RESILIENCE IN FAMILIES OF CHILDREN WHO HAVE DISABILITIES

by

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Abstract

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Families are foundational units that facilitate societal function. They are responsible for many of the integral processes that allow communities to continue to function. Not the least of these processes are providing for the survival of members, and the development of children into adults who constructively participate in society. An understanding of how families adapt, when faced with trauma or overwhelming stress, is important to supporting a constructive external support system and education for future families. How does adaptation successfully proceed when the family includes a child who has a disability?

This exploratory research is intended to reveal practices that families use to regain effective function when faced with this particular issue. Qualitative interviews, from a phenomenological perspective, were conducted with family members of six families. The resulting data was analyzed to reveal the essence of the resilience experience for each family member who chose to participate. Member resilience experiences were compiled to produce resilience profiles for the families. One of the goals of this research was to delineate practices that promote or hinder adaptation in response to being in a family with a child who has a disability and contribute to the evidence base to provide effective supports for families.
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Chapter 1

Introduction

1.1: Statement of Topic

Families find having a family member who has a disability to be overwhelmingly stressful, traumatic or injurious to the family as a unit. When the family member is a child, often the issue is not rehabilitation; it is making arrangements for the child to receive assistance to perform activities of daily living that the child never had the skills for. Family stress may come from insufficient resources to, logistically, care for the child and the family. However, even if the family can purchase resources they need for material things; they may be experiencing emotional trauma. In a social climate in which material resources may not be available, the ability of the family to adapt, and build on present strengths offers opportunities for the family to maximize quality of life. This is resilience.

This research was framed from a phenomenological perspective to collect and analyze data on the meaning of resilience for families that have a child who has a disability. This introduction to the research project, and the researcher’s personal experiences with the phenomenon is followed by a review of the literature. The last section covers the qualitative method used in collecting and analyzing the experiences of families and the meaning they make of the ongoing effort to adapt.

The phenomenon of resilience can be viewed as a concept, a process or a goal. The challenge is to hold all three meanings simultaneously and tease out ways in which to convert esoteric knowledge into a foundation on which to develop more knowledge and inform practice to improve the lives of individuals and groups who face oppression. It is generally held that resilience manifests as an adaptive response to injury, overwhelming stress or trauma. The New Lexicon: Webster’s Dictionary of the English Language (Cayne et al., 1988) defines ‘injury’ as a physical impairment resulting from violence or
accident, and ‘trauma’ as a physical wound or injury, a violent emotional blow which has a lasting psychic effect, or a neurotic condition resulting from physical or emotional injury. ‘Stress’ is defined as a state in which a strong demand is made on the nervous system, and is related to ‘distress’ which is defined as to cause considerable mental or physical discomfort or pain. ‘Overwhelm’ is defined as to overpower or to submerge suddenly by irresistible force.

1.2 Autobiographical Frame of Researcher

This researcher came to an interest in resilience through having been the mother of a child who had severe cerebral palsy. Cerebral palsy is a physical disability in which the neurons in the brain that facilitate muscular movement are impaired or destroyed. The experience of trying to care for my son with insufficient resources left me with a desire to make sure that other families get the supports they need. Unfortunately, in the current restricted economic climate, obtaining physical and material resources is becoming more and more difficult. Thus it becomes more important to provide evidence for what helps families adapt most effectively.

When my son was born in 1987, there were no Medicaid waivers to help families keep their children at home. As a result, Bryce spent one year and eight months in an Intermediate Care Facility for the Mentally Retarded (ICFMR), 90 miles away from where I lived. Immediately prior to that, he was in a children’s hospital, also at some distance from where I lived. I say this to present the setting in which I first observed that my personal experience parenting a child who had a disability differed from those of families around me. I was already, at that early point, before even considering researching resilience, “ bracketing” my personal experiences to make more objective observations of the experiences of those around me. I soon came to realize that parents of children who had disabilities were at a distinct disadvantage compared to typical families. There were
no mandated classes on parenting. Hence, most parents practiced the maternal/paternal skills they observed when they were growing up with their parent or parents. Adults whose child had a disability usually had no opportunity to learn how to parent a child who has a disability.

