



UNIVERSITY OF GOTHENBURG
DEPARTMENT OF SOCIAL WORK

UNDERSTANDING RESILIENCE IN FAMILIES OF CHILDREN WITH
INTELLECTUAL DISABILITIES IN SWEDEN: THE ROLE OF MICRO,
MESO AND MACRO LEVEL SUPPORT

THE THESIS IS SUBMITTED TO THE UNIVERSITY OF GOTHENBURG IN
PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF
MASTER OF SCIENCE (MSc.) IN SOCIAL WORK WITH FAMILIES AND
CHILDREN

AUTHOR: PRISCILLA AFUA AGYEMAN-DUAH

SUPERVISOR: CHARLOTTE MELANDER

YEAR: 2017



Erasmus
Mundus



UNIVERSITY OF
GOTHENBURG



University of
Stavanger



MAKERERE UNIVERSITY

Declaration

I, Priscilla Afua Agyeman-Duah, hereby declare that this thesis is the result of an original research conducted by me under the supervision of Charlotte Melander at the Department of Social Work, University of Gothenburg. No part of it has been submitted anywhere for any other degree. All references cited have been duly acknowledged.

Signature: P.A.D

Priscilla Afua Agyeman-Duah

(Student)

Signature: C. M

Charlotte Melander

(Supervisor)

Dedication

I dedicate this thesis to myself and my parents (Janet Agyeman & Franklin Agyeman).

Acknowledgement

All thanks to God for the life and strength he gave to me throughout this educational journey, particularly during the process of writing the thesis. Secondly, I wish to express my profound gratitude to Charlotte Melander for her selfless supervision and believing in my ability to complete the study when I lost hope. I say thank you and God bless you abundantly.

I also wish to show appreciation to all the families who participated in the study for their invaluable contribution in making this piece a success. I thank the Mfamily team for providing me with the wonderful opportunity to acquire knowledge and make an impact in society.

I can never end this section without acknowledging the support of my family. To my parents, Mr & Mrs. Agyeman-duah, thank you for your prayers and support. I also want to show gratitude to my brother Franklin Agyeman for his professional research guidance throughout the thesis process. To William Nyarko, the husband I love dearly, I say thank you for all the emotional support and understanding. I also say a big thanks to my mother-in-law for the practical support she provided me.

Lastly, I say thank you to all who have helped me in diverse ways but whose names have not been captured here. The almighty God who knows all deeds richly bless you and replenish in many folds all that you have lost for my sake.

Abstract

The study investigates resilience in families of children with intellectual disabilities with critical consideration to the role of micro, meso and macro level support in the resilience process. Three overarching questions underpinned this study namely; a) How do families with ID children in Sweden perceive formal support in their resilience process? b) What is the role of informal social support in the resilience process of families with ID children c) How does dynamics within families of children with ID affect family resilience? Qualitative research design was utilized in the collection and analysis of data. Seven parents from six families were purposively selected through the snowballing sampling technique. Study participants were engaged in both in-depth and biographic interviews to gain vivid insights into their experiences. Data was then analyzed using thematic and life line analysis.

Findings of the study indicates that, formal support plays an important role in parent's resilience by setting the pace for resilience. This is achieved through the emotional, psychological as well as financial support provided at the point of diagnosis, a stage that is characterized by high levels of stress. Parents perceived formal support as negative only when it becomes discriminatory and non-inclusive of children with disability. This is more evident in the allocation of resources to special and ordinary schools which sometimes makes it difficult for children with intellectual disability to be in an ordinary school. The study also identified other support systems of which support groups and family bonds proved to be the most beneficial. In situations where formal support is unavailable or limited, support groups and family bonds tends to contribute immensely towards family resilience. It was seen that family dynamics in households of children with intellectual disability is one that requires a constant reorganization of roles and resources to them function properly. For example, the study found that, to cope and function properly as a family, women often worked part time or quit work to care for the child with disability as well as take up other caring roles in the family. This seems good to maintain family equilibrium but could have negative effect on the trajectory of women in such households.

Based on these findings, the study recommends that, policy makers in Sweden should review laws regulating the allocation of resources to schools to ensure inclusiveness in the school system especially for children with intellectual disability. Social workers and related professionals are called upon to provide strength- based services by helping families identify resources that support growth and development in the face of adversity. Further research should aim at having the perspective of the whole family especially that of siblings and the child with disability. Also, the long-term effect of gender roles on the economic situation of women in families of children with disability should be explored.

Inconclusion, resilience is conceptualized as a complex process which requires the organization of resources at various levels to help families become strong and functional amidst the challenges of parenting a child with intellectual disability.

Keywords: intellectual disability, resilience, family resilience, families of children with disability, formal support, informal support

List of Abbreviations

AAIDD	American Association on Intellectual Disability Development
ASD	Autism Spectrum Disorder
DOAJ	Directory of Open Access Journals
DSM-iv	Diagnostic and Statistical Manual of Mental Disorder
ICD-10	International Classification of Disorder
ID	Intellectual Disability
LCA	Life Course Approach
LSS	Lägen Om Stöd Och Service Till Vissa Funktionshindrade (Translated As “Act Concerning Support and Service For Persons With Certain Functional Impairment”)
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Operational Definition of Key Concepts

Intellectual Disability

Significant limitations in an individual's intellectual functioning such as learning, problem solving and reasoning that affect their social, practical and other skills needed for everyday living (AAIDD, 2013)

Resilience

“The capacity of a dynamic system to withstand or recover from significant challenges that threaten its stability, viability or development” (Masten, 2011, p.494).

Family Resilience

“The path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families respond positively to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook” (Henry et.al, 2015, p.23).

Family

A group of people who have common history, present reality, and future expectations of mutually interwoven transactional relations (Štěrbová and Kudláček ,2014)

Formal support

It refers to social security transfer and in-kind benefit provided by the state.

Informal Support

The help received from family members, friends and/or acquaintances excluding assistance from household members (Armi, Guilley, & D`Epinay, 2008)

Table of Contents

Declaration.....	ii
Dedication.....	iii
Acknowledgement.....	iv
Abstract.....	v
List of Abbreviations.....	vi
Operational Definition of Key Concepts.....	vii
Chapter One.....	4
1 Introduction.....	4
1.1 Background of study.....	4
1.2 Problem Statement.....	5
1.3 Objective of the Study.....	5
1.4 Research Questions.....	6
1.5 Significance of the Study.....	6
1.6 Organization of the Study.....	7
Chapter Two.....	8
2 Literature Review.....	8
2.1 Children with intellectual disability.....	8
2.2 Effect of Child Disability on the Family.....	9
2.3 Resilience Understood.....	10
2.4 Coping and Resilience.....	11
2.5 Evidence of Resilience Among Families of Children with Disability- A Family Resilience Outlook.....	13
2.6 Disability Policy in Sweden.....	14
2.7 Informal Social Support for Families of Persons with Disability: Sweden as a Unique Context.....	17
2.8 Gender Roles in Sweden.....	18
2.9 Gender Practices Among Families of Children with Disability.....	19
Chapter Three.....	21
3 Theoretical Framework.....	21
3.1 Family Resilience Framework.....	21
3.2 Strength-Based Approach.....	23

3.3 Ecological Systems Perspective.....	24
3.4 Life Course Approach (LCA)	26
3.5 Chapter Summary	29
Chapter Four	30
4 Methodology	30
4.1 General Research Approach.....	30
4.2 Exploratory Research Design.....	30
4.3 Study Area	31
4.4 Sources of Data	31
4.5 Target Population.....	31
4.6 Sampling Technique	32
4.7 Sample.....	33
4.8 Sufficiency of Sample.....	35
4.9 Data Related Issues	35
4.10 Managing and Analyzing the Data.....	37
4.11 Ethical Considerations	41
4.12 Quality Assurance	43
4.13 Limitation and Delimitation.....	44
4.14 Process of Doing the Research.....	45
4.14 Chapter summary	46
Chapter Five.....	47
5 Findings and Analysis.....	47
5.1 Demographic Background of Families	47
5.2 Trajectory of Parents of Children with Intellectual Disability in Sweden	47
5.3 Support Systems Enhancing Resilience	54
5.4 Nature of interaction among support systems.....	66
5.5 Obstacles to Resilience	67
Chapter Six.....	71
6 Discussions, Conclusion and Recommendations.....	71
6.1 Discussions	71
6.2 Summary and conclusion	74
6.3 Recommendations.....	75
References	76

Appendices.....	85
Appendix 1: Interview guide	85
Appendix 2: Informed Consent.....	87

Chapter One

1 Introduction

1.1 Background of study

“Resilience is accepting your new reality, even if it's less good than the one you had before. You can fight it, you can do nothing but scream about what you've lost, or you can accept that and try to put together something that's good.” – **(Edwards, 2009)**

Developmental disability is an area that has received much attention from researchers over the period. The term refers to a wide range of conditions resulting from cognitive and/or physical impairment (May Institute, 2010). The most common form of developmental disability is intellectual disability, which is also the focus of this research. In a report submitted to the UN Committee on the Right of Persons with Disability, the Swedish Federation of Disability (2011) estimated that, about 38,000 people had learning difficulties, between 1500 to 2300 children suffer from autism and asperger syndrome, 5% of all children suffer from speech and language development with about 1-2% having severe conditions. People with intellectual disability have problems with major life activities such as language, self-help learning, independent living among others and requires assistance especially in the case of children. Miles (1998) noted that, the key support system for such children is the family since it's the first point of contact for most individuals.

Considering the enormous body of research about children with intellectual disability and their families, the literatures are fragmented, narrow and majority have focused on exploring the challenges and coping strategies of these families with little said about the empowering ways families deal with the presence of a child with disability (Beresford, 1994; Levine, 2006). However, current trends show a gradual shift from only viewing families of children with disabilities from the pathogenic point of view to a strength based and resilience approach (Leone, Dorstyn, & Ward, 2016). This new approach focuses on the strength and resources of families that enable them to handle the demands of having a child with disability. Yet, there is still very little

that has been done about family resilience in relation to families of children with disabilities (Bayat M, 2007). A review of various writings on disability and family by Farrell and Krahn (2014) showed that, majority of individuals with disability are cared for by their family. This informs why families need to be strengthened to meet the challenges associated with having a child with disability. Since most studies about resilience have focused on individual resilience, this research tends to consider family resilience in the context of families of children with intellectual disability in Sweden.

1.2 Problem Statement

With the increasing research on child disability and family life, most are based in Anglo-Saxon countries like the UK and US, with few emanating from contexts like Sweden (Broberg, 2011). Sweden is regarded as a social democratic state based on Esping-Andersen classification of the welfare state (Esping-Andersen, 2007). Thus, the state plays an active role in providing for the welfare needs of its citizens. In Sweden, parents of children with disability receive substantial support from government and the community to care for their disabled child (Olsson & Hwang, 2003). A research conducted by Broberg (2011) to explore the “expectations and reactions to disability and normality by parents of children with intellectual disability in Sweden” found that, families acknowledged the helpful nature of various social assistance but also expressed worry in how those services sometimes become disempowering. Parents in some cases make their situation look worse and only focus on the negativity to get the needed help, a situation that keeps families vulnerable and can affect their process of resilience.

Adding to this, research on family resilience has seen that, social support and family organization are key processes that helps families in crisis to cope and enhance their resilience (Walsh, 2003). Combining and putting all these into perspective within the Swedish context, the researcher seeks to understand how families of children with intellectual disability in Sweden incorporate various support systems to manage the daily demands of everyday life to remain strong and functional.

1.3 Objective of the Study

The general objective of this study is to understand resilience in families of children with intellectual disability in Sweden and the role of micro, meso and macro level support within this process. Specifically, the study seeks to understand how families perceive formal and informal

support in their journey of raising a child with intellectual disability. It would then assess how these support systems enhance or hinder resilience.

1.4 Research Questions

1. How do families with ID children in Sweden perceive formal support in their resilience process?
2. What is the role of informal social support on the resilience process of families with ID children?
3. How does dynamics within families of children with ID affect family resilience?

Each research question tries to address issues pertaining to the various levels of support systems as reflected not only in the ecological perspective but also in the family resilience framework and life course perspective. Question one therefore focuses on support at the macro level, question two at the meso level and question three at the micro level.

1.5 Significance of the Study

As part of my work with persons with disability in my home country Ghana, I have noticed how families struggle in dealing with the pressures of having a child with disability. This has led to neglect of such children and in the worst cases, children with disability have been killed at birth due to cultural beliefs and inability of parents to manage their situation. The problem is not unique to Ghana but exist in many other developing countries. A study by Hartley, Ojwang, Baguwemu, Ddamulira and Chavuta (2005) in Uganda about disability and family life, found that,

“One of the main problems encountered by children with disabilities in Uganda, as seen by their care givers, is negative attitudes. These were reported to manifest primarily as rejection of the child by family members, peers or teachers. Several informants mentioned that some members of the community still believe that children with disabilities are shameful or embarrassing to the family and should be hidden from other people” Pg.174

The purpose of this study is to explore how families of children with intellectual disability in a developed country like Sweden cope and the systems that support their resilience. This would help professionals understand the needs of such families and provide the necessary support to enhance resilience. It would also help to address gaps within policies in Sweden that make the process of resilience difficult for families.

Since the research was informed by a personal experience, I hope to use the results in advocating for policies and interventions that focuses on enhancing family resilience among such families in Ghana and other developing countries with proper consideration to context, knowing they are different.

Again, family resilience is an understudied area in the field of disability and its conceptualization and assessment remains unclear (Bayat M, 2007). The study therefore hopes to add to existing knowledge on the concept.

1.6 Organization of the Study

The study has been presented in six (6) chapters. Chapter one introduces the study by providing a background information on resilience and families of children with intellectual disability. The chapter discusses the study problem and outline the objective and research questions that the study seeks to find answers to. It further provides the significance of the study and its potential use for practice and policy. Chapter two reviews relevant literature related to the topic under investigation. The discussions in chapter three focus on theoretical perspectives that provides a framework for this study. In chapter four, the research methods detailing the choice of research design, data collection, management, and analysis procedures as well as the sampling technique used in recruiting participants were discussed. The chapter further outlines ethical issues and challenges experienced during the research process. Chapter five presents findings of the study and provides a detailed discussion of these findings. The final chapter summarizes the findings, draw conclusions and makes recommendation.

Chapter Two

2 Literature Review

Doing literature review is an important activity for various reasons. According to Bryman (2012), reviewing literature helps a researcher know what has been done in their area of interest to avoid what he described as “reinventing the wheel”. The chapter therefore focuses on discussing relevant literature in relation to the research topic under study.

2.1 Children with intellectual disability

Intellectual disability as an area of research has received much attention from researchers over the period with a prevalence rate of 1 to 3% in developed countries. In a research of developmental disability in 15 European countries, severe intellectual disability prevalence was seen to be 3-4 in 1000 births (European Intellectual Disability Research Network, 2003), suggesting that out of about 380 million population of these countries, about 1.1-1.5 million have severe intellectual disability whilst the figure for mild intellectual disability stands at 2.3-2.7 million. The term forms part of a wide range of delays that sets in the developmental life of a person, mostly before age 18.

The American Association on Intellectual and Developmental Disabilities (AAIDD, 2013) defined the concept as significant limitations in an individual’s intellectual functioning such as learning, problem solving and reasoning that affect their social, practical and other skills needed for everyday living. The WHO (2017) also defined ID as a condition that makes it difficult for a person to live an entirely independent life due to limited ability to understand novel and complex skills as well as application of those skills. ID has various causal factors which is broadly categorized into three(3): genetics, acquired (congenital and developmental) and socio-cultural (Katz & Lazcano-Ponce, 2008). Genetic factors account for majority of ID cases and it’s mostly due to a chromosomal or hereditary disorder. Some children also acquire ID during developmental processes particularly the prenatal and postnatal period as a result of pregnancy related complications or infections. The sociocultural factors are those that results from poverty and poverty related issues. Most children with intellectual disability have been known to have other forms of diagnosis such as Autism Spectrum Disorder (ASD), Down syndrome among others (Boström, 2012; Morris & Kratochwill, 2012).

In a normal IQ test, a score below 70-75 can be an indication of some level of intellectual challenge. Other tests that are also used in making a diagnosis includes but not limited to Wechsler

Intelligence Scale for Children, Raven's Progressive Matrices and Vineland Adaptive Behavior Scales. According to the WHO (2017), most countries in Europe use the International Classification of Diseases (ICD-10) as well as the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in diagnosing cases of intellectual disability. Apart from children with genetic disorders which can be detected during pregnancy, some children with ID get diagnosed of their situation during later ages when they are unable to reach a milestone expected of an average child, mostly at school going age. ID is not curable but can be managed through early diagnosis, interventions and adequate support from the family and society.

In addition to limitations in daily activities, children with ID could also have temperamental and behavioral difficulties. The most reported according to Boström (2012), are high withdrawal, low adaptability and negative mood. He added that, some of these temperament or behavior problems in children with ID could be positive traits but parents and society tend to cloud their judgement with the disability in assessing the child's behavior.

2.2 Effect of Child Disability on the Family

Expecting a child can be an exciting experience for many individuals and families. For the majority, having a child with disability is something unplanned for since the dream of most people is to have a normal healthy child (Carroll, 2013). Families who become aware of the child's condition before birth sometimes underestimate its accompanying responsibilities. Therefore, the presence of a child with disability can have tremendous impact on the family resulting in much stress and extra responsibility (Appleby, 2014; Greeff & Nolting, 2013; Taanila, Syrjäälä, Kokkonen, & Järvelin, 2002; Ytterhus, Wendelborg, & Lundeby, 2008). This however differs from individual families based on their resources and access to external support.

Research has shown that, families consisting of single mothers, low income families, the less educated, unemployed and those with little social networks are comparatively susceptible to higher stress (Di Giulio, Philipov, & Jaschinski, 2014). This does not in any way suggest a stress-free life for families who do not possess the above- mentioned characteristics. Many studies however indicate that, families of children with disability generally experience more stress than those who do not have children with disability (Neely-Barnes & Dia, 2008). This is because, children with disability have certain needs that may require the family to adjust their regular routines or totally change them to properly meet the care demands of the child with disability. Many of such children

could have behavior problems which may have great toll on parents' emotions. The presence of a child with disability in the family comes with extra financial burdens, limited social life and can disturb family relationships which may result in divorce. In a study of disability in the family, Bank (2003) noted that, mothers compared to fathers become more stressed and are most likely to disengage in active employment or limit working hours to take care of the disabled child if it becomes necessary.

Another effect that could occur with the birth of a child with disability in a family is the decision to have more children. Sometimes due to the stress parents experience with having a disabled child, it takes away their enthusiasm of having other children. In some cases, fear of having another child with disability becomes the reason. This decision could result in loneliness for the disabled child especially when parents are not available. In as much as siblings can be a great source of strength for a child with disability, it could also provide them with more responsibility when they have to take up care roles or change routines to accommodate the child with special needs. Siblings, especially younger ones who lack proper understanding of the situation, might think of the child with disability as getting too attention from parents which could result in hatred and jealousy.

