think that one faces such a situation that we face. It's a huge variety. Fortunately, we are practical, and it helps when one doesn't become emotional. The practical works.*

The mothers reported that they experienced stress arising from daily chores. They wanted their children to learn daily routines and to master them, but this is time consuming. They said that their children can brush their teeth, put on clothes and shoes, although these chores should be monitored by an adult. The mothers linked difficulties in mastering these tasks to the diagnosis that the children have and their cognitive ability to learn. They stressed that repetition and accompanying their children help the children to concentrate and to accomplish daily tasks. In cases when children are older, the mothers reported less stress in relation to daily chores because the child mastered more daily routines. A mother described a stressful morning situation:

> *"I tell her to put on clothes and after 2 seconds she stands on her hands, so I say please put on your clothes and I go to the kitchen. Then she goes around and then comes downstairs with only with her panties on, and she forgets her clothes upstairs".*

The mothers reported health related appointments, school appointments and other appointments with Social Services (NAV), to the Child Protection Services (BVT) as time consuming and tiresome. They said that the time they spend in these appointments is hidden to society. Some of them said that they postponed appointments due to lack of time and in some cases, they gave up. Giving up such appointments had consequences for support that they might receive from public health services. A mother explained her experience of accompanying her daughter to see the eye doctor:

> *It's bothersome to have a child with special needs, for one thing it's everyday; to have all these controls and tests both routine and acute. To wait 5 hours*

> *at the eye doctor clinic. To go through 6 stations and then to the optician to get the eyeglasses. Parents of children with special needs have to finish the doctor appointments in a pleasant way so the child will not be afraid to have an injection or anaesthesia next time. So we go to a café or to look at the books in the library. It's time that is implicit to the society in which we use to facilitate these appointments.*

The mothers described playing and leisure activities as meaningful and amusing, and they tried to make time for it. In some cases, mothers said that activities come at the cost of bedtime or the parents' relaxation time. Most of the mothers experienced satisfaction and pleasure after playing with their children regardless of the fact that their day became more hectic. A mother described her understanding of the benefits of a playing activity:

> *"It's a duty more than a job and it's not like other children. You think you may give her a Lego and she will learn to use it later on, but with her she needs many repetitions and an available adult. She has been a small child for a long time compared to typical child development.*

5. Relationships with professionals

Relationships with professionals are important when one has a child with special needs. Some of the mothers reported that they did not get information after their child was diagnosed. Information regarding services which their child is entitled to was missing. The parents had to find out information about services by themselves. They read articles about the diagnosis and they joined related groups on social media. Relationships with professionals' in the Social Services (NAV), to the Child Protection Services (BVT) and to the public health services, were challenging in the mothers' experience.

> *It's like this with children with special needs, we don't get coordinators. There is something about the attitude of professionals from the health department. We must find everything by ourselves: special warm gloves, shoes and soles, no one calls us or asks, we must keep our eyes open. The municipality stopped the support group suddenly. I struggled all these years to get a support group for my son, and now my son will not join the group anymore.*

Although mothers reported a demanding process in establishing relationships with the professionals and applying for different services, most of them have received some help from the professionals. They reported that their children profited from having such services in the long term.

> *"I bought an annual subscription for him for the swimming pool, and he can have one companion with him for free with his membership, so he goes there with his friend once a week".*

A mother described her experience with Child Protection Services (BVT) as tiresome. She said that they were supposed to provide an assistant to help their child with homework two years ago, but they had not done so yet. She explained that the parents must apply for services, and this is a complicated process. Another mother described the relationship to school as exhausting and demanding. She told me that she is always anxious when he is in school and she feels helpless.

> *"When his teacher was absent, he became sad and angry and cried most of the day. The substitute teachers didn't understand him and didn't know how to deal with him. He cried a lot in the school, and this breaks my heart".*

6. Challenges and support

A mother talked about the implications of not speaking the Norwegian language fluently. She explained that she depends on her husband and her mother-in-law when it comes to social and health services appointments. She receives help from the Child Protection Services (BVT) but she must apply herself to receive further services for her child. She said that she could not apply due to her poor level of Norwegian and she barely knew what one should apply for. She leaves these procedures to her husband. She also talked about cultural differences and how living in Norway is a challenge to her. She had many things to think about, her child who needs help and herself as an immigrant.

> *"We should apply for other services such as discounts in transport and gadgets, but we have to contact NAV (Social Service Office) and we need to prepare many documents and it takes a few months. For example, gadgets,*

> *he can get for free, but we need to apply for them, and my husband didn't apply, he is so tired and has no time".*

The mothers considered their health situation as a barrier especially when they have many daily tasks. The mothers reported health problems such as: anxiety, ADHD, high blood pressure, prolapse and lack of sleep. In some cases, poor health prevents them from doing things, or doing things in a proper way. Additionally, the mothers explained how being a single mother makes things difficult sometimes because they have the entire responsibility for their children and for the household. A mother who is diagnosed with ADHD and has two children with two different diagnoses explained her daily routines:

> *"I have ADHD, so I do things differently than others. I am a little bit spontaneous and I don't manage routine or structure as others. I got a child that has had difficulties since he was small. Life has been challenging for me and my children"*

Mothers reported that communication between them and their spouses can affect their daily life. They reported that discussions can lead sometimes to misunderstandings and conflicts with their partners. They have different points of views regarding bringing up the child and daily tasks are left to the mothers in most cases. The mothers felt exhausted and they did not get enough help from their husbands or enough breaks. A mother said:

> *"I told him that I can't do everything alone because I'm sick and I'm on medicine. He said that I must visit the doctor. I don't want to visit the* doctor, *I only want to relax".*

In this study, mothers reported that support is crucial to manage the challenges of everyday life. Some of them sought support in praying and meditating either alone or with friends. Religious rituals and praying gave them hope that things will be better and made them feel stronger, not alone and to think positively.