When Bryce was diagnosed as having severe cerebral palsy at the age of three months he was admitted to a large children’s hospital about 90 miles from where his father and I lived. He had lost the suck reflex, and having muscle problems was unable to learn to suck. He was diagnosed with failure to thrive. Unbeknownst to me, when children went in the hospital, an adult in the family was expected to stay with the child. Since I could not quit my job and was unwilling to leave my husband and go on welfare; Bryce was also diagnosed as suffering from parental neglect. When the staff saw me up there all weekend, every weekend and work holiday; they soon realized that Bryce’s failure to thrive was not due to neglect. In the hospital, I did not see many parents. I assume they were similarly fatigued and consumed with intensive caregiving. In any case, there was no parent-to-parent caregiving or mentoring available.

When Bryce’s weight stabilized, the hospital social worker noted we had no capability to provide a caregiver for our son while I was at work and recommended placing him in an institution; the ICFMR (Intermediate Care Facility for the Mentally Retarded, now called Intermediate Care Facilities for the Intellectually Disabled). There I experienced a complete turnaround from expectations at the hospital. It seemed most parents who had put their children in this ICFMR saw their children only a few times a year. I don’t know if this was due to distance, psychological self-protection, or other reasons. There was only one other relative who was there almost every weekend. The nursing staff at the facility became paranoid when I called in every day, wanting to know my son’s weight status. The facility social worker put me in touch with a local family who
had placed their daughter in the ICFMR but their comfort zone of bringing their daughter home for a few hours, a few times a month, was not mine. I wanted my baby back home.

After Bryce had been in the institution for over a year and a half; I took nine months of leave without pay to bring him home. With no support services (personal, philanthropic, nor governmental) I had to provide his hourly care. I also provided his transportation to weekly early intervention classes, physical therapy, occupational therapy and speech therapy. I tried to start a parent support group but it was unsuccessful. Again, I conjecture that other parents were similarly overwhelmed and fatigued. After nine months, when my son turned three years old, he became eligible for daily early intervention classes through the school system and my employer was expecting me to return to work. If I had not been working for Louisiana Civil Service, I probably would not have had a job to go back to. I called every childcare center in the phone book and newspaper, trying to find one that provided care for children who had disabilities. By this time, the Americans with Disabilities Act had been enacted and most of them had enough knowledge to not say, outright, that they did not provide that level of care. However, as soon as the staff person I was talking with learned that Bryce had a stomach feeding tube; the childcare centers became full, taking no new children. I finally found, by word of mouth, a lady providing childcare in her home who was willing to let me teach her how to use a feeding tube (…real difficult): 1) unplug tube, 2) poor in liquefied food, 3) replug tube. But most people were unwilling to even learn the process involved. There Bryce lay, on this lady’s sofa, every afternoon after school until I could return from work to pick him up.

As I continued to search for services for my son, I unknowingly ran across a parent involved with the Louisiana State Planning Council for Developmental Disabilities. Also, unknown to me the federal government was starting to let the states experiment
with Katie Beckett Medicaid Waivers. These waivers were begun with the realization that, if a child’s disability is severe enough, few typical families can pay for that child’s care out of their own pockets. Medical insurance is designed to provide acute care, not ongoing care for the rest of an individual’s life. The parent who had observed my search for services, placed us on a list for a pilot project in which these Medicaid Waivers were being provided to families of children who were living in institutions. The pilot was designed to give these families the help they needed to bring their children home. I still don’t know the name of the parent who helped us get a Medicaid Waiver for Bryce. Wherever he or she is, they made an enormous difference in Bryce’s quality of life and mine.

The Medicaid Waiver provided for attendant care so Bryce had one on one care when he was not at school and I was still at work. I even obtained some respite care so I could have a break from 24 hour a day, seven day a week care; when I was not at work. Equally as important as the attendant care was the Medicaid payment for the atypical amount of medical care my son needed from therapists, doctors and obtaining medical equipment like a wheelchair and a speech device to help him communicate.

However, Medicaid Waivers were, and still are, ‘conferred’ state by state with no reciprocity. So when Bryce’s father had to move to another state for work; we lost all of those services and I was, again, unable to work because I could find no child care centers for children who have severe disabilities. Medicaid Waivers are not entitlements, as institutions are, and I was unable to get help for my son for the rest of his life. After three and a half years of living in this other state, Bryce did become eligible for Medicaid medical and therapeutic care. But because we lived in a rural area; we could not get the attendant care needed so I could return to work. My son died eight months later.
One thing I did discover, living in this other state, was an effective parent support group. It was attending these meetings that I realized that, even as a parent of a child who had a disability, my family's needs could not be assumed to be typical. Where I was trying to get attendant and medical care for Bryce; most other parents were struggling to obtain an appropriate education for their children.