The discussion so far seems to highlight the negative effects of having a child with disability in the family. It is however worth mentioning that, the presence of a disabled child in the family can equally have positive effect on the family. Families in some research have expressed that, having a child with disability has increased their tolerance, understanding and patience for children in general, enriched their social capital and made them more resilient to face other challenging issues in life (Neely-Barnes & Dia, 2008). A research by Lusting (1997) quoted in Neel -Barnes and Dia (2008) noted that, poor family functioning is not synonymous to childhood disability. On the contrary, the study showed that, families showed flexible profiles with very few exhibiting ill functioning profiles. Poor family functioning in most cases result from stress of which childhood disability can be a part but not an automatic product.

2.3 Resilience Understood

Masten (2011) defined resilience as “the capacity of a dynamic system to withstand or recover from significant challenges that threaten its stability, viability or development” (p.494). The whole idea behind resilience thinking is people`s ability to manage well during and after life events that are considered extremely stressful such as the death of a loved one, prolonged unemployment,

catastrophes, the birth of a child with disability just to mention but a few. Several research has shown how traumatic events can result in negative outcomes for individuals which may last throughout their lives. To serve as an example, is the outcome of a research conducted on children who lost their parents during the 11th September terrorist attack in New York (Fitzpatrick, 2009). The results showed that, such children exhibited high levels of psychological disorders like post-traumatic stress disorder and anxiety disorder. Nonetheless, other research has equally proven that, not all individuals faced with adversity experience a negative outcome. On the contrary, some use their situation in developing a positive outlook on life and have a better future. These variations developed an interest in some researchers and professionals to investigate the factors accounting for differences in adaptation in the face of adversity.

Resilience can therefore be conceptualized as having the ability to function effectively or positively in adverse circumstances (Muir & Strnadova, 2014). The idea of resilience was developed in ecology by Holling but has now gained popularity in the social sciences leading to changes in its aim and development. According to Masten (2011) and Rutter (2000), the initial phase of resilience research focused on a set of inner traits of individuals that resulted in either resilience or non-resilience. This way of thinking faced some criticisms which subsequently led to considering resilience as a process as well as a dynamic phenomenon resulting from an interaction between individual and environmental factors. It is this expansion that has given birth to the concept of family resilience.

2.4 Coping and Resilience

Coping and resilience are concepts whose definition and usage has become quite unclear. They are mostly used interchangeably in most research. In as much as there exist some similarities, there are some clear differences between the two terminologies. This paragraph aims at clarifying the confusion surrounding the two constructs by identifying their point of convergence and divergence.

Coping is a broad term used to explain how individuals deal with stressful life situations. According to Beresford (1994), coping refers to the cognitive and behavioral efforts used to handle unpleasant emotions resulting from the presence of a problem. Efforts or strategies developed in the face of a crisis could lead to positive outcomes and help a person function normally amidst problems, whereas others might result in outcomes that are not beneficial to the individual in crisis.

Referring to Lazarus and Folkman (1984), Carver, Scheier, and Weintraub (1989) explained that, the presence of a stressful situation in the life of a person activates three processes. The first phase referred to as primary appraisal is when the individual estimates the situation to know if it's positive, negative or neutral. This is followed by a secondary appraisal where they assess their resources and capabilities deal with the challenge. During the last phase, coping strategies are adopted to deal with the stressful event.

Generally, approaches to coping are of two types; problem-focused and emotion-focused. With the former, individuals cope by basing on their capability to think about ,and change a situation whilst the latter is majorly concerned with altering the way one thinks or feels about a situation without necessarily taking action to change the situation (Carver et al., 1989; Manoj, 2014). Each of the strategies could have a unique way of assisting families develop their coping skills. Although these ways of coping are used by many in the event of a crisis, problem focused is higher when individuals feel the situation can be changed. On the other hand, when it's difficult or impossible to change, emotion focus dominates. For example, in the case of intellectual disability which is incurable, families have been observed to utilize more of emotion-focused coping compared to problem focused. A third type of coping that is discussed in current literature is avoidant coping. As the name suggest, individuals deal with the stressful situation by avoiding or escaping from them. Depending on the situation at hand, avoidant coping could be a maladaptive way of handling a crisis. Coping is therefore a broad concept which encompasses all the strategies (positive and negative) that people adopt to deal with difficult situations in their life.

In trying to untangle the enigma between coping and resilience, Soji (2013) in her dissertation on resilience in youth headed households in south Africa noted that, resilience is “the existence of positive coping strategies that facilitates adaptation in the face of sustained and acute negative circumstances” (p.39), acknowledging that, resilience involves coping but has positive coping strategies as its main preoccupation. Walsh, a renowned writer on resilience also reemphasized that, “ Resilience involves more than coping or adapting: it's about thriving in the face of adversity and forging personal and relational growth” (McDonald, 2013, p. 236). Therefore, whenever coping is used concurrently or interchangeably in resilience research including this study, its reference is in relation to positive coping of individuals and families.

2.5 Evidence of Resilience Among Families of Children with Disability- A Family Resilience Outlook

For a long time, the child-centered approach in service delivery has been key in providing services to children with little or no focus on the family. In fact, the family has been perceived as the source of problems and is mostly excluded from the solution (Allen & Petr, 1998). This notion has been strongly challenged and has subsequently paved way for family-centered approaches where family strengths are identified and used to help overcome the challenges they face. Family resilience has developed from such thinking and has since been concerned with how families remain strong and functional during or after a crisis. Recent paradigm in childhood disability and family functioning has also been concerned with resilience and how it helps certain families function normally even with the presence of a disabled child (Patterson, 2012). The new shift has been due to the limited effectiveness of problem focus interventions in the spheres of social work and other helping professions. Henry et al. (2015) referred to Hawley and DeHaan (1996) definition of family resilience as

“The path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families respond positively to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family’s shared outlook” (Henry et.al, 2015, p.23).

The definition is one that gives a reflection on key elements of family resilience. These elements according to Henry et. al (2015) are family risk, family protective factors, family vulnerability and family adaptation. Resilience occurs when the interaction between family risk and protective factors reduces vulnerability and enhances positive adaptation. According to (Bayat M, 2007; Leone et al., 2016; Retzlaff, 2007), family resilience is characterized by features such as; families believe system (spirituality and values), organizational skills (parenting styles and social networks) and communication patterns (parent-child relationship). Most resilient families of children with disability have been observed to pull their resources together and make positive meanings of their situation. Below are quotes from various studies that shows how resilient families have viewed their children’s disability and worked to normalize it within the family;

“I knew her condition was serious and her prognosis was bad but, to me, she was my firstborn, beautiful child. Every time I expressed my joy to the staff at the hospital, they

said, “she is denying reality”. I understood the reality of my child’s disability, but for me, there was another reality” (Kearney & Griffin, 2001 quoted in Carroll, 2013, p. 31)

“My son’s autism has made our family life tougher, emotionally and financially. Each member has to devote additional time and effort to help him, and learn how to live peacefully in such environment. Through working together, we all learned how to help my son together. In some sense, this also makes our family closer, because an individual cannot handle the toughness alone” (Bayat M, 2007 p.709).

Knestrict & Kuchey (2009) noted that, family resilience requires a constant adaptation by families based on their resources. It is therefore not a static set of strengths but varies with time and circumstance.

2.6 Disability Policy in Sweden.

Sweden is considered a pacesetter in social insurance and welfare policies. The country has a long history of providing substantive support for individuals as well as families which is majorly funded through public taxes (Gustafsson, Höjer, Shi, & Pei, 2013; Ozawa, 2004). The family oriented social policy in Sweden came into being as a response to the “population question” raised by renowned social scientists Gunnar and Alva Myrdal in 1934(Kälvesten, 1955). According to the Myrdals, the anticipated diminishing number of the Swedish population at the time could be addressed by reducing the economic burdens on caring for a child as well as enhancing social security among citizens. This gave birth to benefits that have primarily made it easier for women to combine work and child birth, neutralized gender roles and enhance childcare within the Swedish society.

Families in Sweden are entitled to a monthly child allowance of about US\$95 for every child living in Sweden, paid maternal and paternal leave for 390 days and an extension of 90 days with limited pay, 120 days per year to stay away from work and care for a sick child, subsidized day care, the right for parents of preschoolers to work part time, housing allowance, affordable health care including free maternity and free baby clinics. (P. Boström, 2012; Olsen, 2007; Olsson & Hwang, 2003). Whilst these provisions are available to all families, those with children suffering from disability are by law entitled to additional support.

The main law regulating support for persons with disability and their families is the Lagen om stöd och service till vissa funktionshindrade (LSS) law, translated as “Act concerning support and service for persons with certain functional impairment” introduced in 1994 (Clevnert & Johansson, 2007). The law was based on principles of equal rights and dignity for all persons allowing for individuals with disability and their families live normal lives. Gadea (2016), in throwing more light on the LSS Act explained that, to qualify for support, an individual must have at least one of the following impairment; autism spectrum disorder, intellectual disability, significant physical or mental disability not resulting from ageing. Once a person meets these criteria, he/she is entitled to ten different kinds of assistance.

According to the LSS Act 1994 (Västra Götalandsregionen, 2016), the ten (10) help that the law allows for persons with disability in Sweden include;

Advice and personal support: individuals with disability by the LSS law have the right to seek professional advice and support relating to their disability. The support can take the form of counselling, therapy, linkage to relevant services and education about the disability and how to manage. Professionals who provide these supports are social workers, psychologist, therapists, dietician and any other professional whose knowledge would be beneficial to the individuals with disability and their families.

Contact person: To make life easier and encourage leisure activities among persons with disability, they have the right to choose a contact person. This person could be a family member or friend whose main task is to help identify or find activities with the individuals to prevent social isolation or boredom. Activities might include going to the movies, engaging in sports, organizing parties and any other leisure the person with disability is interested in doing.

Escort services: This provision is available to persons without personal assistance. It allows them to have a companion who would escort them during social activities such as going for an event.

Personal assistance: An Individual with disability is entitled to have a personal assistance(s) if he or she is below the age of 65 and has difficulty in doing basic things such as cooking, communication, maintaining personal hygiene, eating, among others. Personal assistance can be recruited through a private company, municipality or individuals can choose their own assistants and receive funds to pay them. After meeting the eligibility for having a personal assistance, an

individual has twenty (20) hours of assistance per week which is financed by the municipality. Those who require more hours apply using a different law known as Compensation for Assistance (LASS) which is funded by the social insurance agency.

Short stay outside the home: short term stays or respite care is a way to give the person with disability an opportunity to have other experiences outside the home. This could also be a gradual way of practicing autonomous living and relieving families of their caring role within that period. The service can take place in family homes, at a camp or specialized home built for that purpose.

Short term supervision for families of school children: families of children with disability above the age of 12 years and are enrolled in school can have supervision for their children during school hours, after school or during holidays. This supervision may have different arrangements and are mostly done outside the home.

Home relieve services: the service provides the opportunity for families to have someone come in to care for the child or person with disability on a temporary basis at home. Families can access this service on a regular basis or only during emergencies.

Residence with special services for children and adolescents: children who cannot live with their families at all or only on a part time basis can be in special homes with services tailored towards their unique needs. It's mostly available for those who despite all the support provided to the family cannot still live at home, implying that, the service is mostly not the first option for many persons with disability and their families.

Residence with special services for adults: since adult's needs vary greatly compared to children, adults with disability are also entitled to housing services specialized to meet their needs as adults with disability. It can be a group housing or individual housing adapted to the specific disability. The group homes are mostly for individuals with need for extra care and attention. The homes are made up of small apartments within the same location and have permanent staffs. The individual housing is for those who can live alone with little supervision.

Daily/ regular activities: persons with disability who are of working age but are unemployed or not studying are provided with the opportunity to engage in activities geared towards having a gainful employment.

Most of these supports provided to persons with disability and their families are free with just few exemptions. In cases where payment is required, the fee involved is highly subsidized. Adding to the support offered by the LSS (1994). Försäkringskassan (social insurance) in Sweden also provides specific allowances if your child has a disability. The agency provides monetary compensation to parents or care givers of the child with disability from the time the child is born till they are 19 years. Parents can also receive money for up to ten days per year and per a child to go for education about their child's disability and how to appropriately support them. Also, parents can receive car allowance to buy a car or make changes to an existing one to meet the needs of the child (Försäkringskassan, 2016). Even though these supports are available to individuals and families, getting information on where to get what could be difficult sometimes. Like White & Hasting (2004) observed, formal support can be quite unclear and bureaucratic which may increase parental stress.

2.7 Informal Social Support for Families of Persons with Disability: Sweden as a Unique Context

Social support is an important resource utilized by many in their lives especially during adverse or difficult situations. Sources of social networks for families of children with disability includes household family, extended relations, friends, neighbors and community support groups. A new and increasing form of social support is social media groups where families with similar situations share experiences and provide support without necessarily knowing each other. According to the research findings of Taanila et al. (2002), families with high coping in Finland expressed the incredible role of family and friends in dealing with the stress of having a child with physical and/ intellectual disability compared with their counterparts in the low coping category. In the United States, it is estimated that there are about 43.5 million informal family members providing care to persons with disability (Grossman & Magaña, 2016). In a study of resilience among long-term social assistance recipients in Sweden, families and friends were assessed to be very important during crucial moments in their lives. Though the support might not be financial, it came in other practical forms such as providing clothes, helping with the kids, offering good company, listening to them among others (Marttila, Johansson, Whitehead, & Burström, 2013). According to (Bromley, Hare, Davison, & Emerson, 2004; White & Hastings, 2004), mothers of children with autism reported high levels of stress which was partly due to low levels of family support. These conclusions were derived based on a qualitative research on mothers supporting their children with

autism spectrum disorders at different times and context. Another study examining the effect of social support and hardiness on stress levels of mothers with ID showed that the above mentioned variables were important in positive outcomes in such mothers according to the regression analysis (Weiss, 2002).

Sweden is a unique context where citizens including those with disability and their families have relied extensively on state support compared to other support systems such as family and friends. However, recent cut backs on social expenditure especially in the area of disability and elderly care has led to an increase need for informal support in the country (Jegermalm, 2005; Sundström, Johansson, & Hassing, 2002). Yet, changing values about family life and obligations are factors that affect people's readiness to offer informal care. This present an interesting area for exploring the specific roles that informal social support plays in the resilience process of families with ID children in Sweden and the points at which families turn to or refuse such support.

The literature and discussions clearly emphasize the importance of social networks and how they help in the resilience process of families with disability. However, these networks that families would ideally rely on for help sometimes become the source of stigmatization, a situation that can increase family stress and make coping much difficult. Grant and Whittell (2000) and Schilling, Gilchrist and Schinke (1984) noted that, families in this situation either reduce their networks or cut completely from them.

2.8 Gender Roles in Sweden

Gender issues have received much attention over the years with vast development in both its definition and application. It refers to the socially constructed roles that define males and females. A closely related concept that emerge in gender discourse is sex. Sex is the biological features that differentiates male and female primarily on their reproduction potential (Kammeyer, Ritzer & Yetman, 1997). This distinction helps to put gender into its proper perspective. Since gender is a social construction, it is non-static but varies from society to society and from time to time. Sweden like many western countries used to be dominated by traditional gender roles. It was a common phenomenon in household to have men as breadwinners whilst women take up caring roles in the home. However, the 19th century saw a different turn where the country took action to provide equal opportunities for both males and females in significant areas of life such as education, employment, politics and family life (Bernhardt, Noack, & Lyngstad, 2008). This has been

achieved through its social policies that are championed by the idea of creating a society free from gender inequality. Today in Sweden, most families are dual earners, there are more women in the labour force, fathers are more involved in childcare and house work and more women have education. Though the country has made huge progress in ensuring gender equality, various studies have shown that mothers in Sweden still do more house work compared to fathers (Evertsson, 2006; Wissö & Plantin, 2015) and fathers again have been seen to use a limited portion of their paternity leave. Nonetheless, the situation in Sweden is one that is promising especially in comparison to other developed countries like the United States.

2.9 Gender Practices Among Families of Children with Disability

In the book, “Rethinking Family Practices” by (Morgan, 2011), the author in an attempt to give an exposition on how families are constructed, presented the different definitions and usage of the word `practice`. From the many dictionary definitions, he presented, `practice` seem to be such a versatile word that can have different meanings in different context. For the purpose of this research, the definition of Morgan (1996) referred to in Finch (2007) is preferred.

“Practices are often little fragments of daily life which are part of the normal taken-for-granted existence of practitioners. Their significance derives from their location in wider systems of meaning”. (Finch, 2007, p. 66)

Using this definition as a point of departure, gender practices in the family can be understood as the various ways gender manifest itself in the activities of a family. Majority of research on families of children with disability has countlessly shown that gender practices in such families are more traditional. In the United States, women in the household mostly opt out of work to care for a child with disability (Banks, 2003). A study in the UK also revealed that, fathers of children with disability work full time to avoid the care demands of their children (Rimmerman, 2015). Result of a comparative study of mothers and fathers of disabled and non-disabled child in the USA showed that, fathers of non-disabled children shared child care and house work more equally and a possible reason is that the mothers in such households are mostly in active labor. It was however surprising to see that, fathers involvement in childcare and housework where there is a child with disability was minimal even when the mothers work (Bristol, Gallagher, & Schopler, 1988 ; P. K. Boström & Broberg, 2014). This was seen to increase stress among mothers and makes coping difficult. Following the discussion of gender roles in Sweden in the previous paragraph, it

is therefore interesting to know how gender plays out in families of children with disability especially considering how social policies makes it easier for women to combine work and family life as well as encourage men participation in the family in Sweden.

Chapter Three

3 Theoretical Framework

Theory plays an important role in research and its relevance in qualitative research cannot be overlooked. Stereotypes about qualitative research has often portrayed the method as devoid of theory. Yin (2015) noted that, such stereotypes “might regard qualitative studies as being similar to the chronicles of a medieval scribe, or even the dryly worded clinical details of a coroner’s report”(p. 93). He then advised qualitative researchers to refrain from such thinking and approach. In his view, a good qualitative research is one that reflects on theories and concepts to understand social phenomena though the extent of its usage might vary. Whether a study takes an inductive or deductive approach, theories and concepts are essential in putting the study into perspective. According to Bradbury-Jones, Taylor, and Herber (2014) theoretical framework “can provide rationalization or justification for the methodological approach used, it can offer a comparative context or an organizational framework for the interpretation and representation of data or it can serve as a scheme for representing findings” (p.136). Following this critical role of theory, the current study utilizes a number of theoretical concepts which serve as guide in understanding information gathered throughout the research. They include family resilience framework, strength-based approach, ecological perspective, and the life course approach.