CHAPTER FIVE: DISCUSSION

1. Who is my family? Writing a family list

Answering the question *who are my family*? and writing a list of family members who the mothers consider as a family, was a reflective question. The mothers thought thoroughly about who should be included in the family. Family lists exhibited similarities and differences. The similarities are embedded in applying their own perceptions and the comprehension of each mother to her family at the present time. The mothers decided who they wanted to write on their family lists based on their individual understanding of how a family should look (Levin, 1994, p. 95). The differences in the family lists are embedded in relationships to those who are included in their lists. Some of the mothers included only people who they have contact with at the present time, and some included people whom they knew in the distant past and barely have contact with them now (Levin & Trost, 1992, p. 29).

Kinship, household, support to the mother/the child, geographic distance and pets were criteria for inclusion of family members as presented in chapter four. Mothers' own kin and partners' own kin are people who the mothers have contact with at in the present time and on different levels.

Living in the same household is a criterion that qualified one to be included in family lists. All the persons who live in the house are necessarily included in the family lists (Levin & Trost, 1992, p. 8). However, the mothers included their adult children who moved away from the household. According to the mothers' perception of family, household was not equivalent to family.

Being supportive or not supportive to the mother and her child with special needs is an important finding of this research and is a basic criterion for awarding inclusion in the family. All the mothers considered "being supportive" as a threshold for their relationships to people in their family lists. Any support that is given to the mother and her child led to people being included in the family lists. Family members who helped and supported the mothers on a daily basis came first in the list.

Support is a cuddly word which refers to different actions that reflects love, care, and commitment such as helping someone, providing sympathy, and giving encouragement. The support which was given to mothers made them feel closeness and loyalty to those who provided them with support, and consequently they included them in family lists. Giving supporting as this research found, is a common principle between people within kinship groups and others such as friends and neighbours. Finch stressed that "family activities" are important in defining family rather than simply "blood or legal ties" (Dermott & Seymour, 2011, p. 21). And in the situation of a mother of a child with special needs, support is defined as a kind of family activity.

Supporting the mother by engaging in daily family practices and routines is explained by Morgan's concept "*doing family*" which is embedded in the actions family members employ in everyday life. Doing family was supported by the concept *displaying family* which implied the meaning that family actions "convey" (Finch, 2007, p. 66). The term of *displaying family* is rooted in the invisible practices in families that concern intimacy and feelings and relate to the quality of relationships (Dermott & Seymour, 2011, pp. 32-33).

Both emotional support and instrumental/practical support were regarded and described as imperative for the mothers. The mothers experienced emotional support through conversations with their family members and friends, colleagues, and neighbours. By meeting with others or talking to others via telephone or via social media, the mothers felt that they have been embraced and been supported by such contact. They could share worries and thoughts with their family and friends, and they experienced feeling heard and understood. Such conversations incorporated kindness and caring, and the mothers felt relief. Emotional support could be unnoticed by everyone, but it was not considered less important than practical support by the mothers. Instrumental support is any practical help such as assisting in preparing food for the child, playing with him/her, taking care of siblings, driving, hosting them in the holidays and so on. The mothers felt that those who give them assistance are their family because they show that they care for the mother and her child's/ family and they contributed to enhancing family's well-being. (Finch, 2007; Levin, 1994) implied the importance of acting as family to be included in family. Being supportive to the mother or to her child's life was a gateway to the entire family and vice versa based on the mother's own experiences.

Family lists demonstrated and emphasized the changes that have taken place in the family life course, and consequently, have impact on family relationships. Some of the mothers are divorced or separated. The fathers left the households and moved to another city in Norway or to another country with a new partner. Nevertheless, the fathers continued to have contact with their children and with the mothers. The relationships to the fathers varied from consistent to unpredictable and occasional. The fathers were included in the family lists regardless of their support or their presence. They were *"separate yet connected* "and their parenthood was not dismissed by moving out from the household (Finch, 2007, p. 68). Likewise, the father's kin are partially included in family lists. A stepmother who hosted the child during the holidays was considered as family and half brothers and sisters were also considered as family. Former partner's kin are described as important for the child and therefore, they were important for the mothers, as they stressed. Including former partners and their own kin stressed that women are "relationship oriented" in terms of caring for and committing to other people, based on kinship relationships and not on sharing the same household (Levin & Trost, 1992, p. 8). Previous family experiences such as divorce, were recalled by the mothers as both pleasant and sad.