Even after my son's death, I have been noticing differences. We lost him when he was eleven years old. He quit breathing, and although he was given cardio-pulmonary resuscitation immediately; his body was unable to resume control of the automatic breathing function. He had never regained consciousness. As I looked at the experiences of other parents whose children have died; I found no good coming out of the loss. However, as 15 years have passed since Bryce died; I find increasing comfort that he is not here. Nursing homes and institutions are still entitlements. Services to help people live with their families are still restricted. Children and our elders sit for years on waiting lists waiting for someone in a ‘slot’ to die so the person without services can get what they need. My solace, that he is not still living is based in the probability that if my son had outlived me; he probably would have been placed back in an institution.

1.3: Implications/Relevance

This research was designed to explore resilience in families of children who have disabilities (FCD). Michael Rutter (1999) has defined resilience as “…overcoming stress…” (p. 119). Additionally, he wrote that resilience can be found when “…there has been a relatively good outcome for someone despite their experience of situations that have been shown to carry a major risk for the development of psychopathology” (Rutter, 1999, p. 119-112). Most families don't plan for stressful living conditions. Even adults who were raised facing challenging events in childhood may face different problems in adulthood. Adversity seldom announces itself. Yet, how families deal with these
situations can make an enormous difference in where they come out on a scale of inability to take care of themselves or finding themselves not only thriving but having skills to share with those facing similar situations. This research was designed to explore the lived experience of resilience in families when a child in the family has a developmental disability.

Due to many changes in society, not the least of which is the medical ability to save the lives of people who would have died in less technologically advanced times, some families find themselves having family members with chronic medical conditions or disabilities (Switzer, 2003; Walsh, 2006). Families, not having planned for these situations, may find themselves in crisis when a family member is born with or develops a disability. Family members may suffer, emotionally, when one of their members faces atypical challenges. In addition, with the expenses of medical care, assistive devices, and logistical support; many families find themselves unable to provide the support that their loved one needs.

Governmental bodies and philanthropic organizations have, increasingly, responded by providing supports that enable people who have disabilities to live with their families instead of receiving the assistance they need in institutional living environments. Nonetheless, many families do not get a significant amount of the material help they need (University of Connecticut, n.d.). Resilience is a response, a process and a characteristic that families and individuals use to help them deal with the discrepancies between what is available and what they need to deal with challenging conditions.

1.4: Knowledge Potential

A review of the literature indicated inquiry into resilience would yield more information on occasions during which the need to adapt existed. And valuable practice knowledge might be gained on how to support families who were adapting to having a
child who had a disability. The research question is, “What is the meaning of the lived experience of adaptation for families who have children who have disabilities?”

1.5: Terms of the Study

For the purposes of this study, ‘family,’ meant any grouping which included an individual who had a diagnosed developmental disability and a caregiver whom both the person who had the disability and others in the family viewed as family. Examples would be a grandparent caring for a child who was disabled and still under the age of 22 years old, or the more traditional parental caregiver of a member of the family who had a disability and was under the age of 22 years. Disability indicates a diagnosed inability to perform necessary activities of daily living without assistance, and that the disability was acquired before the individual reached the age of 22 years.

1.6: Background

There have been two main, societal trends that affected the challenges facing families that have a child who has a disability. There has been an attitudinal trend toward inclusion of, not only FCDs, but also families that are atypical (Inclusion Press, n.d.). These might be families of Gay/Lesbian/Bisexual/Transgender individuals, families headed by a single father, families where grandparents are raising grandchildren, or families headed by a single mother. With the increase in divorce over the past few generations, blended families and families headed by a single parent have become normal. As far as FCDs are concerned, societal trends toward community-based living have resulted in more children who have disabilities being raised at home instead of receiving care in institutional settings away from their families. Community-based living has become a viable alternative to historic institutional care as attitudes of acceptance have coincided with provision of logistical and financial supports. The recent changes in Medicaid provision are an example of an economic support that has assisted FCDs, and
families with members who have a disability, being able to have the family member live at home (TASH, n.d.).