3.1 Family Resilience Framework

Previous studies have conceptualised resilience as a set of personal traits or an outcome but resilient researchers are beginning to consider the processes involved as well. According to (Becvar, 2013; Martha Kent, Mavis, & Reich, 2014), these processes involves a constant interaction between intrapersonal, interpersonal and social factors which results in resilience leading to the development of family resilience concept. A family resilience perspective looks at the family as a whole and account for family processes that allows them to cope with stressful situations and function properly (Henry, Sheffield Morris, & Harrist, 2015). The family resilience framework developed by Walsh involves three key processes; belief system, organisational patterns, communication and problem solving (Walsh F, 2003).

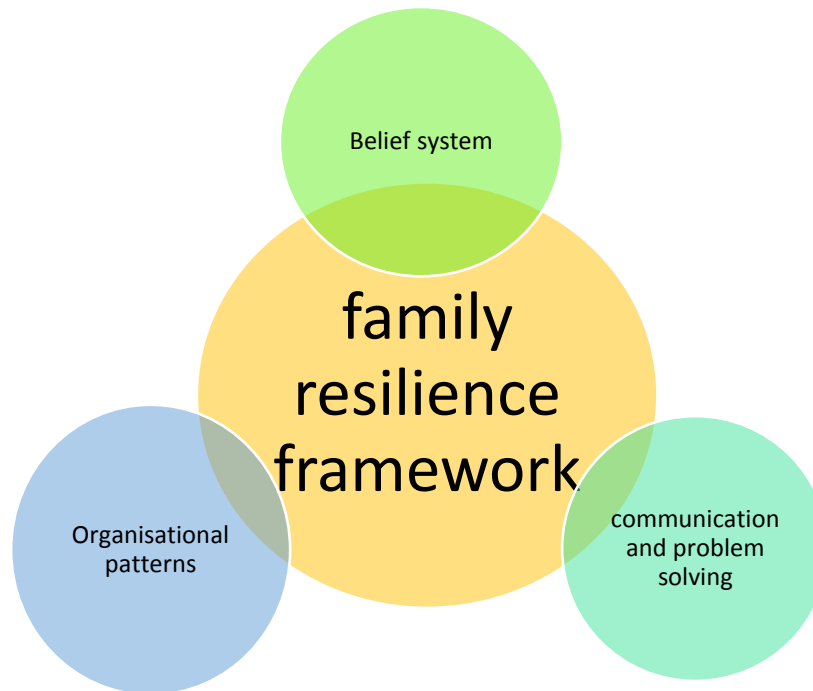


Fig 1. family resilience framework

3.1.1 Belief system

According to Walsh, belief systems consist of the values that shape a family's thinking about a crisis. These beliefs are critical in how families respond to events in their life. In becoming resilient during stressful situations, belief systems should be adopted to processes that provides strength and development such as making meaning out of adversity, having a positive outlook and increasing spirituality.

3.1.2 Organisational patterns

Families in one way or the other organise themselves in different ways to meet challenges that come their way. To be resilient, family organisation should be flexible, reflect mutual support and have economic security.

3.1.3 Communication and problem solving

As humans, communication is key in solving problem hence, families should be clear in their communication with each other, express their emotions openly and work collaboratively to address their problems.

A Family resilience framework is therefore helpful in identifying strengths in the midst of stress, acknowledging the diversity among families and the effect of time on achieving resilience.

3.2 Strength-Based Approach

Baker (2003) cited in Muzinguzi (2015, p. 21) explained the strength-based approach as “an approach in social work and other professional practice that emphasize the clients` resources, capabilities, support systems and motivation to meet challenges and overcome adversity”. The perspective agrees with the orientation of resilience where people`s capacity to remain strong is the main agenda. According to Saleeby (1996), this approach deviates from traditional social work practice which has for some time been preoccupied with seeing problems rather than possibilities. For example, the DSM form used in the diagnosis of mental disorders contains several pages describing the causes and signs of mental illnesses with little to say about peoples` strength even in such condition.

Until recently, the social work profession has mostly perceived service users as persons with deficits who come for help from social workers calling themselves experts. This kind of thinking sometimes increase client`s vulnerability and dependence. The strength perspective according to Saleeby (1996) is driven by certain philosophies, concepts as well as principles. Close to the heart of this perspective is the idea of possibility and hope. Saleeby explains that, all humans are surrounded by unlimited resources both within and without which when capitalized on, can help individuals survive adverse life situations. Though the perspective focus on strengths and capacity, it does not however over look traumatic events and its effects on individuals. It just calls attention to a “balance” (Saleeby 1996) where professionals and researchers don`t only get preoccupied with the challenges of society, but also make conscious efforts to identify strengths and build on them to overcome or cope with adversity. A strength-based approach is therefore essential in the study of resilience as it tunes researchers` attention to the ways that people have and continue to manage in the face of challenges, particularly families of children with intellectual disability. As a strength

thinker, this approach served as a guide in recruiting families bearing in mind that no matter their struggles, families still possess strengths which helps them to the manage the daily struggles of raising a child with intellectual disability especially in Sweden.

3.3 Ecological Systems Perspective

The ecological perspective was developed by the renowned developmental psychologist, Urie Bronfenbrenner in the 1970`s to help understand human development across the life span. According to Bronfenbrenner (1994), human development can be better understood when the whole ecological system that support growth is put into consideration. Thus, growth occurs in humans when there is an active and reciprocal interaction between an individual and other persons or entities within their immediate environment. The system is made up of five (5) subsystems that are socially constructed to help development; microsystem, mesosystem, exosystem, macrosystem and chronosystem. For the purpose of this write up, only the first four systems would be considered.

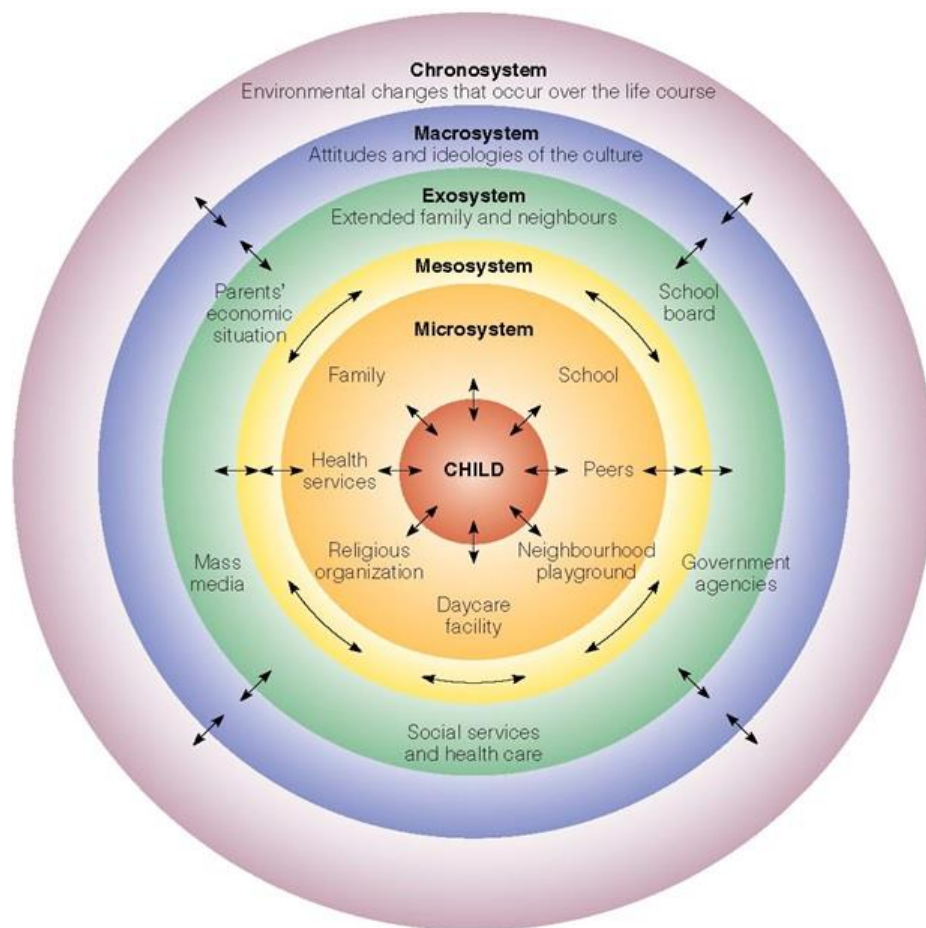


Fig 2. Bronfenbrenner`s Ecological systems theory

3.3.1 Microsystems

The microsystems consist of interactions that are face-to-face such as, those that exist between family, peers and the workplace. This is the immediate environment of an individual where events relating to the child have a more direct effect and vice versa. This explains why parents, siblings and other members of the family are affected by the presence of a child with disability though they do not represent the central focus of the ecological perspective suggested by Bronfenbrenner Boström (2012). For example, families might experience stress, change routines or adjust their work and time to accommodate the needs of the child with intellectual disability. Based on the responses from the microsystem, the development of the child with disability can equally be stimulated or restricted. The microsystem in the ecological model is particularly helpful in understanding the impact of child disability on a family and how families mobilize resources to ensure equilibrium.

3.3.2 Mesosystem

The mesosystem reflects interaction between different microsystems. Bronfenbrenner (1994) explained that this system “comprises the linkages and processes taking place between two or more settings containing the developing person” (Bronfenbrenner, 1994, p.40), which in this case is the child with disability. Examples include the relationship between home and work, home and religion, school and health. The quality of the relationship within this system is critical for the resilience process of families. Although it is common for every family to have interaction with other micro-systems, families of children with intellectual disability experience increasing pressure from these relations which can either improve or hinder family strength. For example, due to the difficulties in the mental processes of children with intellectual disability, a school which is more accommodating can help parents relax knowing that their child is safe and developing in the right direction. However, parents stress can increase if the school becomes less accommodating, a situation that can hinder the process of resilience. Considering the mesosystem in relation to families and their child with ID, it is critical in understanding how interactions among microsystems have impacts on a family`s ability to remain strong and functional.

3.3.3 *Exosystem*

In the Exosystem, there are linkages and processes existing between systems of which at least one does not involve the child with disability (Bronfenbrenner, 1994). Nonetheless, any transaction that takes place have an indirect impact on the child or family. This system includes but not limited to social services, school board, and extended family among others. As an illustration, social services might work with the school board to provide the needed support to facilitate learning of the child with ID in school. This might not directly involve the parents but the outcome of this discussion could affect them positively or negatively.

3.3.4 *Macrosystem*

The macrosystem represent the larger context within which the micro, meso and exosystems operate. According to Bronfenbrenner (1994), it encompasses cultural beliefs, social policies, customs and norms that defines a particular society. Amankwa (2015) added that, identifying a unique feature of the macrosystem affects processes within the microsystem. In the context of Sweden, there are policies provided by the state to support persons with disability and their families. These policies have been important in reducing the financial as well as emotional burdens on families, though it comes with its negative side. The macrosystem is therefore, useful in understanding how structures within the larger society operates directly or indirectly to promote or hinder resilience in families of children with disability in Sweden.

The ecological model is a useful tool for understanding how different systems within society or a person`s environment operate to help individuals and families develop through life and manage daily struggles. As explained by kazak (1989) in Hoffman (1981), the systems in the ecological model are interrelated and interdependent, which suggest that, changes at one level affects the others either directly or indirectly.

3.4 Life Course Approach (LCA)

The life course is an approach that takes up a developmental outlook on issues and considers social and historical context in the lives of people. This new paradigm received much attention after the classical work of Elder in 1974 titled “children of the great depression”. Quoting from Elder (1975), Giele and Elder (1998, p. 22), defined the life course as “ a sequence of socially defined events and roles that the individual enacts over time”. The definition though short, carries with it certain key precepts that are expounded in the life course perspective. Thus, the occurrence of events in an individual’s life varies based on their context and time. Though it is a path, the life

course consists of various continuity as well as twists and turns. In most cases, there are socially constructed time for achieving certain milestones which we unconsciously try to fit in and a deviation can be seen as failure by society. This is especially true for persons with disability and their families. However, the life course unlike other construct such as life-span, recognizes diversity in pathways of individuals and families providing a more inclusive way of looking at social realities. The life course helps to create a sense of understanding of how occurrences in early life affect later events in life (Adeboye & others, 2015).

Initially developed within field of childhood, the approach has been deployed by other fields within social sciences including disability studies. The life course can be a useful way of getting deeper understanding of the resilience process of families with ID children by focusing on their distinctive experiences. According to (Elder & Rockwell, 1979; Giele & Elder, 1998; Hutchison, 2010), researchers and professionals adopting LCA in their work rely on five basic concepts outlined as generation, transitions, trajectories, life events and turning points.

3.4.1 Generation

Very important to the LCA is the influence of historical context in constructing the life course of individuals, especially those born or have lived within a specific period. Usually, a generation shows a period of about 20years or more. Closely related to the generation is the concept of cohort that is also used by many life course researchers. Hutchison (2010) refers to a cohort as a group born within the same time who have been affected by the same social events at about the same age. Unlike a generation, cohorts may comparatively have a shorter age gap. Following this distinction, the families being considered would better fit into the category of generation than cohort. Eligible families for this study are those having at least one child with an intellectual disability who is 6years and above but not more than 23years. The reason being that, the LSS which provides comprehensive support to disabled people and their families was introduced in 1994 and it is assumed that, individuals born after that law benefit from similar rights and provisions compared to earlier generation. This period could obviously have implications for how families respond and care for their disabled child as well as their ability to become resilient.

3.4.2 Transitions

Every individual goes through various transitions in their life and this is very key for the LCA. Examples of such transitions include but not limited to starting school, graduating, starting work, marriage, parenthood, retirement among others (Nilsen, Brannen & Lewis, 2013). With every

transition comes certain roles and responsibilities that are usually different from the previous phase. In most family studies, the concept of transitions has been used to understand the dynamics of the family as members make different transitions throughout life. Becoming a parent is an important transition which most people look up to, however the birth of a child with disability, especially if it's the first, can make this transition unique. It requires not just changing roles and responsibilities as parents or siblings, but also tailoring those efforts to accommodate and meet the specific needs of the disabled child. Thus, families of children without disability might experience the parenthood transition differently. As the disabled child grows, the family might also experience other transitions, which would require adjustments and different responses. A family's ability to become resilient depends on how well these transitions are negotiated.

3.4.3 Trajectories

Closely related to transitions, is the concept of trajectories. Unlike transitions where a new phase marks the end of the previous one, trajectories are a total of a person's transition during the life span (Giele & Elder, 1998). Trajectories are long term stability and change constituting many transitions. Trajectories may correspond with the different aspects of a person's life such as work, school, health etc. For families of children with ID, the birth of the child begins a different trajectory that can intersect with other already existing trajectories within the family.

3.4.4 Life events

Hutchison (2010) referred to Settersen (2003) definition of life event as "a significant occurrence involving a relatively abrupt change that might produce serious and long lasting effect. Life events are the happenings themselves and not the transitions that result from them. For the purpose of this research, a major life event of the families is the presence of a child with ID. This event may be perceived as positive or negative depending on the family's ability to successfully manage. Therefore, life events especially stressful ones provide individuals with the opportunity to develop their resilience.

3.4.5 Turning point

This is a point in a person's trajectory where a major change occurs, which turns the direction of the life course. Life events can serve as a turning point for individuals, however, not all does. Life event can only be a turning point when it opens or close opportunity, makes a lasting change on

the person and his environment, or changes in a person's worldview and way of thinking. Undoubtedly, the birth of a child with ID is both a life event and a turning point for their families. This concept can help to explain how the process of resilience has been for families with ID children, especially a context like Sweden.

3.5 Chapter Summary

The chapter sought to present the theoretical frame of this study which would be helpful to understand and relate to concepts throughout the work. The theories discussed are the family resilience framework of Walsh, the strength based approach by Saleeby, Ecological perspective by Bronfenbrenner and the life course approach developed by Elder.

Chapter Four

4 Methodology

The chapter focuses on the general research strategy used in this study by discussing the research design, participants, methods and tools used in collecting data. It also presents information on data management and analysis. The chapter concludes with an examination of the various ethical issues considered during the study as well as the challenges encountered during the research process.

4.1 General Research Approach

The framework of this research is set within the qualitative research method. A method that focuses on words rather than figures. It provides a subjective way of constructing social reality by focusing on few cases (Bryman, 2016). Adopting qualitative methods in this study was helpful in not just knowing, but also understanding the process of resilience for families of children with intellectual disability in Sweden and the resources that help them to remain strong and functional. It provided me with the opportunity to capture feelings and emotions which otherwise would not be captured when using quantitative methods. This helps to present a detailed account of participants' experiences and the meanings they attach to those experiences.

Epistemology and ontology are deemed important when selecting a method for your research (Bryman 2016; Hollies, 1994; Harding, 1987). This research took the interpretative epistemological orientation which acknowledges that, the social world is better understood by the interpretations given to it by people. Thus, families of children with intellectual disability can provide actual interpretation of their experiences to help understand the concept of family resilience, making it exploratory.

4.2 Exploratory Research Design

Identifying a research design in qualitative study is a strong way of substantiating the validity of a study and ensuring data is collected in ways that achieve the purpose of the study (Yin, 2010). For this reason, Yin refers to research designs as “logical blueprints” which links different parts of a study such as the type of data required, method for collecting data as well as analysis (ibid). Of particular importance is how all these fit together in answering the research questions that drive the study. In this study, the exploratory research design has been deployed to help the researcher explore and gain a better understanding of resilience in families of children with intellectual disability and the systems that support their resilience.

In view of this, more questions on “how” as oppose to “what” was asked to obtain an in depth understanding of the area under investigation. Manerikar and Manerika (2014) noted that, exploratory research is very useful in areas where the researcher has limited knowledge or experience. As it has mentioned in earlier chapters, family resilience is an understudied area and there is also lack of clarity in its conceptualization. Therefore, exploratory research design was deemed more suitable to achieve the objective of the study and adequately answer the research questions. Though the study is predominantly exploratory, it also reflects some descriptive features where the researcher provides a description of the context and the circumstances that promote as well as hinder family resilience.

4.3 Study Area

The study was conducted in Gothenburg, the second largest city in Sweden. I chose Gothenburg because that is where I lived at the time of the research and could easily have access to participants. Though I was initially opened to participants from other parts of Sweden, the snow balling technique used for recruiting families ended up providing participants who only resided in Gothenburg.

4.4 Sources of Data

The study utilized data from both primary and secondary sources. Primary data was collected through in-depth interviews with families using a list of open ended questions. Secondary data were gathered by reviewing journal articles, books, internet information and reports relevant to the research topic. These materials were accessed using databases such as Scopus, google scholar, Directory of open access(DOAJ), sage journals, super search among others. Keywords used in the search engines were intellectual disability, resilience, family resilience, social support and families of disabled children which generated several materials. I then made use of those I found relevant for my study. The reviewed articles were discussed alongside primary data to enhance understanding the themes that emerged as well as understand similarities and differences in the study.