There is no one standard or one framework of how a family should look. Family structure changes over time and space and this explains relationships within a family and how families create a unique identity as a unit (Finch, 2007, p. 68). The mothers in this study have defined and described their families differently. Their own situation and own experience as a mother of a child with special needs has influenced their own perceptions of how their families would look. Although they included several people in their family lists in line with kinship and household conceptions, they emphasized that what is most important for them currently is to be surrounded by people who are supportive and positive. Being a mother of a child with special needs demands and involves much mental and physical effort. By having effective support, the mothers could strengthen their efforts and be encouraged to fulfill their roles as care givers in everyday life.

2. Family map

The family map reflected upon the current situation of family relationships. This included all the changes that had happened in the family system such as separation, geographical change of the household, and changes in health in the family. Both *fluidity* and *diversity* had to be taken in considerations when looking at family relationships. Fluidity involved changes that happened in family relationships over time and diversity impacted upon the differences in family structure (Finch, 2007, p. 67). Family maps presented the closeness and distance of the persons in relation to the mother. Relationships to those persons determined where they should be placed on the map. Here, the mothers referred to several elements that characterized these relationships such as the *nature* and the *intensity* of the contact.

The nature of the relationships to persons on the map embeds how these relationships make meanings in the everyday life of mothers and their children, such as calling, caring, helping, and understanding their family situation. Mothers' and fathers' own kinships networks which supported the mothers were placed close to the mother on the family map. Others from kinship networks which did not provide any support were placed far from the mothers. They are considered part of the family but not supportive.

Intensity of the relationships referred to how often the mother has contact with persons included in the family list, and how near or far they should be placed on the family map. Those whom they regularly contact, were placed closest to them on the family map. Blood ties did not determine where persons should be placed on the family map. For example, an adult child who moved from the household and had little contact with his mother, or his sister/brother was included in the family but placed far from the mother. The mothers explained that kinship relationships between them and a few family members have changed over time, which means that both the intensity and nature of the relationships consequently have been influenced and changed. Some of the grandparents who used to be supportive in the past, became less supportive due to their health situations. This did not mean that they would be placed far away on the family map. Their previous contribution in family life was appreciated by the mothers and the mothers explained that there is even commitment to help grandparents in the present. Not surprisingly, this explanation was not awarded to the mother's friends and colleagues. Consistency and support were demanded from social networks and presented as a condition for inclusion in the family. Little was mentioned about relationships with former friends or neighbours in this research, and I assume, that is because the mother's current situation as a mother of a child with special needs was dominant.

Pets were considered as family members and in the family map, a cat was put close to both a child and a mother. The cat was considered as a link that connected the mother with her child because she was a common interest for them. The relationship to pets influenced an individual's state of mind, it reflected emotional maturity among children and life-mastering.

The role of new technologies and social media in communication has been underlined by the mothers. In the case of living away from family, mothers have maintained contact with their close family members by online calls and chat through Skype calls, WhatsApp, and Facebook. Online calls and social media contact did not determine the quality of relationships for the mothers. On the contrary, they regarded this kind of contact to be both crucial and supportive, and appreciated their family members who maintain such demanding contact. Such conversations had been integrated in family practices. Finch (2007, p. 66) argued that "families need to be displayed". And family members who were connected by online calls were placed close on the family map. Levin stressed that family was not accorded to a specific sphere or household, but it also spread out over larger areas and over different countries (Levin, 1994).

Writing a family list and making a family map revealed the importance of family and social support to the parents of a child with special needs. Several studies emphasize the impact of social support on “reducing stress, empowering parents, contributing to higher self-confidence and well-being among the parents” (Duvdevany & Abboud, 2003, p. 265). Family health depends on family resources that enable that family to cope with stressors which accompany having a child with special needs. Supporting a family practically and emotionally helps to extend the family repertoire in coping with difficulties in everyday life. Family support which is provided by family and social networks contribute to increasing family resources and consequently improving the family’s health.

It is crucial that family therapists as a part of their work with families in therapy, think who else they can involve in the therapy from the wider family and social network.

3. How to manage hectic everyday Life

The mothers experienced everyday life as hectic and characterized by tight daily schedules that consisted of daily practices, school, meals, leisure time activities and child health related appointments. The mothers organized their daily life by establishing daily routines. However, establishing consistent daily routines was described as challenging for the mothers. Denham (2003, pp. 305-311) described family routines as repetitive behaviours that are organized by the family by delegating responsibilities to family members. Family routines are established in the household and they take place in a specific time and space, and they are subject to change in accordance to different circumstances associated with family health and family constructions.

In the families that have managed to establish daily routines, daily life was described as more predictable despite the unexpected events that might occur regarding family members' health or other issues. Predictable family routines seemed somehow to assist in giving the feeling of security and mastery to the mothers and the children. Previous studies stressed the impact of having “structure and control” in creating a manageable and steady life (Moen et al., 2014, p. 3169).

Teaching the child, a daily routine was realized by the mothers to be important for the child’s development and for the family. Teaching the child daily practices requires the parents to start the process of teaching at an early age, when the child is more receptive to learn about the surrounding environment and how to interact with it (Haavind, 2011, pp. 25-30). Adaptation to daily routines by the children of this study varied in accordance to their age, mental and physical functions and to the persistence of their parents in establishing family routines. Studies on family routines indicated the importance in teaching children appropriate behaviours to achieve good health and to manage illness. Family routines are important in terms of responding to challenges that the family encounters in relation to chronic illness, by carrying out specific practices by both the parents and the child. Additionally, predictable family routines and health practices were associated with better health and satisfaction in families of children with illness (Denham, 2003, pp. 312-316).