Secondly, there has been a societal trend to provide logistical and/or economic supports to FCDs. However, the societal trend to provide these supports has not shown the same kind of steady, constructive gains as has occurred with attitudes about inclusion and community-based living. When a family had a child who had a disability, family members who have typical abilities provide assistance with activities of daily living. That assistance may have been as unobtrusive as providing guidance or behavior management or may be as effortful as taking someone in and out of bed, clothing them, feeding them, . . . in essence taking care of needs that necessitated body movement, or of self-control and self-protection. And the needs of the family member could occur twenty-four hours a day and seven days a week. Meeting these needs may have required the assistance of several adults. Typical families do not have that many adults, who can devote that many hours, to intensive care giving (Taylor, 2008). In addition to the logistical demands involved in caring for a child who has a disability, there have also been financial demands. People who have disabilities may need assistive equipment, special devices, custom transportation, specialized housing, atypical clothes, medicine, therapy, and medical care. Many of these things, as well as others, may require extra expenditures. Even if a child’s family had health insurance, it has not been designed for chronic conditions, hence the financial burden on the family may have been severe (University of Connecticut, n.d.).

In the past, government sponsored health insurance, in the form of Medicaid was not available to a child of a family of moderate financial means. Parental income was deemed against the child, no matter the child’s health or ability impairments. In the early 1980s, with advocacy from FCDs, the United States government made waivers available
to the states. In these waivers, states were allowed to deem the income of only the disabled child against the child if his or her disability was severe enough (Semansky & Koyanagi, 2004). However, these waivers were not entitlements, so if a family did not have access to medical supports or money with which to buy these supports; the only entitlement option for care was an institutional setting. Some children who had disabilities were sent to nursing homes, state schools, ICFIDs, or other settings outside of the family home. When there have been economic downturns and governmental bodies trimmed budgets, these community-based supports were often cut (Families USA Foundation, 2008). Advocacy has continued by FCDs to end waiting lists and make care in one’s own home as much of an entitlement as institutional care is. Although there has been a trend toward providing more social services, resources, and income maintenance for FCDs; this has not been a smooth upward curve. Philanthropic organizations, no matter how well meaning, seldom have access to sufficient resources to provide for every family that has a child with a disability. Additionally, private, non-profit groups don’t have stability of funding to guarantee that a family they help this year will be helped next year.

Another societal viewpoint, held by many, that has been a result of a blend of constructive attitude but withholding of resources has been the provision of an education to children who have disabilities. Children currently should have access to an “individualized, free and appropriate” education in the “least restrictive environment” (U. S. Department of Education, n.d.). In the past, children who had disabilities had not been provided an education in public schools. As FCDs advocated for their children to receive an education, various laws were enacted to mandate that children who had disabilities had access to their schools. Fine tuning of these laws required that education for children who had disabilities should be individualized. All the services that are provided to a typical child, by law, were supposed to be provided to the child who has a disability. And
those services were supposed to be adapted so that the child could take advantage of them. The child who had reduced vision had the right to access math or English classes with provisions so that he or she could receive the material through means other than vision. The child who had a physical disability was supposed to have the right to access physical education classes and sports with changes in the program to individualize them so the student could use programs at their level of physical ability. Provisions in laws governing the education of children who had disabilities also mandated that the education be appropriate. In other words, it should have been provided so that the child had goals specified as objectives that could, likely, be attained. The child with an intelligence quotient that made it unlikely he or she could perform at a typical level in some academic subject should nonetheless have had the opportunity to learn things that were appropriate to their ability. These topics that they received instruction in were to have been tied to activities of daily living, if necessary, such as bathing or shopping so that their capability for self-care as adults would be maximized. There has also been a mandate that the education that is provided be ‘free.’ That is; the family could not be charged for their child’s education beyond what was charged for the education of a typical, nondisabled student. The education of the child with the disability may cost the school more, but the school could not pass those costs on to the family. Increasingly, with more and more inclusion of adults who have disabilities in their communities; people were realizing that inclusion should begin in childhood. With that goal in mind, education was supposed to be provided in the least restrictive environment in which the child could benefit from the education and make progress. Removing a student to a special class that contained only students who had disabilities came to be viewed as restrictive because it was not a typical class setting. Students may be instructed in some subjects away from their classmates but were supposed to be included in the classroom as much
as possible. Attitudes of acceptance toward students with disabilities in typical classes have been becoming more positive over the past few generations. However, some parents of typical children resent the extra expense entailed in providing support services such as physical therapy, accessible transportation, special equipment, and other things the student may need to take advantage of educational opportunities. This researcher has had a great deal of contact with other FCDs, through parent support groups. A common complaint of those families is that their child has not been receiving a free and appropriate education. Schools have hesitated to spend money they didn’t have. And families of typical children resent the amount of money spent educating children who will never ‘produce more than they consume.’ In response, many FCDs pointed out that (humanity aside) it was less expensive to teach a person to maximize their independence and ability to perform activities of daily living when that person was a child, rather than keeping that person dependent and paying someone to care for them for the rest of their lives.