4.5 Target Population

The target population for the study were families of children with intellectual disability living in Sweden. An eligible family was one who had at least a child with an intellectual disability diagnosis, where the child was not less than 6years and more than 23 years old. Six years was

chosen as the minimum age to be able to capture how the process of resilience has been, since time represent an important factor in constructing trajectories. The maximum age of the child with disability was set based on the LSS law which was introduced in 1994. Since the law provides parents with certain support, children born before this law might benefit from a different arrangement whose impact on a family`s resilience could be different. In choosing families, I was guided by the strength perspective, which stresses the need to also focus on people`s strength rather than getting preoccupied with weaknesses and challenges (Saleeby, 1996). In this regard, I wasn`t looking for only families who seem to be functioning well, rather, I was open to all families having a child with disability within the specified ages.

4.6 Sampling Technique

Sampling is an important process that can have consequence for the outcome of a study. The type of sampling technique adopted in qualitative study is mostly dependent on the research topic and/or methodology used (Higginbottom GMA, 2004; Noy, 2008). Since the goal of qualitative research is to increase understanding of a social event, sampling is not necessarily focused on the principle of generalization as it`s mostly the case in quantitative research. Families in this study were therefore recruited using the snowballing method. With this method, the first person I interviewed was helpful in establishing contacts with other families by affirming my legitimacy and clearing any possible doubt. Subsequently, I was contacted by friends of some of the parents I had already interviewed due to their recommendation. Having access to these families on my own was initially difficult but became easier when referrals came from people they could identify with. Snowballing works better with hidden populations such as drug users, prostitutes, persons with disability just to mention but a few. Wiebel (1990) referred in Kelly (2010, p. 672) described a hidden population as "segments of the general population whose membership is not readily distinguished or enumerated on the basis of existing knowledge and/or sampling capabilities". This may result from actual or perceived stigma which may make it difficult to reach or access them.

At the start of the study, I decided to use purposive sampling by contacting organizations that work with families of children with intellectual disability across Sweden. However due to issues of confidentiality and sensitive nature of this group, getting access to participant through this method yielded no results. The snowballing method was rather efficient in this regard affirming Noy, (2008) who pointed out that, the method is mostly used when other contact avenues have "dried up". Like many phenomena, this sampling technique has been criticized for not resulting in a

sample that is representative due to how participants are obtained. As it has been emphasized earlier, the preoccupation of this study is to have an in-depth understanding of resilience in families of children with intellectual disability and not to necessarily generalize my findings making this approach the most appropriate and effective.

4.7 Sample

Seven parents from six families having a child with intellectual disability in Gothenburg, Sweden were interviewed. They included 4 mothers, a father and a couple including a father and mother. The couple was interviewed together and considered as a single interview. At the time of the interview, only one parent was divorced, the rest were living together with their married partners. The families had children diagnosed with Down syndrome and/or autism and intellectual disability. Four of the children in these families were 13years and two were 17years. Below is a tabular representation of the sample described;

Participating families	Age (years)	Type of child`s diagnosis
Family 1		
Mother	Na	Down syndrome
Father	Na	
Child with disability	13	
2 siblings	older	
Family 2		
Mother	Na	Down syndrome
Father	Na	
Child with disability	13	
Family 3		
Father	Na	Intellectual disability

Child with disability	13	
A sibling	older	
Family 4		
Mother	Na	Down syndrome
Father	Na	
Child with disability	13	
2 sibling	Older, younger	
Family 5		
Mother	Na	Down syndrome and autism
Father	Na	
Child with disability	17	
3 siblings	2 Older ones, 1 younger	
Family 6		
Mother	Na	Autism
Father	Na	
Child with disability	17yrs	

Considering the aim of this study, it would have been interesting for me to have the perspective of all individuals constituting the family unit of the child with disability. However, due to time constraints and busy schedules of the families, only one person was available in most cases to represent the whole family. Out of the six families, there was just one family where both the mother and father were available to be interviewed. Though the result captures the contribution of other

members within the family, it cannot be representative of the whole family's perspective on how their resilience process has been.

4.8 Sufficiency of Sample

Unlike quantitative research where large samples are mostly necessary for generalization, qualitative research does not necessarily dwell on large sample size. A methodological approach such as phenomenology which is used in this study often utilize small samples due to the nature of the in-depth interview (Higginbottom GMA, 2004). Sandelowski (1995) referred to Morse (1994) recommendation of having six participants in phenomenological studies and based on that, I decided six families were enough to have a deeper analysis of the experiences of the families and their resilience process. Also, I reached saturation when no new themes seemed to be emerging from my data. I therefore consider my sample sufficient enough to achieve the aims and objectives of this study.

4.9 Data Related Issues

This section describes the data collection process and the tools used. It further addresses issues to data management and analysis and conclude with issues of validity and reliability.

4.9.1 Data collection method/tools

Data collection is considered key in many research since it forms the pivot around which a particular study revolves (Bryman, 2012). Due to the qualitative nature of this study and its aim of understanding the process of resilience among families of children with intellectual disability, biographical interview was combined with in-depth interview to solicit for information from participants.

4.9.2 In-depth interview

This method was deemed appropriate as opposed to a focus group discussion or participant observation because, it provided a detailed description of participants' experiences which would have been missed if the latter was used. The interviews were carried out in a semi-structured way using open ended questions. Open-ended questions helped to get understanding and obtain participants own interpretation without predetermining those points of view through selection of questionnaire categories (Patton, 2002). Questions were asked using an interview guide informed by my research questions, literature review and theoretical framework. The interview guide provided me with a point of reference which constantly guided me throughout the interview

session. It also helped me to ask participants the same kinds of questions to avoid getting responses that were not related to my research objectives. My interview questions and actual interviews were done in English. There was no need for a translator since all the participants could express themselves in English. My interview questions were pretested with a colleague to practice how questions would be asked during the actual interview. After that, the structure, arrangement and some wordings in the guide were changed to achieve clarity and get the right responses from participants. This was done together with my supervisor before I entered the field for actual data collection.

The interviews lasted between 45 minutes and one hour maximum. With the permission of participants, all the interviews were recorded with a phone and later transcribed. I also complemented it with note taking as a backup in case of technical failure with my recording device as suggested by Bryman (2016). Having this backup was extremely helpful to me because, I accidentally lost one of my recordings along the line. With the notes I had taken, I was able retrieve some of the information and followed through with an email to get information that I missed out. Interviews took place at different locations based on where participants identified as convenient for them.

4.9.3 Biographic interview

The biographic interviews were merged together with the in-depth interview in this study in-order to capture the life events of families and the process involved in resilience. This was informed by the life course perspective discussed in my theoretical framework chapter. Nilsen et. al (2012) cited Kholi (1981) definition of biography as “a story told in the present about a person’s life in the past and his or her expectations for the future” (p.34). They further identified three elements that are relevant when doing biographical interviews. These are the factual events in the person’s life, the meanings these have for the person and the way the story is told, adding that, all these must have a context based interpretation. Participants were asked to draw a life line in relation to their child with disability and indicate with age, major events that has occurred with the presence of the child with disability. Participants were not given predetermined events but were allowed to come up with events they themselves consider as major with some guidance. This helped to capture certain differences in families’ trajectories which would otherwise have been overlooked. After the life line was drawn, participants were then asked to comment on the various events and the resources that has been useful at every stage to enhance resilience. Beginning the whole interview

with the biographical interview was very important in giving participants something to remember and reflect on the past before the actual talking took place. As an interviewer, the time participants used in drawing their trajectory helped me to calm myself when I was nervous, especially with my first interview. I also used that time to cross check my recording equipment. For example, in one of the interview session, after exchanging pleasantries, the participant started to comment on what she thinks I would ask her based on what her friend had already told her (due to the snowballing sampling technique discussed earlier). I was taken unaware and my recorder was off but when I asked her to draw the trajectory first, we were both ready for the actual interview by the time she was done. Incorporating biographical interviews in my study had some financial implications (Bryman, 2012) since I provided all participants with the needed materials (pencils and paper) to aid them construct their life course trajectory.

4.9.4 Data transcription

The recorded data was listened to several times and then transcribed manually to text format by the researcher. The denaturalized approach was used during this process since focus was more on the content rather than how it was said. In view of this, pauses, stutters, silence, involuntary actions and repetition of words that seem habitual were all removed during transcription. Grammar was corrected where needed to give a clearer understanding of the information provided by the participants. It must be noted that, this was done with extra caution to avoid changing the meanings and interpretations that participants gave to their situations.

During the transcription, actual names, ages and places were replaced with pseudonyms to increase interviewee's confidentiality and anonymity. I decided to use Ghanaian names instead of typical Swedish names not because participants come from Ghana but that was to strengthen anonymity among participants themselves. Considering my sampling technique (snowballing), participants undoubtedly knew each other which could make it easier to identify themselves if they read the research later.

4.10 Managing and Analyzing the Data

The section focuses on discussions relating to how data was handled and analyzed. Patton (2012) noted that, interpreting and analyzing the data involves making sense of what participants have said on the topic, putting together patterns and integrating different dimension on the information provided. This is crucial in determining whether a particular research has been successful in

answering its research questions or not. Qualitative research often rely on different analytical tools based on the type of data collected and the goals of the research.

Analyzing the data was quite overwhelming considering the enormous data generated after transcription. However, through the thematic and lifeline analysis utilized during this process, I restricted myself to information in the data that was relevant to my study. This corresponds to Bryman’s (2012) advice on the need to avoid including all results from the data but only stick to those that relate to your research questions. He agrees this can be quite difficult especially if it requires discarding large portions of the data but it becomes necessary to ensure a coherent argument for your study.

4.10.1 Thematic analysis

The thematic analytical method is regarded the most commonly used approach in qualitative research according to Bryman (2012). The method involves locating and interpreting patterns of meaning normally referred to as themes by familiarizing with the data (Clarke & Braun, 2017; Weisser, Bristowe, & Jackson, 2015). In this study, the thematic analysis process begun with reading the transcribed data repeatedly. Line by line coding was done to avoid losing important perspectives provided by participants as mentioned by Charmaz (2004) cited in Bryman (2012). This is an advantage of using thematic analysis and a reason for choosing to use it in this study. Considering the many benefit associated with thematic analysis, it gives shallow and weak analysis of data majorly because sometimes meanings are not just in the words spoken but how it is said and the context.

The codes identified were grouped into subthemes. The subthemes were further grouped to form the main themes discussed in the results and discussion chapter. My themes and subthemes followed the abductive approach where “theoretical concepts and passion for identifying patterns without referring to theoretical framework both informed the identification of codes “(Amankwa, 2015 p.45). The table below show an extract from the coding system

Tab 2. Extracts from coding system

Question – what do you think	Ama - family 1	Abena- family 2	Kwesi- family 3	Adwoa & Kwame- family 4	Afia- family 5	Kukuwa- family 6
------------------------------------	-------------------	--------------------	--------------------	-------------------------------	-------------------	---------------------

<p>are the inner workings of the family that helps to handle everyday life and specific demands relating to the child with disability?</p>						
<p>Quotes</p>	<p>` support of course from my husband, if he did not support me, we would probably have divorce I think`</p>		<p>I think the family bounds. whatever the mother wants to do, if she couldn't do it, I have to complete it. Concerning Kojo we work hand in hand otherwise it will not</p>		<p>we had always had strong bonds so to speak and uh, there has been a very strong feeling that this is his family</p>	

			work. I can't do it all by myself			
--	--	--	--	--	--	--

In this extract, I was able to develop the theme ‘spousal support’ as part of the micro level support based on the similarities in parents’ responses. Certain themes emerged from asking direct questions because I wanted to have parent’s perspective on them while others were lifted up by parents themselves. For instance, I specifically asked parents about the gender roles in the family and how this affect resilience. I did this, to have a gender perspective in my study. This would not have emerged if I probably didn’t ask. I tested this with my last interview, where I decided not to ask about gender roles. The interview was about ending and the parent had not mentioned any gender related issues. This confirmed my initial justification for asking some direct questions. I hereby provide the final themes and subthemes in the table below

Tab.3 Themes and subthemes

Themes	Subthemes
Support systems enhancing resilience	Micro level-spousal support, sibling support, gender roles, child’s development, personal disposition
	Meso level-support groups, close extended families, school
	Macro level-institutions & policies
Nature of interactions among systems	
Obstacles to resilience	Personal
	Structural
	Significant others

I followed up with phone calls or email to get clarifications on information that were unclear during the analysis. In presenting the themes, I provided a brief description of the content and supported it with relevant quotes from the transcripts. Quotes were presented both verbatim and in parts to be able to carry across the issues that participants raised. In cases where part of the quote was used, it was presented as follows `.... our elder sons are very helpful`. Also, when Swedish words were used or action was done by the participant, I put the English translation or word to help in understanding the meanings provided. With this same intention, I corrected grammar where necessary. The pseudonyms of parents and the type of family were presented alongside every quotation to show that, the information presented was from my data. As I explained earlier, the actual names of participants were changed to Ghanaian names to strengthen anonymity especially among participants due to the snowballing sampling technique I used. The names therefore do not relate to the background of participants or the context within which the research was carried out. The study was done in Sweden and most participants were Swedish by birth or naturalization.

To conclude, further discussion and interpretation of the data was done by relating it to my theoretical framework and earlier literature to identify similarities and differences and thereby increase the understanding of resilience.

4.10. 2 Life line analysis

The life line analysis was done based on the various life events that were provided by parents in relation to their child with intellectual disability. Following the trajectories provided, I realized most of the parents had similar life events with few differences. I then decided to use the life line of two families in my discussion chapter to explain the life trajectory of parents in relation to their child with disability. These families were chosen based on some similarities they had and also some distinctive difference in their life course which had implication for certain life choices and outcomes. As noted by Nilsen et.al (2012), the life line analysis is useful in making comparison in order to identify similar and dissimilar patterns in different life events as well as transition phases.

4.11 Ethical Considerations

Ethics relates to the application of moral principles to prevent harm and promote the good of participants (Hammersley & Atkinson, 2007). The importance of ethics cannot be overlooked in social research as it revolves around issues of human dignity and worth. Considering this importance, discussions on ethics still have opposing views among researchers. Bryman (2012)

discusses stances on ethics that differentiates researchers. According to him, whilst some authors believe ethical principles should never be compromised no matter what (universalism), others believe that, it's alright to be unethical if it results in a greater good (situation ethics). This makes ethics an area of subjectivity or personal discretion. As a social work student doing this research, I was guided by the ethics and values of my profession as well as common ethical principles in research such as confidentiality, anonymity, informed consent, voluntary participation, protection from harm and exploitation (Hammersley & Atkinson, 2007; Bryman, 2012).

In this study, ethical sensitivity was adopted at every stage of the research from beginning to the end as suggested by (Hammersley & Atkinson, 2007). I began by having some discussions with my supervisor regarding potential ethical issues and how best these can be addressed. Before the start of every interview, I provided participants with an informed consent form which gave adequate information on the purpose of the study, the rights of the interviewee, benefits and the consequences for participating in this study. This was done to help interviewees decide whether or not to proceed with the interview. Interviewees were made aware that, their participation was voluntary and could opt out when they feel uncomfortable. Due to the sensitive nature of this area of study, some parents became emotional in some of the sessions and began to cry. As a researcher and a social worker, I paused the interview and allowed them to express themselves after which we tried to talk things over. We then continued or ended the session depending on what the participant decided. All participants were treated with respect and their contributions were highly regarded. I made sure to say thank you at the end of every interview session and followed with a text message showing appreciation. I also sought consent from participants to record before proceeding. To ensure confidentiality, all the recorded interviews and transcribed materials has been kept in a safe and secured place and would only be used for its intended purpose. However, participants were not assured of absolute confidentiality but were provided with the conditions under which this principle can be broken such as threat of harm to self or others.

As I have mentioned earlier, due to the snowball method I used in recruiting participants for this study, I tried to strengthen anonymity by replacing the actual names and places with Ghanaian names since most of them are Swedish. Also, any details that was likely to make them easily identifiable was taken from the data during transcription and analysis. This is to help keep participants anonymous of each other and others who read this research.

As part of my ethical responsibility, I tried to give back knowledge to participants and not only take from them. I gave various explanations and clarifications relating to my research and social work in general whenever participants asked me. The interview raised consciousness of strength in some parents who openly said they had not paid attention to the strength they possess but talking about resilience has made them realize how far they have come in coping with the challenges of parenting a child with disability. For some of the parents, this was the first time they shared that aspect of their life with someone outside their network and for them that was a giant step in their resilience process. To demonstrate my genuine interest in the situation of participants, I honored an invitation to a program that was so dear to their heart and they were really pleased.

Adding to all the above, I ensured the proper citation and referencing of materials used in this study to avoid plagiarism.

4.12 Quality Assurance

Providing a detailed account of research process is critical in ensuring the quality of the research. In qualitative research, concepts such as trustworthiness defines quality assurance as oppose to reliability, validity and generalizability in quantitative research. Noble and Smith (2015) argue that, since qualitative and quantitative research differ in their orientation and philosophy, it is justifiable to have different frameworks to assess the quality of a research. Because quantitative studies are preoccupied with generalization of findings, its researchers are required to account for consistency in the methods (reliability) used as well as integrity (validity) of their conclusions based on certain tests and measures (Bryman, 2012). Applying these test and measures in qualitative research can be extremely difficult or impossible since social realities cannot have an absolute description. Considering the nature of my research and its aim of having an in depth understanding of resilience without necessarily generalizing, adhering to reliability and validity would not be able to examine the scope of issues discussed (Noble & Smith, 2015).

Yin (2010) noted that, quality assurance in qualitative research should focus on building trustworthiness and credibility by properly documenting the processes and procedures used in carrying out the research. In view of this, I have carefully provided a detailed description of how this research has been conducted from its inception to the end in my methodology chapter. Musinguzi (2015) refers to this as “thick description” as oppose “thin description”. In his view, thick description provides interpretation of data by considering context and subjective meanings

provided whilst this description only presents information without addressing context and other relevant issues. I also linked my results to the theories and previous studies to improve its trustworthiness. I however acknowledge that, social desirability bias might make participants provide information to portray a positive self-image, especially as the study relates to resilience. This could affect the study's trustworthiness but I mediated this by constantly encouraging participants to be truthful and honest.