In the cases where children could carry out some of the daily chores, the mothers were more satisfied, and they were even proud that their children could master some tasks. This reduced stress among the mothers and opened new chances for them to engage in other social activities. Persistence was demanded in order to maintain daily routines that have been established, and this was not easy for all the mothers. They needed support from the fathers, siblings, and cooperation from the child. As mentioned above, when it comes to the child, age, and mental and physical functions, are determinant in cooperating with their mothers, in addition to the motivation to cooperate. The mothers however, consciously, or unconsciously have established daily routines that worked for them at the current time. Whether these daily routines are beneficial in promoting family health, was a question that was partially addressed in this study. They talked about a better scenario for their daily lives, if they had adequate and enough resources that they lack at the present time. By resources, the mothers meant their health, support they get from family members and support they get from friends and professionals. Financial resources were not discussed directly, but they were linked to getting services from the government and enrolment of the child in leisure activities.

Stress and lack of time were mentioned as two factors that influenced family life. Carrying out all the daily chores and especially in the families with numerous children, demanded both time and energy. Family life was described as “surrealistic” due to the contradiction in chores that parents carry out on the same day. Daily life stress has a negative impact on parents’ health. Parental stress is related to the child's health, behaviour, and lack of sleep (Valicenti-McDermott et al., 2015, p. 1731).

The mothers experienced health problems**,** and they indicated the stressors that they confronted in their daily life which contributed to their poor health**.** Depression, anxiety and lack of sleep were associated with being a mother of a child with special needs (Tétreault et al., 2014; Whalen, Odgers, Reed, & Henker, 2011). Concerns related to the child such as adopting inappropriate behaviours, isolation, overeating, preferring computer games instead of other outdoor activities, were stressed by the mothers. Previous studies demonstrated that adopting unsuitable family practices and challenging relationships between the parents and the child have been associated with stress and poor health among parents. Consequently, parents' engagement in a child's treatments would be less effective due to their poor health. Family routines and family lifestyle have an impact on the functioning of caregivers in cases of illness. In addition, it contributes to managing stress and good self-image among the mothers (Denham, 2003; Whalen et al., 2011).

Engaging the child in outdoor activities has been described as beneficial for the child and the mothers. The child gets the chance to socialize with others, establish and maintain relationships, mastering feelings and the mother gets time for herself. Having leisure time activity routines, assists children in terms of socializing, stimulating, building confidence, and coping with daily challenges, and is regarded as a coping practice. Social activities promote the integration of the child into the society (Tétreault et al., 2014, p. 277).

To have a leisure activities routine for the children was considered to be important by the mothers. The children in this study have been engaged in different activities either out of their home or at home. The mothers experienced less stress when their children were with friends and they could have a break which is crucial for their health as the main caregiver. In the case of playing with siblings, and despite some sibling' conflict, the mothers were satisfied that the child played with his/her siblings. The engagement of the parents in leisure time and activities with children proved to be a successful way to establish good and healthy daily routines for the children and to empower parent/child relationships. The mothers described good experience as creating meaningful activities for their children. Parents engage themselves in playing with children at home, eating out with them, arranging outdoor activities, visiting other families, or inviting children's friends' home. All these sorts of arrangements created a safe and secure environment for the children; building identity and positive self-image and creating harmony between the children and their parents and siblings. New technologies such as iPad, memory-planner and PlayStation were mentioned as tools that were used by parents and children and were beneficial. Leisure activities are considered as a coping strategy which depends on family resources.

4. Everyday life challenges and support

The mothers mentioned several challenges which they encounter in everyday life such as relationships with family members, social and health professionals, establishing mealtime routines, their own health and being a single mother.

Relations with family and their network could be supportive as it has been discussed above, but it also could be a barrier. Mothers experienced criticism of their lifestyle and the way they were bringing up their children. This resulted in isolation and created distance from family members who were critical and not supportive. Explaining their children's behaviour to others was an extra burden for them. Therefore, having relationships with other families who have a child with special needs proved to be more successful and supportive. The mothers adopted lifestyles that fit in with their situations as mothers to a child with special needs and helped them to cope with daily stressors. Solem (2013, p. 2) has suggested studying parents' practices contextually to find out why parents have chosen a specific method in coping with everyday life and how they make meaning by their family practices.

In some cases, the mothers experienced inappropriate situations in meetings with professionals in the health and social sectors which demotivated them. Some of them got little support regarding information about services and financial support. In some cases, they struggled to get services for their children. Informational support for parents of children with special needs is crucial especially in the first phase after the child is diagnosed; it empowers the parents and gives them hope (Tétreault et al., 2014, p. 273).

The mothers experienced difficulties in dealing with schools and in some cases, this resulted in children dropping out of the school. Teachers have problems in tackling child behavioural problems, lack of concentration in the class and difficulties in communicating with the child. Some of these problems were partially overcome by enrolling in another appropriate special education school which enabled a relevant educational program, but this took time and the child lost some years from his/her life. In these cases, the mothers were satisfied with the school framework and the cooperation with the staff, so the mothers were relaxed. In the opposite situation, when school did not meet the mother's expectations, the mothers felt stressed and anxious. A good experience of school and good cooperation with the staff, assisted the family and eased the daily stress and vice versa.