Psychological observation of people is complicated in and of itself; especially as one considers the mind processes in the body. The two affect each other. Hence, observations should be bio-psychological in nature. To add another dimension, one takes into account social processes between other living organisms, the bio-psychosocial perspective. The social work field has a long history of considering the person (both mind processes and physical condition) in the environment. However the environment consists of more than inter-relationships with other living beings. One should also take into consideration the physical environment. This has come to be a perspective of psychological processes, physical function, inter-relationships, and physical environment; none of which can be considered apart from each other.
Therefore, when considering “resilience in families that have a child who has a disability,” one is considering the: 1) internal psychological processes of each individual, 2) family psychological functioning in terms of the inter-relationships between family members (the inter-relationships can be viewed as the inter-psychological environment), 3) the physical condition of each family member (not just the child who has an atypical condition), and 4) the socio/physical environment the family lives in. This tapestry of processes, relationships, physical conditions, and surroundings is difficult to untangle with any sense of coherence. Since each affects the other, when one pulls on one “thread,” one often ends up with two or three threads twisted together. With this understanding that “a” effects “b,” which effects “c” and so on, one factor to be considered is the child’s social surroundings. These include the environment and conditions created by relationships between the family and other members of the community.

A variety of other factors have impacted the ways FCDs have lived their lives, within their families and communities. One of these factors is the sheer number of families involved. The increase in medical skill and technology has resulted in children surviving, when generations ago they would have died (Walsh, 2006). Some disabilities, such as autism, seem to be on the rise. Toxicity in the environment, caused by various factors, is also resulting in an increase in the number of FCDs. Fetuses and infants are exposed to chemicals in the environment, changing chemical compounds in food, illegal drugs ingested by parents, and prescribed medicines.

As technological advances have been made, problems with pollution have been changing and new chemicals have been produced. Sometimes these chemicals initially appear inert or non-destructive but are later found to have debilitating effects on those exposed. Chemicals used in growing food, processing it, producing it, and packaging it
may also result in unintended consequences years later. Examples of this are seen in pesticides used on crops, and hormones and antibiotics used in managing livestock. Some pesticides have been observed to persist in the environment, effecting living things over the long term.

Hormones and antibiotics used in livestock can have negative consequences for physiological development in both children and adults. Chemicals added to food in order to increase shelf life, or improve taste, have been seen to have an adverse impact. Packaging of manufactured food can sometimes leach chemicals into the food. Alcohol and other recreational drugs can adversely affect the developing fetus, resulting in long-term disability to the child. Prescription medicines may have deleterious effects. Despite studies and trials performed to reveal destructive side effects in advance of FDA approval, sometime such effects do not appear for years. All of this exposure to harm, combined with the medical capability to prolong life but not necessarily protect health, have impacted the number of FCDs that are part of our community today. One can pick up a social environment/community “thread,” proceed to a physical “thread,” and end up with an environmental “thread.” The next paragraph takes into consideration the interactions between the social environment and the family.

Also impacting the acceptance that FCDs find in the community has been advocacy that families themselves have been doing over the years. As a result, it has become more “expected” that children who have disabilities will live and grow up at home, rather than in institutions. Disability is viewed by fewer people as a “disfigurement” and more as a difference that brings variety to the tapestry of life. Some of this attitude of acceptance comes from the different way that diversity is now framed. As subcultures have become empowered, they are refusing to be marginalized. They insist on being seen and respected for the aspects they have to contribute that enrich society. More
information is presented below on the ways members of the community “gate keep” or conserve resources when resources are viewed as scarce.

There has been a continuing conundrum in society that has acted as a stumbling block for FCDs, and for other traditionally oppressed populations. This is related to instability in economic conditions and barriers to resources. Marginal economic conditions have resulted in more frequent episodes of deterioration in the ability of even non-disabled people to provide for themselves. These conditions have made it difficult for families to meet their needs for food, clothing, shelter, education, transportation, and goods/services necessary to maintain health. Families of children who have disabilities often have more trouble taking care of a family and maintaining a job. They also face increased expenses related to caring for the family member who has the disability. With these restrictions and challenges, this segment of the community tends to face greater challenges to survival.