4.13 Limitation and Delimitation

The limitations of this are discussed as follows;

First and foremost, the study was meant to understand the resilience process of the family as a whole, which include parents and siblings. However, there was difficulty in meeting the family together due to their busy schedule and time constraints. Except for one family where I interviewed the couple together, the rest were individual parents from different families. This resulted in getting the perspectives of only parents which could be biased especially when it concerns the whole family. For example, parents talked about the joy siblings have when providing support in relation to the child with disability but the siblings were not available to provide their own perspective on what parents have lifted up. At least for the couples that I interviewed together, parents agreed and disagreed on the issues they raised and could finally present what they think has been useful in their resilience process as a family, something that didn't occur in the case of individual parents. I therefore deduce that, the data I have could have presented a different reality if I had the views of all members.

Secondly, the level of intellectual disability of the children in this study were not considered though I acknowledge this could have influence on the coping and resilience of families. For example, families of children with severe intellectual disability might respond and cope with their situation different from those of children with mild intellectual disability. However, assessing level of functioning in the children required the professional use of some test and assessment tools which I didn't have access to. It was also difficult to meet the children due to their schedule and time constraints. Nonetheless, the families were quite homogenous with most having children with down syndrome diagnosis. In view of this, information provided by participants might not be very much affected by this limitation.

Again, most of the interviewees had Swedish as their first language but could express themselves in English. This affected the quality of the information provided because parents sometimes struggled to find English equivalent words to explain Swedish expressions to help the researcher understand better. Where Swedish words were used, I used Google translate for translation and then crosschecked with Swedish friends. Because I don't speak Swedish and couldn't afford to have a professional translator, I run the interview in English which I believe could influence information provided even though participants fairly expressed themselves in English. However, I still think I got enough rich data to back this study.

Lastly, due to the number of sample and the method used in recruiting them (snowballing), generalization of results and application to other context must be done with extreme care (Silverman, 2010).

Regardless of these limitations, the study has been able to contribute to literature and would hopefully be a useful tool for professionals and policy makers in understanding family resilience and support them accordingly.

4.14 Process of Doing the Research

This research was conducted following different phases to arrive at the final work. The process include proposal writing, data collection, data management and analysis and the report writing.

4.14.1 Proposal

A research proposal was written and presented to my supervisor for deliberation. This was done by a thorough review of literature on my topic to know what to include or exclude. The proposal therefore served as a guidance for conducting the main study without much difficulty. It's worth mentioning that, after discussing the proposal with my supervisor, some changes were made to help improve the quality of the research accounting for slight differences in the proposal and main work at this point. I identified all the resources I would need for my research and planned necessary strategies for recruiting participants and collecting data.

4.14.2 Data collection

It was during this stage that the collection of primary data occurred through interviews. I met participants in their homes, offices or places they found convenient to conduct the interview.

4.14.3 Data management and analysis

At this phase, primary data for the study was collected. The data was then stored in a very secure place and transcribed, after which analysis was done to identify various themes for discussion.

4.14.4 Report writing

Writing the report has been an ongoing process but during this point, writing was more focused on discussing themes that emerged from the analysis and relating them with theories and concepts to answer the research questions. Drafts were constantly sent to my supervisor for discussion. This provided opportunity for improvement.

Tab.3 timetable for the research process

Period (2017)	Activity
Early January	<ul style="list-style-type: none">• Meeting with supervisor to discuss research topic and preliminary planning• Gathering literature• Submitting research proposal
Late January	<ul style="list-style-type: none">• Submitting research proposal to supervisor
February	<ul style="list-style-type: none">• Reading and writing up literature review
March	<ul style="list-style-type: none">• Data collection (interviews) and transcription
April & May	<ul style="list-style-type: none">• Data analysis and writing of report
June	<ul style="list-style-type: none">• Submission of research project

4.14 Chapter summary

This chapter has focused on giving a detailed description of the processes and methods used in conducting the study. Issues discussed include research design, data related issues and analysis, methods for recruiting participants and data collection. Also included are discussions on various ethical issues as well as challenges of this study.

Chapter Five

5 Findings and Analysis

This chapter provides results on the resilience process of parents of children with intellectual disability in this study and the various support systems that contribute to their resilience. The findings are based on themes that emerged from the analysis of the life course trajectories of parents in relation to their child with intellectual disabilities. This section begins with a description of the demographic characteristic of families and then proceeds to provide a summary of two parent's trajectories in relation to their children with disabilities. Themes that emerged from the field data are subsequently discussed.

5.1 Demographic Background of Families

A total of seven persons from six families having a child with intellectual disability in Gothenburg, Sweden participated in this study. They included 4 mothers, a father and a couple (including a father and a mother). At the time of the interview, only one person was divorced, the rest were living together with their married partners. Number of siblings to the child with disability differed among the families ranging from zero to three. Families had children diagnosed with down syndrome and/or autism and intellectual disability. Four of the children in these families were 13years old and two were 17years old.

5.2 Trajectory of Parents of Children with Intellectual Disability in Sweden

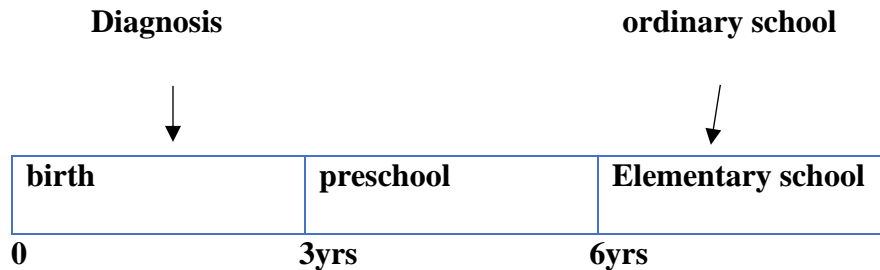
In this study, trajectories of parents were assessed in relation to their children with disabilities. The trajectories therefore reveal major life events that has occurred in the life of parents from the birth of their children until the interview. Life events of the parents were similar although differences showed up in the ways parents responded to these events and managed them to remain strong and functional. For all parents in the study, the trajectory begins from when the child was diagnosed of having a disability which represent a major life event as well a major transition for parents particularly because most of the children were at the school going age. This did not make it possible for parents to include other possible life events such as work or family life.

The initial response of the parents upon the birth of their child with disability was one characterized by shock, grieve and denial. At this stage, formal support is prompt and aims at providing psychological as well as practical ways of dealing with the situation. This is mostly provided by healthcare professionals. Though acceptance of the situation might not occur at this stage, it serves as the starting point. Due to the family oriented policies in Sweden, parents get to spend a year or two with the child whilst having some financial support. Parents receive about 80 percent (80%) of their salary from the state for 390 days to be able to stay home and care for their children and additional guarantee days with a lower amount of money not related to one`s salary (P. Boström, 2012; Olsen, 2007; Olsson & Hwang, 2003). It is worth noting that, this parental insurance is built on their previous income from work. Parents who have not been in employment prior to the birth of their child receive a very low amount, almost impossible to live on. Parental benefit is provided to compensate for the time parents spend with their children instead of working, looking for work or studying. For this reason, parents can leave work to take care of their child without experiencing financial difficulties. By the end of the parental leave, most parents have accepted the reality of having a child with disability and are prepared to support their child through life.

The next event in the trajectory is marked by the start of preschool. On average, parents expressed satisfaction with the preschools and had little struggles, something that they described as good for their mental health. Basic school and secondary school represent the most difficult transition phase for parents of children with intellectual disability in this study as they interact with lots of systems to help keep them strong. As an illustration, the trajectories of two parents is presented to show how the life course of parents having a child with intellectual disability may look like. These cases were purposively selected to flesh out the differences and similarities in the trajectories of parents as well as sufficiently explore the conditions that shaped the choices they made to remain strong and functional.

Adwoa and Kwame- Family 4

Events



This is a family of 5 consisting of the father, mother, the child with disability and two siblings living together. The parents decided not to take a pre-natal test when the mother was pregnant based on their reservations about such testing. They understood the risks associated with their decision but were willing to take their chances with the hope of having a healthy baby.

“We did not take any test, we were willing to have any child and even if it`s disabled you know... anything is fine”

In this quote, parents seemed to have a balance expectation of the child which was quite unusual based on Carroll (2013) study of families of children with developmental disability in the United States. She explained that, the dream of most families is to have a normal healthy child and do not desire to have a child with disability (ibid). When the child was born and doctors detected the problem, several examinations were made leading to a down syndrome diagnosis. Contrary to their initial expressions and thoughts, the family experienced what they themselves described as shock.

“It`s still a shock and the shock comes from not knowing what this is, that`s a shock because it`s not something we know anything about. There is fear in that because that`s something new and different. I remember things felt quite overwhelming and we felt like we couldn`t really cope with it. There was definitely something around this period, I have a very clear picture ...it`s like my heart was taken from here [pointing to chest], it`s always protected behind all these ribs right, it`s strong. My heart was taken out and it was here in front of me all the time and it was soft and anything could happen to it. We couldn`t watch violent films anymore. It has to do with this shock thing around the birth”

The feelings and emotions expressed by the parents in this quote is a clear contradiction of what would have been expected based on their comments in the previous quote. This gives an indication that the family might have underestimated the consequences of their action.

During this critical moment, the parents received a lot of psychological support at the hospital to help them deal with the stress. They were then given information regarding services and benefits available to them as well as links to networks of families with a similar situation. The services are included in the medical care provided to citizens and residents by the state (Anell, Glenngard & Merkur, 2012). The information given to parents are to help them access other forms of support once they are discharged from the hospital.

At age 3, the child started preschool. It was a bit of a worry for parents at the beginning knowing the special needs of their child. However, their determination and support from the networks of families with down syndrome children helped to empower the school to support the child. This was fulfilling and created a sense of safety for the parents. It was described as helpful, making room for parents to work and have time for themselves and friends.

“We even went with other parents, we did role playing where one person will play the headmaster and then we swap roles so we could practice because we were so worried about how they handle him because we have heard a lot of bad experiences you know and schools being unwilling but on a whole and we worked really hard at it. On a whole they have reacted pretty well so far, he’s had a good period in the school”

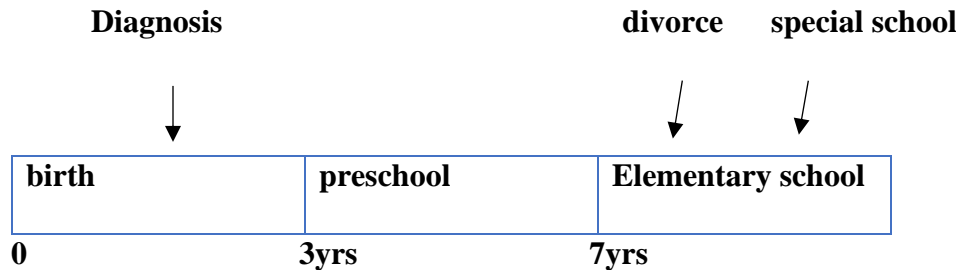
It is interesting to note how parents organize themselves to educate the school and empower them to meet the needs of the child. In my personal experience as a social worker, service providers are those who take such initiatives and invite service users to participate. This is a different dynamic where parents become experts and advocate for their children and themselves.

The action of parents and their networks is a clear reflection of how meso-level support in the ecological model operates to support resilience (Bronfenbrenner, 1994) and confirms Martilla et.al (2013) study which showed that, support from informal networks usually comes in practical forms rather than fiscal forms. After spending three years in preschool, the child started basic or elementary school at age 6. This represented another transition for the parents. It was difficult to get the child into an ordinary school because they had no provision for special needs but parents

persisted until he was accepted. Though the Swedish law allows parents to have a choice whether or not to have their child in special or ordinary school, the formal support system makes it very difficult or almost impossible for parents to make a genuine choice. Thus, majority of state resources supporting the learning of children with intellectual disabilities are channelled to special schools. Opting for an ordinary school would mean less state support and more efforts and financial commitment by parents to ensure that, both the school and the child cope effectively. Parents who do not have the capacity to handle the challenges of choosing an ordinary school are indirectly forced by the system to opt for special schools which may not be what they really want for their child. To be able to cope well, a decision was made by the family for the mum to work part time and channel the rest of the time and energy to helping the child go through this phase and successfully transition to the next one. Since the man earned more, it was more beneficial for the family if the mother instead of the father works part time. This agrees with Štěřbová & Kudláček (2014) reflections on coping strategies where he noted that, families develop a specific coping style in order to create a balance between demands and resources available to them. According to these authors, some families achieve this balance by reducing the demands on them which is the case of this parent. The decision of the mother also shows how families reorganise themselves to deal with daily pressures of parenting a child with disability as suggested in the family resilience framework by Walsh (2003). Connecting this with earlier discussions on formal support and choice of school, there is an indication that, where there is limited formal support systems, parents adjust their inner family dynamics to enhance resilience. Now, the child is 13years and will soon start his secondary education. Parents are still faced with the need to decide on having him in an ordinary or special school.

Kwesi – Family 3

Events



This is a family of three comprising of the father, child with disability and a sibling. Unlike the first family, the doctors detected the problem early in the pregnancy but couldn't give an exact diagnosis until the child was born. The family was still hopeful things could change and the baby would be healthy. Knowing that parents were aware of the problem even before the birth didn't change their response when the child finally arrived. The father puts it this way

“it had a lot of psychological effect and it needs a lot of psychological help”

As was the case with the other family, support system at that point was majorly formal and it sought to provide information to the parents, siblings and stabilize them psychologically to accept the realities of having a child with special needs.

“They [doctors, nurses and psychologists] were always with me like to talk to me and they give me feedback what can happen tomorrow if we must go on with another meeting. It's like they will keep you informed, whatever is going on. But we got our chances and they will tell you almost everything that is happening, what they are going to do or what they will not do, what is going to be needed soon. They give you all those kinds of support, you always get support from both the doctors concerning the child and the mother. Not only that but, they will extend also the support to the other family members who live in the same house with the mother or people who are going to live together with the child because they need everybody on board to support...and you don't have to pay anything”

It is interesting to note that, parents received services without payment. This is because healthcare and welfare provision in Sweden are mainly considered a public responsibility financed through taxes (Anell et al., 2012; Gustafsson et al., 2013; Ozawa, 2004). With the parental leave

arrangements in Sweden, the family had some time off work to care for their child and recover from the shock. Since both parents worked before the birth, they were all entitled to this benefit which they both utilised.

The next major event the parent described as important was when the child started preschool. This period was characterised by anxiety knowing the medical needs of the child and being uncertain about how the child is going to cope with a different system he is not used to.

“when Kojo started school, it was quite difficult because that time he wasn’t all that strong physically so it was a big challenge for us to go and leave him at the dagis [preschool] when we know where he is. I remember two or three times I will go drop him there but yet I will be hanging around. I have told them already if you feel that he doesn’t want to sit please call me immediately, I am just some meters from the dagis. I cannot go home, but fortunately the people who worked there they did all they could professionally and Kojo made it so I will give special thanks to those people who worked with him at the beginning at the dagis, the kind of support they gave us”

The preschool phase is undoubtedly satisfactory as illustrated in this quote and that of family 4 presented above. At age 6, the child moved to a special school for his basic education unlike the first family. This decision was based on two reasons; the parents divorced around the same period and couldn’t cope with the pressures associated with opting for an ordinary school. Secondly, the parents felt special schools have systems that meet the needs of the child without stressing him unnecessarily. The family described this school as helpful and less demanding which gave both parents the serenity to work full time and engage in other activities. The experience of this parent in contrast with the previous one provides a clear picture of how the interactions among different systems operate to result in resilience for both child and parent. With the former family, the couple was able to reorganize themselves and change family dynamics to support their choice of an ordinary school. However, it seems quite impossible in this case considering the divorce that occurred. A critical reflection on this difference shows that, single parents may find it difficult to make certain choices like choosing an ordinary school. A reason being that family dynamics might make it difficult since formal support is limited in that regard. The Child is still in elementary school and hope to transition to secondary school soon. The parent is looking forward to this phase as it marks an important milestone in the life of the child.

The two trajectories presented, provides an overview on resilience in families of children with intellectual disability within the frame of this study. Using the life course approach as a theoretical tool, the trajectory is characterized by different life events, transitions and turning point that occurs over a period to achieve resilience. The trajectories of families in this study support the thinking that, resilience is a process and not a static set of outcome or trait (Becvar, 2013). Within this process, families organize themselves in different ways by relying on both internal and external resources to become strong and functional. Like Giele and Elder (1998) explained, the life course consists of various continuity as well as twist and turns that helps to understand events in the life of individuals and how these are managed to achieve resilience. With this, families experience different levels of functioning (high, average or low) in their resilience process as life events unfolds. However, all these variations in functioning has been identified by parents as necessary to enhance resilience.

5.3 Support Systems Enhancing Resilience

This section presents results on the various systems that interviewed parents outlined as important in keeping them strong and functional. The support systems were categorised into three levels based on the ecological model proposed by Bronfenbrenner. They are micro, meso and macro level support.

5.3.1 Micro level support

Micro level support was identified by parents as support that exist within the immediate family unit. It relates to the inner dynamics of the family that supports their resilience. At this level, the kind of support that parents identified were further categorised into spousal support, sibling support, gender roles, child's development and parent's personal disposition.

5.3.1.1 Spousal support

Spousal support represents an important area that interviewed parents reflected on and considered as very useful in keeping them strong. This is the kind given to parents by their partners. It may come in different forms like advice, emotional support, sharing responsibilities and having a common agreement on issues relating to the child as reflected in the quotes below.

“support from my husband has been important, if he did not support me we would probably have divorced I think. We wouldn't have the power or he will be too tired to fight if I was

not around but together we learn lot of things, together we argue over things and that makes the bond between us stronger” (Ama-family 1)

The statements above are reflective of how corporation among couples helps parents cope with the stress of parenting a child with intellectual disability. According to parents, spouses are persons with whom intimacy is shared and support from them in difficult times is perceived as a prove of love and provides a sense of security. Surprisingly, divorce does not overrule the need for such assistance, supporting the adage; two heads are better than one.

“even though we are divorced I don’t think Kojo [child with disability] sees it like he has two houses. He still sees one family because whatever the mother wants to do, if she couldn’t do it, I have to complete it. So, it’s like the same procedure, wherever she stops I have to continue from there, what she can’t do at all, I have to start it. Concerning Kojo we work hand in hand otherwise it will not work. I can’t do it all by myself, not the mother either” (Kwesi-family 3)

With this, single parents who lack the support previous spouse might be more susceptible to higher stress which can make resilience difficult. This could explain why single mothers of children with disability experience higher stress according to the research findings of Levine (2006). The study which focused on resilience in single mothers of children with disability found that, non-spousal support increases one partner’s responsibility (financial and practical) of handling the various challenges associated with parenting a child with intellectual disability. This could increase stress levels and result in breakdown. Getting support according is therefore crucial in enhancing strength since stress is shared among the couples. Adding to that, when one spouse is down, the presence and support of the other helps to maintain the family functioning as opposed to doing everything alone or seeking external help. Families tend to have boundaries which could make it difficult for external persons to play certain roles, it may be seen an intrusion of family privacy which is often uncomfortable.