Being a mother who is diagnosed with ADHD is another barrier that makes everyday life more challenging. The ability to organize life duties in a functional way is difficult without external support. Avoiding escalating conflict with children was a strategy that was used often. But this resulted in irregular bedtimes, meals and behavioural problems in some cases. Child Protection Services (BVT) were experienced as slow in assisting in such cases.

Being a single mother and having sole custody over the children has several implications in everyday family life. Daily chores must be carried out mostly by the mother especially if the mother did not receive any support from the family or the children. In the best cases, the mothers got help from the grandparents. Moving to live in the same city where the grandparents lived, was helpful in some cases. Many of the methods of rearing children and dealing with them were characterized by avoidance of conflicts.

Avoidance strategies are defined as “a way the parent withdraws, physically and mentally from difficult situations involving their child” (Solem, 2013, p. 3). The mothers have previous experience of how things could develop into conflict, children behaved aggressively in the past, they could hurt themselves and their mothers and consequently they had strategies to avoid making their children angry and to avoid conflicts. Creating separate arenas in the home helped to create harmony in child-mother relationships during puberty. Eating separately created less discussions over healthy meals. Previous studies stressed the increasing level of stress in parents with a child with special needs during puberty (Al-Yagon & Margalit, 2009, p. 112). Although the mothers wanted the best for their children, they knew that they could not do things differently at the current time. Such methods are meaningful and awkward: on one hand, they created harmony and a conflict-free relationship with their children: on the other hand, they created a situation of less parental control over internet surfing, gaming, and more time alone for the mother and the child. Meaning making is described as sophisticated in terms of involving several factors such as “personal characteristics, social support and environmental factors” (Solem, 2013, p. 3).

Another aspect that was crucial to discuss was that single mothers have experienced difficulties with their children since they were little. They did not manage to establish family practices that they would be satisfied with at the current time. They did not get adequate help from professionals and the family practices that they established have been changed because they were not persistent enough to maintain them as their children grew up or when their partner left the home. Parents’ practices should be understood through parents’ life experiences and their actual situation. Early intervention programmes of training for parents could help in these cases. Solem (2013, p. 3) emphasizes that situated parenting is “expressed through organization of daily life which changes as the child develops and is influenced by socio-culture dimensions”.

Language and cultural differences were recognized as a barrier that has an impact on making relationships and network, on communicating with professionals and on school related issues. A child with special needs is a socially constructed concept which is still associated with stigma in several cultures. It is crucial to understand how a mother from another culture perceives her child's diagnosis and to assist her in overcoming thoughts that are associated with stigma. This has implications for the individual resources that a mother has in dealing with everyday life. Stigma is linked to the idea of being different. Stigma is a concept which is culturally constructed and it is comprehended differently indifferent cultures.

CHAPTER SIX: SUMMARY AND IMPLICATIONS

The idea of this research started from my own reflections as a master’s student in family therapy on those families that attended family therapy counselling during my clinical placement as part of my course. These families have a child who has been diagnosed or was in the process of being diagnosed. Parents in these families described their difficulties in tackling challenges that emerged in rearing their child, and they sought help in family therapy. This inspired me to explore the unique experiences of families of children with special needs in line with phenomenological approaches and to look at their everyday life as parents by listening to their stories. Also, to highlight relationships within the family and with others and their impact on family’s everyday life.

I was interested to investigate what everyday life of mothers of children with special needs looked like. I conducted interviews with four mothers. I discovered when I asked them about their families, that their answers were related to their child. If a person was important for the child, then he/she was included in the family and considered to be important to the mother as well. A person who helps the mother in everyday life was also included as family. Looking at the experiences of four mothers of a child with special needs revealed similarities and differences. All the mothers in this research have defined their families in accordance to their own perceptions of how a family is supposed to look. All of them, in addition to their own kin, have included friend, neighbours and colleagues who have been supportive to them. A common and basic principle for the inclusion in the family is accepting their child with special needs, understanding her family situation, and giving her or her child some kind of support.

In order to achieve these results, I used the family map method developed by Levin and I integrated this method into the dimensional concept of everyday life, which is explained by Gullestad, as a “diffuse concept”. Gullestad stressed two different dimensions to the concept of everyday life: the first one is “the daily organizing of tasks and work”: the second one is, “everyday life as experience and life world”. “The experience dimension links everyday life to culture, understood as explaining reality, approaches and symbols”(cited in Gulbrandsen, 2014, p. 42).

I asked the mothers to write a list of family members and then to place them on a sheet of paper in order to express nearness and distance. So, I interviewed them and asked them to describe the previous day. This method obtained information about the everyday life of the mothers and what was important and meaningful for them. I felt that the method was useful for generating data about the themes that wanted to research and with the help of the family map, the family interrelationships were visualized in a way that I would not have achieved if I had used a traditional interview. In addition, the mothers said that the family map was and interesting way to reflect upon at their families and to elaborate their relationships with their own kin, friends and other acquaintances who are important for them.