5.3.1.2 Sibling support

The next kind of support that exist at the micro level is sibling support. Earlier research has been quite uncertain about the role of siblings in the resilience process of parents of ID children (Strohm, 2012). Results from this study brings to bare the important contribution siblings offer to parents. This support normally shows itself in how siblings assist in the care of the child with disability and

in the encouragement provided when parents seems to be giving up. It was particularly interesting for me when parents explained how small but useful this has been to them. According to the parents, society has conceptualized adults to be strong and children weak. Due to such thinking, parents were particularly dismayed about how their children showed enormous strength when they the parents were close to giving up. This has in many ways rekindle parents to stay strong over the years.

“Honestly, my daughter did a lot because sometimes I could see myself as going down, she will just come up with something you know. It’s like everybody has to be there. She is doing what she could even though she is not the one to be responsible for that but she is helping us a lot. She takes care of Kojo when I or the mother is not around” (Kwesi-family 3)

“it was really good with his bigger sister for example her own reflections on her brother with down syndrome happens to be so beautiful throughout the years and it’s really helpful and made me think more than otherwise...why are they sad for this beautiful child, that’s what she would say and it was really good to get that side of things because I saw a lot of work due to what we had talked about earlier [having a down syndrome child]” (Afia-family 5)

“.... our elder sons are very helpful and they don’t live at home anymore but they come as often and they support us and say yes you must keep fighting because this is the thing” (Ama-family 1)

Parents reflection on support provided by siblings seems positive and relevant in contributing to the resilience of parents and the family as a whole. Following a study of brothers and sisters of children with special needs in Australia, Strohm (2002) found that sibling support may be helpful for families but could reflect a different reality for siblings themselves. Her study revealed that, siblings sometimes take up care roles and responsibilities because they feel they have no choice, to win parental approval or to avoid feeling guilty for not being supportive. This could put such siblings under pressure and increase stress which the study found could have a negative effect on the adult life of siblings in such households. Regardless of how siblings feel about the support they provide, it is considered positive for the proper functioning of the family. Since many studies on siblings of children with disability has reported negative outcomes on the siblings (Hendrick,

2015), it is particularly important to note how siblings in this study according to parents showed enormous strength to help the family become strong and functional.

Responses from the quote also indicates sibling support is more evident when the sibling is older than the child with disability. Interviewed parents did not share any information regarding support from younger siblings. From the results, this could suggest that, sibling support is more functional among families having children older than the child with disability and not vice versa.

5.3.1.3 Gender role dynamics

Another interesting theme that emerged under the micro level support system is the nature of gender roles that exist within a family. When parents were asked about their family dynamics that has helped in resilience, gender roles played an important function worthy of discussion. Though previous studies by Evertsson (2006) and Wissö and Plantin (2015) have revealed that, mothers in Sweden perform more house work than fathers, the presence of a child with disability for parents in this study seems to widen the gap as the quotes below illustrates.

“But I think it has a lot to do with competence, I mean it’s about nurturing, you can really talk about the fact that women have certain better functions where children are involved. I think you had, yeah, I think you have certain skills for that [referring to wife]. Then I think also I am working more, we made a decision, you would have your own business but not probably working full time and I would work. So, that makes it difficult for me to be as engaged in his speech development. It’s exactly that one person earns more and often the man. It becomes like that. But then it became that you got a better paid job than me[woman] Before we had kids and good money in Stockholm but then when we moved here, I didn’t have that position and I became pregnant straight away so kind of ended up in more traditional way”-(Adwoa & Kwame-family 4)

“I don’t have a super career now [laughs out loud] but I am acting as the union representative and that’s not boosting for my career. Well I was a manager kind of 25 years ago but after that [having a child with down syndrome] I have been home. I’m a graduate engineer my husband works more of late so I do more of the cooking now than I did before I think “- (Abena- family 2)

The results show that, women in households of children with intellectual disabilities tend to work part time whilst the men work full time. This leaves the care of the children and the house work as

the woman's duty. Similar findings on the shift to traditional gender roles in families of children with disability was also found in a comparative study of eleven European countries by Di Giuilo et al. (2014). It highlighted that, the presence of a child with disability mostly motivate families to adopt traditional gender roles to enhance their functioning. A careful analysis of the situation shows that, it is not necessarily a matter of personal choice but structures within society still operate on notions of traditional gender roles where women are considered home makers as opposed to men with Sweden as no exception. This suggest that the country (Sweden) needs to do more to ensure that its agenda of having a society free of gender inequality (Bernhardt et. al, 2008) is achieved.

It is undeniable that this arrangement has contributed in helping families manage various challenges especially those relating to finance and has in a way helped families cope and keep them strong. It is one that can disempower women and keep them in lower positions of society in the long term. Contrary to the findings of (Rimmerman, 2015) in his UK study, were he found that, fathers of children with disability work full time to avoid the care demands associated with such children. In this study, the obvious reason seems to be financial since the men earn more it becomes prudent for them to keep their normal work schedule whilst the women work part time, set up their own business or quit working to be able to support the child and family. It has been documented that, the cost of raising a child with disability is three times that for non-disabled child and financial support from the state as its done in Sweden cannot bridge this gap to guarantee families of good living standards.

5.3.1.4 Child`s development

The next subtheme to be discussed under micro level support is the child`s development. This theme reflects how systems within a person`s environment affect each other as proposed by the ecological model (Bronfenbrenner,1994). Thus, as parent`s resilience affects a child`s development, so does the child`s proper growth has a reciprocal impact on parents` ability to remain strong over the period. The initial fears with the presence of a child with intellectual disability sometimes revolves around how the child can develop and live an independent adult life. In view of this, interviewed parents spoke about how the child`s development becomes a great motivation for them to keep moving on in life. For parents, seeing their children achieve certain milestones such as walking, talking, reading among others does not only reduce parent`s responsibility but also gives them an assurance that, these children can live their lives without being over dependent on others

for basic things in life especially when parents are not available to support them. A child who is not developing in this regard increases family stress and hinders resilience. Most literatures on family resilience seems to overlook the contribution of the child's development in parent's resilience, however, parents in this study consistently mentioned how this aspect has been critical in keeping them strong and functional. For example, a child who is able to communicate effectively can make their needs known and be able to understand happenings in their environment. This makes it easier to achieve set goals in relation to the child's development. Below are quotes from parents which emphasize this important support system

"The most important thing for me was the development of the child and seeing her make progress. She couldn't talk till she was five years and then when she finally did, it brought hope" (kukuwaa-family 6)

"I know how to take things from one stage to other because he is with me and you may see something that people call it big problems. Right now, I don't know what big problems look like because what I went through with that boy, where he is today I know whatever problem you have, if you are prepared mentally and have patience you can solve it" (Kwesi- family 3)

"I decided I wanted to breast feed him... because he has the ability to have a weaker immune system, I just felt it was really important, he wasn't strong enough to do that in the beginning. So, I borrowed the scale from the medical Centre and I weighed him, I breast fed him and then I weighed him again... if he hadn't drunk enough I pumped and then I gave him the rest in the bottle and I did that for six weeks and then he could breast feed which was great. It's like when a normal child starts walking after one, it's absolutely amazing, when a special child walks at age two and you struggled and you trained and you supported them it's even more amazing, you know it becomes even stronger because you had to fight for it" - (Adwoa & Kwame-family 4)

From the quotes, parents' expectation of their children is to see them achieve socially acceptable development milestones. Though the pace of such children is comparatively slower, it serves as reward to parents for all the hard work involved in caring for a child with intellectual disability and an encouragement to fight on with hope. Hope has been identified by many writers as a virtue

that help individuals rise above their circumstance (Saleebey, 1996; Webb, 2010) and subsequently contribute to enhancing their resilience.

5.3.1.5 Personal disposition

The last support system to be discussed under the micro level is parents personal disposition. This theme came across through the data in the form of parent's belief system, personal motivation and self-esteem. It represents support that emanate from within the individual which keeps them going even when other support systems fail or are difficult to access. In Walsh (2003) family resilience framework, belief systems are essential tools in determining how families respond to events that occur in their life course. Interviewed parents personal disposition seems to be adopted to making positive meaning and seeing strength out of the challenge.

“I feel in some ways very strong. My opinions are more developed and sharper I think in some ways. When I get a letter and I see is from a principal, if I open it my body reacts quicker because I think it means I must start to fight but I know more and I probably win the fight but I don't want to fight. I am strong because I know life is short that is why I started to write instead of just working eight to five and appreciate life”- (Ama-family 1)

“I normally don't give up and I will say stubborn ...yeah I think I am...I think that's how you are of course your background etcetera” (Abena-family 2)

“.... the last thing I do is to listen to my gut. So, I think perhaps I do that in that order and have been better to listen to my gut” (AFia-family 5)

Parents disposition seems to come naturally and forms part of who they are as individuals (personality) though environmental influence cannot be completely ruled out. In a cross validation study of resilience scale among a group of applicants for a military college, measures on personality factors were related to scores on the resilience scales. Personal strength positively correlated with the resilience variable and emerged as the measure that is most associated with emotional stability. It was seen that, persons who scored high on the resilience scale were reported to be “psychologically healthy, better adjusted and thus more resilient” (Narayanan, 2008, p. 112) This could provide an explanation to why there are variations in the resilience level of individuals and families dealing with stressful life events. In this study, these variations were also detected based on how families talked about their situation and experiences. Nonetheless, all interviewed

parents seem to possess inner strength, something unique to them which helped to manage the struggles of parenting a child with intellectual disability. This shows that, all individuals possess some amount of strength regardless of their circumstance as explained by Saleeby (1996) in his strength perspective.

5.3.2 Meso level support

At the Meso level, interviewed parents discussed various systems outside their immediate family that has been critical in their resilience process. Parents identified support groups, school and their extended family as the three most important source of support in helping them remain strong. The paragraphs below would critically analyze these subthemes as they emerged in the data.

5.3.2.1 Support groups

I observed that support groups served as an important resource for parents in their resilience journey. These groups consist of families who also have a child(ren) with intellectual disability. According to parents, the groups provide a platform where parents meet each other to interact and share ideas relating to their challenges and how best they can support their children. The quotes below illustrates how the support groups organize themselves to help families deal with various challenges that arise from having a child with intellectual disability to remain strong.

“...we got a letter from the principal saying we should meet the school area boss sort of and we think it means trouble, we don't know what is going to happen but every time, we feel sad or upset we just go to our new friends [other parents with down syndrome children]. We know the child's condition, we know every law we need to know and we know conventions for disabled people and we think it's right to every person to have a place in the society”- (Ama- family 1)

“I think reaching out and finding other people in the same situation. I think that was the best thing to create this network and to be part of the network. For us we got family, we could share with other people that understood and we could talk often when we went to summer camp and in the evenings when the kids are gone to bed we all sat up and spoke about the problems, what's happening, what's not happening, how is it going here, how do you do this, how do you handle that, training and then somebody else says “oh I have this special trousers on” and even with relationship stuff to know how is it going. I think that

was the best thing, was to create community that you could talk to openly” (Adwoa & Kwame- family 4)

According to the account of interviewed parents, support groups helps them to know they are not the only ones in that particular situation. It is also a platform where zero stigma is experienced as compared to the general society which helps to reduce stress. Among these networks, parents are able to openly share their concerns without any form of worry which helps to free themselves of societal pressure that increases their stress. Parents further explained that, the support groups serve as a source of power to challenge and advocate for services which otherwise would be difficult to individually obtain. Within these groups, forms of support are unlimited and cuts across different areas such school, recreation, language training, family life just to mention but a few. Interestingly, the focus is not only on parents but support extends to siblings and the family as a whole. The way these networks of families operate clearly shows how the Meso level in Bronfenbrenner (1994) ecological model work where different micro systems as well as Exosystem interact to achieve development. Parents describing the support group as “family” shows the level of safety and assurance that these group provide to them. For those who have small families or family support is limited, the networks serve as a replacement which emphasize its importance.

5.3.2.2 Close Extended family

Extended family support has been explored by many studies as an important resource that helps families of children with disabilities cope well especially in collective societies or families with collective values (Bromley, Hare, Davison, & Emerson, 2004; White & Hastings, 2004). This was based on results from their study on mothers of children with autism, which showed that low level of stress was partly due to family support. In this study, grandparents (parents of interviewed parents) represented the dominant group that parents lifted as playing an important role in their resilience. Little was mentioned about support from parents own siblings, aunties or cousins. Implying that, families with no grandparents are more likely not to have extended family support. It was also clear parents had support from extended family members with whom they had close relationship with.

“My mother-in-law came down and cooked for us (laughs) for a while and that was also good” (Ama-family 1)

“My mum and dad were very helpful. They encouraged us and did most of the house chores which was really good for me because I could relax” (Abena- family 2)

“My mum helped as much as she could and it was just so nice...my brother hasn't been that interested, he is very kind and nice and he doesn't get it that he could kind of help out”
(Adwoa & Kwame- family 4)

The quotes bring to bear the kinds of support provided by extended family members and persons mostly involved in providing these supports. From the quotes, support seems to come in practical other than fiscal form. This involves giving emotional support and helping with housework to relieve parents of some duties which interact with the care of the child with disability to increase stress. Another interesting dimension that these quotes presents is the issue of gender. Grandmothers seem to be more actively involved in providing support than grandfathers giving more evidence to the fact that, traditional gender role still exist within Swedish households more than it is talked about. Though parents find help from extended family very helpful, there is relatively low expectations in this regard especially due to the nucleation of families in Sweden and most European countries over the period. This is particularly scaring considering the recent cut back on social expenditure in Sweden (Jegermalm, 2005; Sundström, Johansson, & Hassing, 2002). It could put families who have little to no contact with their extended family in a vulnerable situation which could hamper their resilience.

5.3.2.3 The school

Issues relating to education was one theme that study participants continually emphasized in the field data. This is mainly because the development of the child as it has been discussed earlier is very crucial in helping parents remain strong. The role of the school in family resilience seem to be silent in many studies. From the data, support from the school is directly related to the child but its trickling effect on the parents was identified as enormous showing the interrelated nature of system within a person's environment according to Bronfenbrenner (1994). In this study, preschools came across as the most talked about school system that supports resilience as illustrated in the excerpts below

“...it was quite easy to get good place for him right from the start and they had really good team with the ordinary team that were there at pre-school, one

particular staff had experience about children with Down syndrome sort of” (Afia-family 5)

“Fortunately, the people who worked there did all they could professionally and my son made it so I will give special thanks to those people who worked with him at the beginning at the dagis [preschool], the kind of support they gave us” (kwesi-family 3)

From the two quotes, parents seem satisfied with the help received at the various preschools. Staffs were able to meet the needs of the children and support their learning which made parents more relaxed to deal with other issues. According to parents, preschools are more inclusive and accommodating to children with disability compared to other levels where parents struggle with the system. In particular, when the child with disability is to go to an ordinary school instead of a special school. A critical analysis of this situation shows how school policies in Sweden tries to segregate against persons with disability by providing more support for special schools and having minimal to no support for disabled children who decides to go to an ordinary school. Explicitly, everyone has the right to choose the type of schools but indirectly children with disability are being coerced by the system to choose special schools. The case seems to be different with resource allocation to preschools accounting for its inclusive nature. According to information provided by parents, the school only helps in enhancing resilience when its more inclusive and supports the development of the child in the right direction.

5.3.3 Macro level support

Macro level support was identified as support in the wider context of a country which is mainly formal. The support is provided through formal institutions and policies. The two go hand in hand making it difficult to discuss them individually. Macro level support are given in the form of financial compensation, emotional support and information. This is mostly the first form of support parents receive once the child is diagnosed of having a disability. The institution mostly responsible is the hospital. They attend to the medical needs of the child and provide counselling to the family especially parents. As it was seen in the trajectories of parents presented earlier, the diagnosis phase has always been turbulent for most of the parents. Providing this emotional and psychological support was identified by interviewed parents as a very good way to start their journey of resilience. The hospital also provides information regarding the child’s disability and

practical information on the kinds of support available and where to find them. Another institution parents identified as useful in their resilience process is the rehabilitation center (rehabilitating in Swedish). This institution picks up from the hospital and continues to work with families for a longer period of time. Decision to receive services from the rehabilitation center is however voluntary. The excerpts below illustrates how the institutions identified by parents have contributed to their resilience process

“...you always get support from both the doctors concerning the child and the mother. Not only that but, they will extend also the support from the other family members who live in the same house with the mother or people who are going to live together with the child because they need everybody on board to support....it needs a lot of psychological help So they will put people in place who will help you and it’s all free of charge. Even though you get support from the state, it doesn’t come often” (kwesi- family 3)

From this quote, it is evident formal support takes a family oriented approach in addressing the needs of family. This is consistent with recent paradigms in the social work and other helping professions as Allen & Petr (1998) have noticed. Also of importance is the fact that, services are provided on a free basis once a person is registered in the Swedish population system creating an opportunity for poor families to receive support and enhance their proper functioning. In contexts where such services are paid for, it could account for why poor families are mostly regarded as less resilient according to Henry et.al (2015). The parents in the quote below also describes the role of financial assistance provided by the state. According to them, this assistance helps to support family income when one partner is working part time or has no employment

“...as a family with a child with special needs in Sweden you get some money I don’t know what we get, 8000 a month... I don’t remember but we get money each month to cover up for the fact that Adwoa (mother) wasn’t working full time” (Adwoa & Kwame- family 4)

By supplementing family income and providing another benefit enumerated in the LSS law (1994), the state helps families become resilient by relieving them of certain responsibility which would otherwise have increased their stress. For example, respite care gave parents some time off to rest and engage in other activities different from that of caring for the child with disability. Families

use this time to regain lost energy to continue with the demands associated with parenting a child with disability. This process has been identified by parents as helping in keeping them strong. However, access to this level of support could also be stressful. According to interviewed parents, the services are fragmented and information are not readily available. It also involves lots of bureaucracies making accessibility frustrating sometimes. Though parents have the right to support, they must constantly “fight” to get the needed support.

5.4 Nature of interaction among support systems

The nature of interaction among support systems is one that is complex and characterized by constant negotiation between the family and other external systems resulting in resilience as explained in the ecological theory of Bronfenbrenner (1994).

Parents rely on the different support systems identified above to help them remain strong and functional. However, this occurs at different times in their trajectory. For example, formal support has been prompt at the early years of the child compared to later years and when it fails, network and family support are strong. This suggest that, no system is self-sufficient or adequate and requires parents or families to constantly use the strengths of the various support systems to enhance their resilience.