Previous studies on families with special needs have used different methods based on interviews with parents, diary writings, observations and focus group methods. But I have not found anyone who has used the family map method to discover information about the reality of family life in special situations. Although, this study is about the everyday life of only four mothers, it gives theoretical insight for further research which could be used to investigate other life situations for families of children with special needs, by using the family map method. For example, studying family relationships with professionals, focusing on other family members' experiences of being related to a child with special needs, for example siblings or fathers.

This research emphasized the importance of support the mothers receive through interacting in relationships with their own kin, partner's kin and in their social network. In line with previous studies the results of this research confirm the importance of supportive relationships with family members and social networks to families with a child with special needs. This research did not aim to focus on the impact of the supportive/not supportive family relationships, but the results highlight the meaning such relationships give to the mothers in their everyday lives, because the mothers considered supportive persons from social networks as part of their family. The results have implications for family therapy approaches that should take into consideration the role of supportive social networks and their contribution to supporting families and appraise their inclusion into therapeutic counselling together with the family. Rethinking the definition of family and re-considering how one defines his/her own family would give an opportunity to think through new approaches to supporting families and children. In addition to a family's own resources which this research confirms as imperative in coping with challenges and stressful daily life, children's own resources were highlighted.

Children with special needs are considered vulnerable as are other children due to their age and maturity. Mental and physical impairments make them require help and consistent attention from adults. Being in a family that does not have enough resources to meet a child's needs, makes a child more vulnerable and exposes him/her to more challenges. Acknowledging the skills which a child has and enhancing them, is crucial in treating children with special needs.

The diagnosis becomes less visible when considering other individual resources, the child has, and focusing on them. The results show how the mothers appreciate the skills which their children have learned over time and how a child’s competence affects their everyday life.

The interviews revealed that despite the similarities that families of a child with special needs share, they have different experiences with their own child. Their own experiences have been influenced by different factors which are related to the mothers’ own comprehension of their children’s special needs, the child, the family situation as well as the support they get from their family and social network or formal services.

A child with special needs is a socially constructed concept which is subject to continual change and is embedded in political, social and cultural perceptions. These perceptions have an impact on how each society approaches a child with special needs and his/her own family. Despite the changes which are happening in macro and micro levels, the family and the child still face difficulties in dealing with several actors in society. The research results confirm that the everyday life of these families has many challenges which are related to other people’s attitudes towards the family and the child. Such attitudes might be negative or positive and they influence the way the family members and the child cope with everyday challenges. Additionally, these attitudes might be influenced by institutional practices and family therapeutic approaches.

Encountering difficulties in dealing with professionals and in getting adequate services might increase the level of stress among mothers and parents and consequently affect the child’s development in the long term. Previous studies and a good amount of literature have implied challenges which caregivers confront in rearing a child with special needs. To overcome these challenges, family resources must be evaluated in the first place during family therapeutic counselling. Recognizing family resources, their strength and their strategies in coping with stress in their everyday life, help in assisting the family to improve their resources and to use them in a suitable way. Moreover, questions related to family routines help in understanding how families organize their daily life and how they contribute or not, to improving family health. Perceiving family situations, their relationships, their resources and their coping strategies contextually and individually, being able to predict future problems that a family might confront and apply early interventions. Family and social support and further formal support can help the family and promote family health and well-being.

This research has focused on the everyday life experiences of families with special needs. The data was collected by interviews with four mothers who are also the main caregivers for five children with special needs. Further research with the fathers and siblings is recommended to investigate their experiences of being related to a child with special needs.

I wrote this paper in very unpredictable times due to the pandemic caused by Coronavirus COVID-19. Everything seemed peculiar for everyone in the whole world and especially when thinking about everyday life at a time when everyday life looks almost the same for everyone. My daughter was at home with me, as other children are currently because of school closures. My thoughts often went to my informants who are probably some most of the vulnerable groups dealing with this unpredictable and demanding episode. I knew that this situation would create more vulnerability in families with special needs and create more challenges. Online calls with my sister in Jerusalem reflected a real situation of how families of a child with special needs are dealing with difficult situations. Home schooling demanded that my sister has to be a teacher for her son who is diagnosed with autism and his siblings. My nephew did not understand the whole situation of being at home, but he was happy because he is there and surrounded by his loving family. His teacher is his mother who gives care and love. My sister’s family situation, however, does not reflect the situation of all the families of children with special needs. Many families become more vulnerable when exposed to such uncertain situations. Mapping out family resources by social and health services can assist in identifying the families who are in most need, and especially in such unpredictable times and provide them with suitable support and help and prevent unexpected conflicts.

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Appendices 1

Information letter to parents and letter of consent

Vil du delta i mastergradsprosjektet

" Hverdagsliv til familier med et barn med spesielt behov"?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke hverdagslivet til familier med barn med spesielle behov. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet vil i utgangspunktet undersøker hverdagslivet til familier som har et barn med spesielt behov. Hva slags utfordringer møter familien i hverdag og hvordan takler familien det.
Prosjektet vil ha fokus på familie struktur og familiestøtte i like situasjoner.

Hvem er ansvarlig for forskningsprosjektet?

OsloMet Storbyuniversitetet er ansvarlig for prosjektet.

Hvorfor får du spørsmål om å delta?

Du får spørsmål om å delta fordi du er forelder til et barn som har et spesielt behov og jeg ønsker å snakke med deg om hverdagsliv og utfordringer som forelder.
Jeg kommer til å rekruttere utvalget gjennom mine bekjenter og nettverk. Hvis du er interessert, ringer jeg deg og forklarer prosjektets problemstilling, sier noe om intervju, lyd-opptak og spørsmålene jeg vil stille deg. Jeg vil intervjue ca 4 personer.

Hva innebærer det for deg å delta?

Hvis du velger å delta i prosjektet, innebærer det at du møter meg og blir intervjuet om hverdagsliv som familie, daglig utfordringer som er relatert til deres barn som har spesiell behov.
Intervjuet vil ta ca 2 timer. Sted for intervjuet vil bli avtalt med deg, da det er viktig at du føler deg komfortabel. Videre vil det også framkomme indirekte identifiseres opplysninger om deres barn i intervjuet, og vi vil trenge samtykke fra deg som forelder til dette.

Du og ditt barn vil bli anonymisert, hvilket innebærer at personlige kjennetegn vil bli fjernet slik at det ikke er mulig å identifisere dere i den ferdige mastergradsoppgaven.

Intervjuet vil ta form som en samtale der jeg har noen temaer jeg ønsker å spørre deg om, samtidig som jeg er åpen for å tilpasse spørsmålene underveis. Det jeg er særlig interessert i å snakke med deg om er- hva slags utfordringer møter dere i hverdagen i sammenheng med deres barn diagnose, og hvordan dere takler de utfordringene. Vi skal snakke om deres familie- struktur og om strukturen ble endret etter at dere fikk barnet eller etter barnet fikk en diagnose.

Intervjuet vil bli tatt opp på båndopptager, og lydopptaket vil bli lagret kryptert på et sikkert sted.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Jeg vil bare bruke opplysningene om deg til formålene jeg har fortalt om i dette skrivet. Jeg behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

- Ved OsloMet vil jeg, mastergradsstudent Jihan Salem og veileder Irene Levin, ha tilgang på lydopptak av intervjuer og de transkriberte intervjuene.
- Navnet og kontaktopplysningene dine vil jeg erstatte med en kode som lagres på egen navneliste adskilt fra øvrige data. Lydopptak og transkriberte intervjuer vil bli oppbevart innelåst og på krypterte enheter.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes *15.05.19. Lydopptaket vil da bli slettet og intervjuet anonymisert.*

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra OsloMet har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

OsloMet ved professor Irene Levin, telf 992 28 325, e-post irene.levin@oslomet.no og student Jihan Salem e-post s231658@oslomet.no

- Vårt personvernombud: Ingrid Jacobsen, personvernombud@oslomet.no
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Irene Levin
Prosjektansvarlig
Professor/ veileder

Jihan Salem
Eventuelt student

Samtykkeerklæring

Samtykke kan innhentes skriftlig (herunder elektronisk) eller muntlig. NB! Du må kunne dokumentere at du har gitt informasjon og innhentet samtykke fra de du registrerer opplysninger om. Vi anbefaler skriftlig informasjon og skriftlig samtykke som en hovedregel.

- *Ved skriftlig samtykke på papir, kan du bruke malen her.*
- *Ved skriftlig samtykke som innhentes elektronisk, må du velge en fremgangsmåte som gjør at du kan dokumentere at du har fått samtykke fra rett person (se veiledning på NSDs nettsider).*

- *Hvis konteksten tilsier at du bør gi muntlig informasjon og innhente muntlig samtykke (f.eks. ved forskning i muntlige kulturer eller blant analfabeter), anbefaler vi at du tar lydopptak av informasjon og samtykke.*

Hvis foreldre/verge samtykker på vegne av barn eller andre uten samtykkekompetanse, må du tilpasse formuleringene. Husk at deltakerens navn må fremgå.

Tilpass avkryssingsboksene etter hva som er aktuelt i ditt prosjekt. Det er mulig å bruke punkter i stedet for avkryssingsbokser. Men hvis du skal behandle særskilte kategorier personopplysninger og/eller de fire siste punktene er aktuelle, anbefaler vi avkryssingsbokser pga. krav om eksplisitt samtykke.

Jeg har mottatt og forstått informasjon om prosjektet *[sett inn tittel]*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