5.4.1 Becoming by giving -a strategy for resilience

This section presents a unique strategy that study participants presented as useful in helping them become stronger. According to parents, resilience is sometimes achieved by empowering other systems to be resilient. This way, such systems can act in ways that decrease family stress by understanding the needs of families with intellectual disability and taking practical steps to meet those needs. The outcome is that, stress is minimized and all systems involved gets stronger. This is what a parent had to say on the issue;

“I think it’s important to acknowledge as well how we parents have supported the state and community to be resilient, the school for example, thanks to us they now have much better teaching for children who have problems with communications and language skills... I think a community gets more resilient because every family has problems, we meet the problems, we cope with the problems and the result is stronger people” (Adwoa & Kwame- family 4)

The excerpt illustrates how parents have provided a school with resources (teaching materials, toys, tutorials etc) to support the development of their child. The results have been a stronger society that is responsive to the needs of children with disability. This strategy has proven to be very useful but the cost involved makes it difficult for parents to continue for a long time. When the parent was asked about state support in issues like this, he said

“They did that after a while...so it’s about getting them to get it” (Kwame- family 4)

From the statement, it is event that trying to make other systems resilient is about persisting till the right results are achieved. In this case, if parents have not taken the lead to ensure the school is well equipped, the state would have not considered it necessary to act. In the long run, parents would always have to struggle which can increase stress and affect resilience.

5.5 Obstacles to Resilience

Under this section, discussion would focus on the various challenges interviewed parents brought up as not helpful in their resilience process. Based on their responses, the challenges have been categorized as personal, structural and significant others. The themes emerged by themselves as parents responded to other questions and I particularly found it useful to discuss.

5.5.1 Personal

The personal obstacles were discussed by parents as their negative attitudes which holds them down and makes progress difficult. There seem to be commonality among all the parents especially at the initial stages when the children are diagnosed of having a disability. Carroll (2013) explained that, this becomes the case because majority of people carry an expectation of having a normal healthy child when pregnant and don’t desire a child with disability. It therefore creates a sense of grief, fear, denial, blame and lack of motivation to support the child. All these have been identified by several research as increasing stress and vulnerability making resilience difficult (Leyser, 1994). Parents noted that, they were only able to function normally once such perspectives were altered and adopted to positive thinking. Below is what one interviewed parent had to share on the issue

“...we had the diagnosis and I think I didn’t take it well at all it was quite turbulent I would say...it took a very long time until I considered that was my child. He was sort of the hospital’s child” (Afia- family 5)

In this quote, the parent denied the reality of having a child with disability resulting in shifting responsibility of the child to the hospital. Finally accepting the child as her own was a major turning point (Giele & Elder, 1998) to achieving resilience. This agrees with Walsh (2003) discussion of belief systems under her family resilience framework. According to her, a way to achieving strength and development is by making meaning out of adversity, having a positive outlook and increasing spirituality. By spirituality, Walsh was not only referring to religion but all forms of beliefs and practices that provide a sense of meaning beyond oneself, family or present struggles (ibid).

5.5.2 Structural

The structural obstacle to resilience was discussed by study participants as weaknesses in the formal systems of support that makes it difficult to achieve resilience. This level of obstacle normally require change in policies or laws of which parents have little control. Most of these laws regulates institutions that parents interact with such as the school and rehabilitation centre. This was mostly evident in discussions on special and ordinary school for children with disability in Sweden. According to parents, some schools and community activities are not able to absorb children with disability because funding provided by the state do not cover such children. Rather, the state puts a lot of resources in special schools which ends up segregating children with disability from the larger society. Parents found this threatening and discriminatory because if care is not taken such children cannot survive with time especially considering the growth of right wing parties as presented by one parent

“Sweden has special issues and its very vulnerable, it’s in danger of giving way to populism, to populist right wing, immigrant, unfriendly leaders who are not very good either with special needs” (Adwoa & Kwame- family 4)

With this kind of fear expressed by parents, opting for an ordinary school is one of the ways parents use to help the society become more accommodating of persons with disability which is captured in the next quote

`if we can just have more diversity in the schools, thanks to yaw[son with disability] and all the lessons, those kids learn all through that journey, then they will be better citizens when they come out and that's resilience` (Adwoa & Kwame- family 4)

This finding provide an opportunity for Sweden to revise its policies by making it more inclusive to achieve the agenda of having a society free of all forms of inequality (Clevnert & Johansson, 2007). Until then, interview parents regard such arrangements as an obstacle that hinder resilience by constantly keeping them in fear for the future of their children with disability.

5.5.3 Significant others

Under this category, all persons who played significant role in the life of the parent were identified as significant others. They include family members, friends as well as professionals. The obstacles were in the form of negative/ discouraging comments and stigmatizing behavior.

`...Some of them [friends] instead of them to come and assist you, they may even make things worse so it's better not to count on them. Maybe it's much better not to listen to them so you can get enough time to concentrate because the more you go in and get any negative information, it pulls you down. The kind of strength you have, you can be sad and a whole lot of things so I don't think it's the best` (Kwesi- family 3)

From this quote, it is evident that negative feedback from significant others could drain the strength of parents and affect their proper functioning. For parents to keep moving and living their new life in a resilient way, they distance themselves from such people or in the worse kinds of situation cut ties completely. This could explain why during the interview, parents had very little to say about support from friends and neighbours in their resilience process.

The next quote brings another interesting but unexpected dimension to the discussion of obstacles in resilience.

`They sent two nurses to talk to me. They had also children with Down syndrome ... one of them had a child about 15years old, the only child...he just liked touching the washing machine and I did not want to hear that at that point. The other parent, her child had autism too and that had broken down their family. It was not encouraging at that time either` (Ama- family 1)

In this quote, it is evident how professionals can sometimes become obstacles to making parents strong. It was interesting to see the formal system using informal ways to assist parents but the latter comments bring the big question, is it the best way to go? Should professionalism be separated from personal life? These questions present an interesting area that could be explored in another study. Since professionals were not present to explain their rationale for giving such comments, not much can be said about it. Regardless of the rationale, this was a non-professional and disempowering way of sharing personal experience especially at this initial phase where parents felt very vulnerable. This brings to the discussion, issues of power and powerlessness in practice. According to Tew (2006), certain groups in society including professionals have access to authoritative resources putting them in positions to exercise power over others. Due to this power relation, professionals are required to work with much caution to avoid disempowering rather than empowering service users. The impact of the comment would have been different if the nurses were just parents and not professionals but for the issue of power discussed above, it was regarded as inappropriate for the situation.

Chapter Six

6 Discussions, Conclusion and Recommendations

The last section of this study discusses selected findings and its implication for practice and policy. This is informed by the research questions and hopes to highlight important learning points

6.1 Discussions

Results from this study indicates that, families of children with intellectual disability can cope well despite the numerous challenges they face. This supports the finding of Lusting (1997) research quoted in Neel -Barnes & Dia (2008) which found that, most families of children with disability showed flexible profiles with very few exhibiting poor functioning. It suggests that, though families might experience some form of break down, they are able to reorganize themselves to become resilient. From the study results, specific life events and transitions were seen as critical in achieving resilience or not.

The trajectory begins with the birth and diagnosis of the child with disability. This is an emotional phase for parents characterized by shock, fear, guilt and shame. At this point, formal support is prompt and focused on stabilizing parents emotionally and psychologically to accept their new reality. The support is very critical in creating a starting point for the journey of resilience by providing parents with information and links to resources that are available to them. The institution actively involved at this point is the hospital. The birth and diagnosis are both a life event and a transition (Giele & Elder, 1998) for parents that requires changing roles and responsibilities to accommodate the needs of the child. The next major event that came across in the data was the start of preschool. Between the previous event and this, parents seem to experience stability and focus on caring for the child. This was possible due to the parental leave arrangement in Sweden which provides financial compensation for parents to stay at home with the child instead of working, looking for job or studying. Parents noted that, by the end of the leave arrangement, they had achieved a major turning point by accepting the child's disability and its accompanying responsibilities. It is worth noting that, both the mothers and fathers utilized their parental leave to care for the child and other family issues.

The start of preschool was a mixture of excitement and anxiety for most parents. Excited about this milestone and opportunity for the child to develop but at the same time anxious about how the child and school could cope to ensure the proper development of the child. However, this phase

was generally described as good creating a sense of hope for upcoming events in the life of the child and family. Saleebey (1996) in his strength perspective identified hope as an important virtue that helps to achieve resilience. Support has been mobilized from different systems during this period with the most active ones being parent support groups and parents own disposition. The next event found in the trajectory of parents is the start of basic school. This event present challenges for parents especially those who opt for ordinary instead of special school for their child. The reason being that, state funding to support children with disability are mostly channeled to special schools with very little available in the ordinary schools. In view of this, opting for an ordinary school for a child with disability requires extra efforts and resources from parents which might make it difficult for both parents to work full time. With this event, family dynamics are altered to enhance the proper functioning of the family. For example, the women work part time and take up the caring roles whilst the men work full time. The divorcee in this study worked full time and opted for a special school indicating that single parents might find it difficult choosing an ordinary school considering the extra resources and effort needed. This indicates that, re-organization of family dynamics to achieve resilience does not follow a specific trend but differs base several factors of which financial and spousal support is key.

Family resilience in this study indeed supports current conceptualization of resilience as a process as oppose to the idea of a static set of strengths that results in either resilience or non-resilience (Masten, 2011; Rutter, 2000). From the data, the process of resilience is one that is ongoing and flexible. Thus, there are times within the process that families attain high level of functioning with a particular life event whereas other times become quite the opposite. Parents acknowledge that, these variations are all important in maintaining balance in their lives. For them, resilience is not about proving to be strong all the time but also accepting periods of exhaustion and taking breaks to recover. In their view, down moments are a time of reflection and a period they use in gathering resources to become stronger. Overcoming a challenge is therefore a key motivation to achieving resilience. However, the experience of constant challenges without solutions increase stress and vulnerability making resilience difficult to achieve.

Adding to this, the study has shown that, families of children with disability achieve resilience by organizing support from both internal and external sources. Formal support has been seen to be more during the early years of the child and reduces with time. It plays an important role by

initiating resilience for parents since the diagnosis phase represent the most critical point in the life of the family. Again, because formal support comes in financial forms other than practical, parents easily lose sight of the important role of this support system. However, parents perceived formal support as generally useful in their resilience process and only sees it as unhelpful when such support tends to segregate against children with disability.

Considering the role of formal support discussed above, help from support groups and family dynamics are the most critical when it comes to resilience in families of children with intellectual disability. Karlsson, Grassman and Hansson (2002) in their study self-help of groups in Sweden found that, such groups seem to be common in areas of “drug abuse, disability and chronic illness-areas in which professional treatment is scarce” (p.159). This could explain why families emphasized the important role of these groups in their resilience process. It was interesting to see that, none of the interviewed parents had negative comments regarding the support they receive from such groups. Since the group is made up of people with shared characteristics, support is regarded as more realistic as oppose to those provided by professionals.

With family dynamics, reorganization of family roles has shown to have a great impact on a family’s ability to be resilient based on results from this study and previous research such as that of Walsh (2003). Walsh explained that, to be resilient, family organization should be flexible, reflect mutual support and have economic security. In view of this, mothers in this study work part time to be able to care for the child with disability whilst the fathers work full time. The decision is influenced by several factors but the most prominent ones are that, men earned more and women are regarded as more capable compared to men in issues of child care. As I have already indicated in the previous chapter, this arrangement is detrimental to the economic and decision making power of women in the long run. In the event of divorce in such households, the women might find it difficult to independently support themselves.

Also of importance is the mutual supportive nature of the various systems in achieving resilience. Parents showed that becoming resilient is not always about receiving support from other systems. It is also about strengthening other systems to be resilient and creating a society that is more sensitive to persons with special needs. In the study, the worth of knowledge and exposure parents exhibited empowered schools well enough to meet the needs of children with disability and other

forms of difficulty. In some situations, this act of parents has prompted the state to take responsibility in areas that has been overlooked. This proves that, service users are not just passive recipient of help but can actively participate in proving solutions to their problem as was proposed by Saleeby (1996) in his strength perspective.

6.2 Summary and conclusion

The study investigated the resilience in families parenting children with intellectual disability in Sweden and the role of various levels of support system in this process. Specifically, it sought to understand how families of children with disability perceive formal support in their resilience process, the role of informal support in resilience and the impact of family dynamics on family resilience.

The study utilized qualitative research design as an approach inquiry to regarding this social phenomenon. Through the snow balling sampling technique, seven parents from six families were recruited to participate and share their experiences to help understand the concept of family resilience. Data was collected through a face-to face interview with participants and later analyzed by using thematic and life line analysis.

The study found that, resilience is a complex process which requires the organization of several resources from different sources. Formal support was generally perceived by parent as very important in their resilience process especially at the initial phase. It sets the foundation for parents to further develop their resilience. Parents only considered formal support as negative only when it becomes discriminatory and non-inclusive of children with disability. Informal support showed up as the most valued form of support that keep families strong. In situations where formal support is limited or unavailable, informal support becomes stronger to achieve resilience. Family dynamics in households of children with intellectual disability is one that requires a constant reorganization of roles and resources to in order to function properly. For example, the study found that, to cope and function properly as a family, women often worked part time or quit work to care for the child with disability as well as take up other caring roles the family. This seems good to maintain family equilibrium but could have negative effect on the trajectory of women in such households. In the case of divorce such women might lack financial independence and become over dependent on welfare benefits. Labor market rigidity might also make it difficult for such

mothers to re-enter the labor force especially if they have stayed out for a long period of time (Gauthier, Emery, & Bartova, 2016). This was found in a research on labour market intentions and behaviour of stay-at-home mothers in Western and Eastern Europe.

The current study therefore concludes with recommendations for policy, practice and further research.

6.3 Recommendations

Based on the findings of the study, the following recommendations are made;

6.3.1 Recommendation for policy makers

Policy makers should review laws on allocation of resources to schools to bridge the resource gap between ordinary and special schools. This would promote inclusiveness and avoid segregation of children with intellectual disability in Sweden.

6.3.2 Recommendation for social workers

Social workers and professionals working with families of children with intellectual disability should offer strength-based services to enhance resilience. Services should move from only focusing on addressing challenges to identifying and utilizing family strengths in interventions. In addition, siblings and other significant others in the life of the family should be involved in planning interventions that helps them to appropriately support the child with disability and live a fulfilling life as well.

6.3.3 Recommendation for future studies

Though this study sought to understand the resilience in families, only parents' perspectives were captured. Future studies should therefore try to obtain the views of other members of the family especially the children with disabilities and siblings to give a better understanding of the family resilience. Further studies should also explore the long-term effect of gender role on the economic situation of women in families of children with disability.

References

- Adeboye, T. K. (2015). *Young people transition process from family-oriented care to adulthood: Unveiling the Nexus Of Reality In Life Course Approach* (Dissertação de mestrado, University Institute of Lisbon). Retrieved from <http://hdl.handle.net/10071/10352>
- Allen, R. I., & Petr, C. G. (1998). Rethinking family-centered practice. *American Journal of Orthopsychiatry*, 68(1), 4-15. Retrieved from <http://dx.doi.org/10.1037/h0080265>
- Amankwa, L. (2015). *The role of child protection professionals in enhancing parenting among immigrants in Gothenburg: The Perspective Of Child Protection Professionals In Gothenburg* (Masters dissertation, University of Gothenburg). Retrieved from https://gupea.ub.gu.se/bitstream/2077/41357/1/gupea_2077_41357_1.pdf
- Anell, A., Glenngard, A. H., & Merkur, S. M. (2012). Sweden: Health system review. *Health Systems in Transition*, 14(5), 1–159.
- American Association on Intellectual and Developmental Disability (n.d.). *Intellectual Disability*. Retrieved from <https://aaidd.org/intellectual-disability/definition#.WTfc92jyIU>
- Appleby, J. M. (2014). *Resilience in families of children who have disabilities* (Doctoral dissertation, University of Texas). Retrieved from https://uta-ir.tdl.org/uta-ir/bitstream/handle/10106/24890/Appleby_uta_2502D_12845.pdf?sequence=1
- Armi, F., Guilley, E., & d'Epinay, C. J. L. (2008). The interface between formal and informal support in advanced old age: A Ten-year Study. *International Journal of Ageing and Later Life*, 3(1), 5–19.
- Banks, M. E. (2003). Disability in the family: A Life Span Perspective. *Cultural Diversity and Ethnic Minority Psychology*, 9(4), 367–384. Retrieved from <http://dx.doi.org/10.1037/1099-9809.9.4.367>
- Bayat M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702–714. doi: 10.1111/j.1365-2788.2007.00960.x
- Becvar, D. S. (Ed.). (2013). *Handbook of Family Resilience*. New York, NY: Springer New York.
- Beresford, B. A. (1994). Resources and strategies: How Parents Cope with The Care Of A Disabled Child. *Journal of Child Psychology and Psychiatry*, 35(1), 171–209. Retrieved from <https://doi.org/10.1111/j.1469-7610.1994.tb01136.x>

- Bernhardt, E., Noack, T., & Lyngstad, T. H. (2008). Shared housework in Norway and Sweden: Advancing The Gender Revolution. *Journal of European Social Policy*, 18(3), 275-288. Retrieved from <https://doi.org/10.1177/0958928708091060>
- Black, B. P., Holditch-Davis, D., & Miles, M. S. (2009). Life course theory as a framework to examine becoming a mother of a medically fragile preterm infant. *Research in Nursing & Health*, 32(1), 38-49. Retrieved from <https://doi.org/10.1002/nur.20298>
- Boström, P. (2012). *Experiences of Parenthood and the Child with an Intellectual Disability*. (Doctoral dissertation, University of Gothenburg). Retrieved from <https://gupea.ub.gu.se/handle/2077/31454>
- Boström, P. K., & Broberg, M. (2014). Openness and avoidance – a longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 58(9), 810-821. Retrieved from <https://doi.org/10.1111/jir.12093>
- Bradbury-Jones, C., Taylor, J., & Herber, O. (2014). How theory is used and articulated in qualitative research: Development of A New Typology. *Social Science & Medicine*, 120, 135-141. Retrieved from <https://doi.org/10.1016/j.socscimed.2014.09.014>
- Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and Spousal Support. *Developmental Psychology*, 24(3), 441-451. Retrieved from <http://dx.doi.org/10.1037/0012-1649.24.3.441>
- Broberg, M. (2011). Expectations of and Reactions to Disability and Normality Experienced by Parents of Children with Intellectual Disability in Sweden. *Child: Care, Health and Development*, 37(3), 410-17. doi:10.1111/j.1365-2214.2010.01198.x.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social Support, Mental Health Status and Satisfaction With services. *Sage Publication and The National Autistic Society*, 8(4), 409-423. Retrieved from <https://doi.org/10.1177/1362361304047224>
- Bronfenbrenner, U. (1994). Ecological models of human development (2nd. Ed.). In *International Encyclopedia of Education*, 3. Oxford: Elsevier.
- Bryman, Alan (2012): *Social Research Methods* (4th Ed.). Oxford: Oxford University Press.
- Bryman, Alan (2016): *Social Research Methods* (5th Ed.). Oxford: Oxford University Press.
- Carroll, D. W. (2013). *Families of Children with Developmental Disabilities: Understanding Stress and Opportunities For Growth*. Washington, US: American Psychological Association.

- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A Theoretically Based Approach. *Journal of Personality and Social Psychology: Personality Processes and Individual Differences*, 56(2), 267–283. doi: 10.1037//0022-3514.56.2.267
- Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, 12(3), 297–298. Retrieved from <https://doi.org/10.1080/17439760.2016.1262613>
- Clevnert, U., & Johansson, L. (2007). Personal Assistance in Sweden. *Journal of Aging & Social Policy*, 19(3), 65–80. Retrieved from https://doi.org/10.1300/J031v19n03_05
- Di Giulio, P., Philipov, D., & Jaschinski, I. (2014). Families with disabled children in different European countries. FamiliesAndSocieties Working Paper. Retrieved from <http://www.familiesandsocieties.eu/wp-content/uploads/2014/12/WP23GiulioEtAl.pdf>
- Elder, G. H. & Rockwell, R. C. (1978). The Life Course and Human Development: An Ecological Perspective. *International Journal of Behavioral Development*, 2(1), 1-21. Retrieved from <http://journals.sagepub.com/doi/pdf/10.1177/016502547900200101>
- Esping-Andersen, G. (2007). Three Worlds of Welfare Capitalism. In C. Pierson & F. G. Castles (Eds.), *The Welfare State Reader* (pp. 160-174). Cambridge: Polity Press. 15 pp. C
- European Intellectual Disability Research Network (2003). Intellectual disability in Europe. Retrieved from <http://enil.eu/wp-content/uploads/2012/07/Intellectual-Disability-in-Europe.pdf>
- Evertsson, M. (2006). The reproduction of gender: housework and attitudes towards gender equality in the home among Swedish boys and girls1. *The British Journal of Sociology*, 57(3), 415–436. Retrieved from <https://doi.org/10.1111/j.1468-4446.2006.00118.x>
- Farrell, A. F., & Krahn, G. L. (2014). Family Life Goes On: Disability in Contemporary Families. *Family Relations*, 63(1), 1–6. Retrieved from <https://doi.org/10.1111/fare.12053>
- Finch, J. (2007). Displaying Families. *Sociology*, 41(1), 65–81. Retrieved from <https://doi.org/10.1177/0038038507072284>
- Fitzpatrick, J. J. (2009). Resilience. *Archives of Psychiatric Nursing*, 23(5), 341–342. Retrieved from <https://doi.org/10.1016/j.apnu.2009.07.001>
- Försäkringskassan (2016). If your child has a disability. Retrieved from <https://www.forsakringskassan.se/privatpers/funktionsnedsattning>
- Gauthier, A. H., Emery, T., & Bartova, A. (2016). The labour market intentions and behaviour of stay-at-home mothers in Western and Eastern Europe. *Advances in Life Course Research*, 30, 1–15. <https://doi.org/10.1016/j.alcr.2015.12.002>

- Giele, J. Z., & Elder, G. H. (1998). *Methods of Life Course Research: Qualitative and Quantitative Approaches*. SAGE.
- Grant, G., & Whittell, B. (2000). Differentiated Coping Strategies in Families with Children or Adults with Intellectual Disabilities: The Relevance Of Gender, Family Composition And The Life Span. *Journal of Applied Research in Intellectual Disabilities*, 13(4), 256–275. Retrieved from <https://doi.org/10.1046/j.1468-3148.2000.00035.x>
- Greeff, A. P., & Nolting, C. (2013). Resilience in families of children with developmental disabilities. *Families, Systems, & Health*, 31(4), 396–405. <https://doi.org/http://dx.doi.org.ezproxy.ub.gu.se/10.1037/a0035059>
- Grossman, B. R. & Magaña, S. (2016) Introduction to the special issue: Family Support of Persons with Disabilities Across the Life Course. *Journal of Family Social Work*, 19(4), 237-251. Retrieved from <https://uic.pure.elsevier.com/en/publications/introduction-to-the-special-issue-family-support-of-persons-with->
- Gustafsson, B., Höjer, S., Shi, L., & Pei, Y. (2013). Introduction to the special issue on children and families, assistance and welfare: Social Work In China And Sweden. *China Journal of Social Work*, 6(3), 223–227. Retrieved from <https://doi.org/10.1080/17525098.2013.840798>
- Harding, Sandra G. (1987). Introduction – is there a feminist method? In Hardin, S. (ed.) *Feminism and Methodology*, Bloomington and Indianapolis: Indiana University Press (ebook)
- Hartley S, Ojwang P, Baguwemu A, Ddamulira M, & Chavuta A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health & Development*, 31(2), 167–180.
- Hendrick B. (2015). Siblings of children with intellectual disability: Development of siblings of children with intellectual disability. Retrieved from <http://www.cidd.unc.edu/docs/lend/Development%20of%20Siblings%20of%20Children%20with%20ID.pdf>
- Henry, C. S., Sheffield Morris, A., & Harrist, A. W. (2015). Family Resilience: Moving into the Third Wave. *Family Relations*, 64(1), 22–43. Retrieved from <https://doi.org/10.1111/fare.12106>
- Higginbottom, G. M. (2004). Sampling issues in qualitative research. *Nurse Researcher*, 12(1), 7-19. doi: [10.7748/nr2004.07.12.1.7.c5927](https://doi.org/10.7748/nr2004.07.12.1.7.c5927)
- Hollis, M. (1994): *The philosophy of social science: An Introduction*. Cambridge. Cambridge University Press. Chapter 1-4, 9-11. 158 p.

- Hutchison, E. D. (2010). A life course perspective. *Dimensions of Human Behavior: The Changing Life Course*, 4, 1–38.
- Jegermalm, M. (2005). *Carers in the welfare state: On Informal Care And Support For Carers In Sweden*. Stockholm: Stockholm University.
- Kälvesten, A.-L. (1955). Family Policy in Sweden. *Marriage and Family Living*, 17(3), 250–254. Retrieved from <https://doi.org/10.2307/346856>
- Kammeyer, C. W. K., Ritzer, G., & Yetman, R. N. (1997). *Sociology: Experiencing Changing Societies*. New York, Allyn & Bacon
- Karlsson, M., Grassman, E. J., & Hansson, J. H. (2002). Self-Help Groups in the Welfare State: Treatment Program or Voluntary Action? *Nonprofit Management and Leadership*, 13(2), 155–167. Retrieved from <https://doi.org/10.1002/nml.13204>
- Katz, G., & Lazcano-Ponce, E. (2008). Intellectual disability: definition, etiological factors, classification, diagnosis, treatment and prognosis. *Salud Pública de México*, 50,s132–s141.
- Kazak, A. E. (1989). Families of chronically ill children: A systems and social-ecological model of adaptation and challenge. *Journal of Consulting and Clinical Psychology*, 57(1), 25–30. Retrieved from <http://dx.doi.org/10.1037/0022-006X.57.1.25>
- Kelly, B. C. (2010). Sampling and Recruitment Issues in Qualitative Drugs Research: Reflections on the study of club drug users in metro New York. *Informa Health Care USA, Inc.*, 45(5), 671–683. Retrieved from <https://doi.org/10.3109/10826081003594799>
- Leone, E., Dorstyn, D., & Ward, L. (2016). Defining Resilience in Families Living with Neurodevelopmental Disorder: A Preliminary Examination of Walsh’s Framework. *Journal of Developmental and Physical Disabilities*, 28(4), 595–608. Retrieved from <https://doi.org/10.1007/s10882-016-9497-x>
- Levine, K. A. (2006). *Against all odds: Resilience in single mothers of children with disabilities*. (Doctoral dissertation, University of Manitoba). Retrieved from <http://search.proquest.com.ezproxy.ub.gu.se/docview/304952067/abstract/12CF2364EP/1>
- Manoj S. (2014), Coping strategies, in Salem Press Encyclopedia of Health, Salem Press.
- Manerikar V. & Manerikar S. (2014). Research communication: A note on exploratory research. Retrieved from http://www.welingkar.org/Corporates/pdfs/aWEshkar/march2014/aWEshkar_11_ResearchCommunication_VijayaManerikarNSumeetManerikar.pdf
- Martha, K., Mavis, D. C., & Reich, J. W. (2014). *The Resilience Handbook: Approaches To Stress And Trauma*. Routledge.

- Marttila, A., Johansson, E., Whitehead, M., & Burström, B. (2013). Keep going in adversity: using a resilience perspective to understand the narratives of long-term social assistance recipients in Sweden. *International Journal for Equity in Health*, 12(8). Retrieved from <https://doi.org/10.1186/1475-9276-12-8>
- Masten, A. S. (2011). Resilience in children threatened by extreme adversity: Frameworks for research, practice, and translational synergy. *Development and Psychopathology*, 23(2), 493–506. Retrieved from <https://doi.org/10.1017/S0954579411000198>
- May Institute (2006). Developmental Disability. Retrieved from https://www.mayinstitute.org/pdfs/developmental_disabilities_fact_sheet.pdf
- McDonald, A. (2013). Family Resilience. *The Family Journal*, 21(2), 235–240. Retrieved from <https://doi.org/10.1177/1066480712465821>
- Mele, C., Pels, J., & Polese, F. (2010). A brief review of Systems Theories and their managerial applications. *Service Science*, 2(1–2), 126–135. Retrieved from <https://doi.org/10.1287/serv.2.1.2.126>
- Miles, B. (1998). Overview on Deaf-Blindness, DB-LINK Fact Sheet. Revised. National Information Clearinghouse on Children Who Are Deaf-Blind, Monmouth. Retrieved from the ERIC database. (ED436056)
- Morgan, D. (2011). *Rethinking Family Practices*. Springer.
- Morris, R. J., & Kratochwill, T. R. (2012). *The Practice of Child Therapy*. Routledge.
- Muzinguzi P. (2015). “You have to talk to those who were There...” *Promoting Children Participation: A case of Expert Meetings and Groups Within the Ombudsman in Norway*. (Masters dissertation, University of Stavanger). Retrieved from <http://hdl.handle.net/11250/297929>
- Narayanan A. (2008). The resilient individual: A personality analysis. *Journal of the Indian Academy of Applied Psychology*, 34(Special Issue), 110-118. Retrieved from <http://medind.nic.in/jak/t08/s1/jakt08s1p110.pdf>
- Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. Retrieved from <http://psycnet.apa.org/journals/eib/5/3/93/>
- Nilsen, A., Brannen J. & Lewis, S. (Ed.). (2013). Transitions to parenthood in Europe: A Comparative Life Course Perspective. Policy Press: UK.
- Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, 18(2), 34–35. Retrieved from <https://doi.org/10.1136/eb-2015-102054>

- Noy, C. (2008) Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research, *International Journal of Social Research Methodology*, 11:4, 327-344. doi: 10.1080/13645570701401305
- Olsen, G. M. (2007). Toward global welfare state convergence: Family Policy And Health Care In Sweden, Canada And The United States Special Issue on Globalization: Social Justice & Social Welfare. *Journal of Sociology and Social Welfare*, 34, 143–164.
- Olsson, M. B., & Hwang, P. C. (2003). Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example. *Journal of Intellectual Disability Research*, 47(4/5), 328–341. Retrieved from <https://doi.org/10.1046/j.1365-2788.2003.00494.x>
- Ozawa, M. N. (2004). Social Welfare Spending on Family Benefits in the United States and Sweden: A Comparative Study. *Family Relations*, 53(3), 301–309.
- Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology*, 58(3), 233–246. Retrieved from <https://doi.org/10.1002/jclp.10019>
- Patton, M. Q. (2002). *Qualitative research & evaluative methods*. (3rd Ed). United States of America: Sage Publication, Inc.
- Retzlaff, R. (2007). Families of children with Rett syndrome: Stories of coherence and resilience. *Families, Systems, & Health*, 25(3), 246–262. Retrieved from <http://connection.ebscohost.com/c/articles/29343057/families-children-rett-syndrome-stories-coherence-resilience>
- Rutter, M. (2000). Resilience Reconsidered: Conceptual Considerations, Empirical Findings, and Policy Implications. In S. J. Meisels, & J. P. Shonkoff, *Handbook of Early Childhood Intervention* (pp. 652-682). New York: Cambridge University Press.
- Saleebey, D., (1996). Introduction: “Power in the people”. *The Strengths Perspective in Social Work Practice*. Fourth Edition. Boston: Pearson Education
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18(2), 179–183. Retrieved from <https://doi.org/10.1002/nur.4770180211>
- Schilling, R. F., Gilchrist, L. D., & Schinke, S. P. (1984). Coping and Social Support in Families of Developmentally Disabled Children. *Family Relations*, 33(1), 47–54. Retrieved from <https://doi.org/10.2307/584589>
- Soji Z. (2013). Practice guidelines for supporting youth-headed families to enhance their resilience. (Doctoral dissertation, The Nelson Mandela Metropolitan University). Retrieved from <http://hdl.handle.net/10948/d1016381>

- Štěrbová, D. & Kudláček, M. (2014). Deaf-blindness: Voices of Mothers concerning Leisure-Time, Physical Activity and Coping with Disability. *Acta Gymnica*, 44(4), 193–201.
- Strohm, K. E. (2002) *Siblings: Brothers and Sisters of Children with Special Needs*. Adelaide: Wakefield Press.
- Sundström, G., Johansson, L., & Hassing, L. B. (2002). The Shifting Balance of Long-Term Care in Sweden. *The Gerontologist*, 42(3), 350–355. Retrieved from <https://doi.org/10.1093/geront/42.3.350>
- Taanila, A., Syrjäla, L., Kokkonen, J., & Järvelin, M.-R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28(1), 73–86. Doi: 10.1046/j.1365-2214.2002.00244.x
- Tew J. (2006) Understanding power and powerlessness: Towards a framework for emancipatory practice in social work. *Journal of social work* 6(33), 18.
- The Swedish Disability Federation (2011). Swedish Disability Movement's Alternative Report to the UN Committee on the Rights of Persons with Disabilities. Retrieved from http://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/SWE/INT_CCPR_NGO_SWE_93_10092_E.pdf
- Västra Gotalandsregionen (2016). Lagen om stöd och service till vissa funktionshindrade – LSS. Retrieved from <http://www.1177.se/Vastra-Gotaland/Regler-och-rattigheter/Lagen-omstod-och-service-till-vissa-funktionshindrade---LSS/>
- Walsh F. (2003). Family resilience: a framework for clinical practice. *Family Process*, 42(1), 1–18.
- Webb D. (2010). Paulo Freire and 'the need for a kind of education in hope', *Cambridge Journal of Education*, 40:4, 327-339. Retrieved from <http://dx.doi.org/10.1080/0305764X.2010.526591>
- Weiss, M. J. (2002). Hardiness and Social Support as Predictors of Stress in Mothers of Typical Children, Children with Autism, and Children with Mental Retardation. *Autism*, 6(1), 115–130. Retrieved from <https://doi.org/10.1177/1362361302006001009>
- Weisser, F. B., Bristowe, K., & Jackson, D. (2015). Experiences of burden, needs, rewards and resilience in family caregivers of people living with Motor Neurone Disease/Amyotrophic Lateral Sclerosis: A secondary thematic analysis of qualitative interviews. *Palliative Medicine*, 29(8), 737–745.

- White, N., & Hastings, R. P. (2004). Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 181–190. Retrieved from <https://doi.org/10.1111/j.1468-3148.2004.00197.x>
- Wissö, T., & Plantin, L. (2015). Fathers and parental support in everyday family life: informal support in Sweden beyond the auspices of the welfare state. *Families, Relationships and Societies*, 4(2), 267–280. Retrieved from <https://doi.org/10.1332/204674315X14327182532695>
- World Health Organization (2017). Definition: intellectual disability. Retrieved from <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>
- Yin, R. K. (2010). *Qualitative Research from Start to Finish*. New York, NY: Guilford Publications.
- Yin, R. K. (2015). *Qualitative Research from Start to Finish* (2nd ed.). *Family and Consumer Sciences*, 44(3), 324-325. New York, NY: Guilford Publications.
- Ytterhus, B., Wendelborg, C., & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood – insights from families with disabled children in Norway. *Disability & Society*, 23(6), 625–636. Retrieved from <https://doi.org/10.1080/09687590802328535>

Appendices

Appendix 1: Interview guide

Topic: understanding resilience in families of children with intellectual disability in Sweden, the role of micro, meso and macro level support.

Total time: 1hr

Background information

Name(s):

Age(s):

Type of family:

No of persons in the family:

Who counts as a family member:

Type of work (full time/part time):

No and ages of children:

Type of diagnosis:

life course

1. Can you draw a life course from when your child was born till now?
2. On the life course, can you indicate with years the major life events of the family in relation to your child? (diagnosis, school going age, after parental leave etc).

How do families with ID children in Sweden perceive formal support in their resilience process?

1. What kinds of state assistance did/does the family access to help cope with the presence of your child?
2. How did you get to know about these services?
3. What do you think about the support you received/receiving? (did/does it empower or disempower you)

What is the role of informal support on the resilience process of families with ID children?

4. Apart from support from the state (formal support), which other support systems do you rely on and at what point? (eg. Friends, neighbors, extended family, social media groups)
5. In what ways have they been beneficial or non-beneficial for the family in this situations?

How does dynamics within the family affect family resilience?

6. How is work (caring for family member, household chores and paid work) allocated within the family?
7. Has this changed with the presence of your child?
8. How do you think the division of work promote or hinder the family's ability to become strong?
9. What do you think are the inner workings of the family that helped/helps to handle everyday life and specific demanding situations relating to the needs of your children and specifically the need of the child with intellectual disability? (eg. belief system, values, philosophy)
10. Overall, what do you think has been important in keeping the family strong till now?

Appendix 2: Informed Consent



Informed Consent

The following is a presentation of how I will use the data collected in the interview.

In order to ensure that the project meet the ethical requirements for good research, I promise to adhere to the following principles:

- Interviewees in this research will be provided with adequate information about the research and its purpose.
- Interviewees have the right to decide whether they will participate in the project, even after the interview has been concluded but not after the research has been published.
- The collected data will be handled confidentially and will be kept in such a way that no unauthorized person can view or access it.
- All interviewees would be kept anonymous.

The interview will be recorded as this makes it easier for me to document what is said during the interview and also helps me in the continuing work with the project. In my analysis, some data may be changed so that no interviewee will be recognized. After finishing the project, the data will be destroyed. The data I collect will only be used in this project.

You have the right to decline answering any questions, or terminate the interview without giving an explanation.

You are welcome to contact me or my supervisor in case you have any questions (e-mail addresses below).

Student name & e-mail

Priscilla Agyeman-duah
priscie66@yahoo.com

0728688422

Supervisor name & e-mail

Charlotte Melander
charlotte.melander@socwork.gu.se

031-786 6384

.....

Interviewee`s Name and date