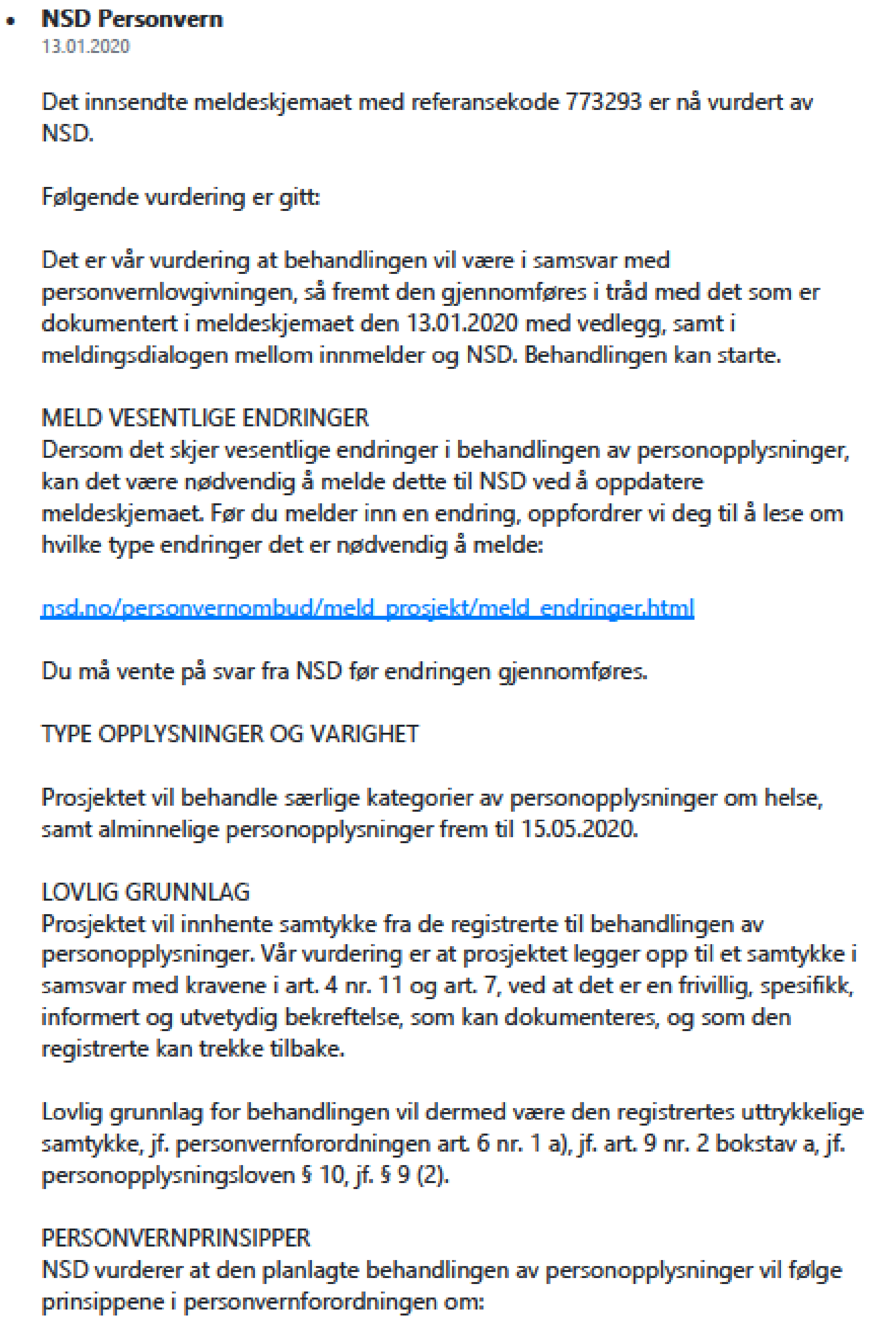
☐ å delta i *[sett inn aktuell metode, f.eks. intervju]*
☐ å delta i *[sett inn flere metoder, f.eks. spørreskjema] – hvis aktuelt*
☐ *at lærer kan gi opplysninger om meg til prosjektet – hvis aktuelt*
☐ *at mine personopplysninger behandles utenfor EU – hvis aktuelt*
☐ *at opplysninger om meg publiseres slik at jeg kan gjenkjennes [beskriv nærmere] – hvis aktuelt*
☐ *at mine personopplysninger lagres etter prosjektslutt, til [beskriv formål] – hvis aktuelt*

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. *[oppgi tidspunkt]*

(Signert av prosjektdeltaker, dato)

Appendices 2

NSD Approval for the research



- **NSD Personvern**
  13.01.2020

Det innsendte meldeskjemaet med referansekode 773293 er nå vurdert av NSD.

Følgende vurdering er gitt:

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 13.01.2020 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:

nsd.no/personvernombud/meld_prosjekt/meld_endringer.html

Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle særlige kategorier av personopplysninger om helse, samt alminnelige personopplysninger frem til 15.05.2020.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 a), jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

Appendices 3

Interview guide for parents

Family list

When you think of your family, who do you think about? Can you write a list of those who you include in your family? Is there anyone you did not include in your family list? Why? Who are those in the list? Give a description of the contact between them and the interviewee?

Family map

What is your relation to those on your family map; to your mother: friend, neighbour? What kind of activities do they with your child?

Questions related to the child with the diagnosis

1. *What diagnosis does the child have: when was he/she diagnosed?*
2. *What is special about this and how does it influence your life and his/her life?*
3. *What information did you get about the diagnosis?*

Questions related to everyday life

Tell me about yesterday, what did you do from the minute your child woke up until he/she slept? How did he/she wake up? Who woke him/her up? Questions related to school? What do parents do with their child: who takes the initiative for this activity? What do other people, family members, do with the child? Tell me more about (these) situations; what happened, description of situation: if was like this before, or if this is something new for you? Challenges: how the parents tackle situations: who can be helpful in these situations [by using the family map]? What can be helpful in such situations? What is help and support is there for you? How important is support for you in everyday life? What do you do when you have free time for yourself?

What is a typical day for you? Questions about family routines: people who are involved in daily routines: questions about themes which arose while talking about everyday life.

Questions related to professional support

What kind of support you get from professionals, social services, child protection services? Tell me about it?