1.6.1: Independence and Self-Sufficiency

There appears to be an unspoken, societal expectation that individuals and families will “take care of themselves.” There are differences between cultures, and even between families, about what this means. In the United States, it may seem that this attitude is exacerbated by some of the events that occurred upon European exploration and domination on this continent. Some people came to The Americas to escape imprisonment or poverty. Others came to escape other kinds of oppression.

There has been a tradition of religious freedom that comes from those who immigrated here seeking exactly that. This part of the genesis of the culture of the United States is significant because it speaks to a tradition of “individualism.” The other side of a culture that values individualism is a decrease in “community” and an increase in responsibility being placed on individuals (Spicker, 2006; Wilkinson, 2002). In this
context, “community” means not operating in isolation. When families can depend on each other and create social systems of support, they are more likely to have access to resources. Sharing and caring for others benefits the whole group.

Existing in such social isolation is particularly pernicious for those who face atypical challenges, like families that have children with disabilities. Along with the societal expectation that individuals will plan to be able to take care of themselves is an assumption that one will also take care of the family that one forms. There are two aspects of planning for being “injured” or disabled that hinder those who otherwise try to accept total responsibility for themselves. One of these is the psychological distaste for addressing existential issues. It would be very hard for people to function if they were constantly considering worst case scenarios. However, this also causes a situation where denial of possibility of misfortune is comfortable. This may extend to an aversion to noticing misfortune in those around us. It is daunting to view the challenges faced by those around us and be cognizant of how fine the line is between their situation and ours.

Closely related to the view that people should be self-sufficient has been the expectation that they would exhibit “personal responsibility.” However, assuming personal responsibility has been related to planning for contingencies. It has been nearly as “useless” to plan for catastrophic events as it has been to be constantly aware of possible destructive events. If a family was aware that they were in a high risk group, some planning could be done. For example, those who live in earthquake, hurricane, or tornado-prone areas usually have a level of awareness of risk. However, natural disasters can strike in unexpected areas or with unusual ferocity. Likewise, a family may have been aware that its members were at higher risk for certain medical conditions, but accident and unexpected illness can affect even those who were prepared. Unexpected events happen even during a typical life course, so some instability would be considered
normal. Nonetheless, as brought up previously, preparing for all possible eventualities is difficult. Along with the unpredictability of events over the life span is the dilemma of obtaining treatment for disabling conditions.

1.6.2: Healthcare

When a child has a disability, whether that disability is cognitive, emotional, behavioral, perceptual, or motor; the caregivers’ constructive response is to seek treatment to improve or cure the child’s condition (Newacheck & Halfon, 1988; Simeonsson, Leonard, Lollar, Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003). The family’s internal resources and culture, and the conditions in the environment around them, have a discernible impact on its ability to care for family members. Some factors that may act as barriers to receipt of adequate care are economic insufficiency, available healthcare, other means to access healthcare, and the family’s ability to provide treatment in the home.

Healthcare received from “for profit” entities (such as hospitals, clinics, medical personnel, etc.) is expensive. Most families and individuals have insufficient income to pay for even normative health care out of their own income. When someone has a chronic condition, purchasing ongoing, day to day, year to year (even lifetime) treatment is even more difficult. Whether the community values an individual, the community’s attitude toward healthcare, societal attitudes toward sufficiency, and how community as government provides access will have a critical impact on the ability of the family to maintain health and, therefore, function.

Even typical families have had trouble obtaining care to maintain wellness. When treatment of a chronic condition is needed, they may use more medical resources that, correspondingly, are more expensive to purchase. In some societies, communal funding of government resources insures that most citizens have access to wellness care and
treatment for illness/disease. Despite the overt attitude toward acceptance of people with chronic medical conditions/disabilities in United States society, there is a less seemly, covert mindset. In an Exchange Theory mindset, an individual is only granted “access” if they can provide something of equal value in return. Frequently people who have disabilities consume more financial resources/commodities than they will produce. This, sometimes, results in a mindset to withhold resources from people who have disabilities as a “bad investment,” unlikely to present sufficient “return.” In the area of medical care, when scarce resources become an issue, discussions arise about whether medical care is futile. Currently, treatment is considered futile if it does not significantly prolong life or reverse a comatose state (Gampel, 2006, p. 98). However, the question has been raised about the erosion of trust between medical professionals and patients when there is disagreement about futility (Miller, 2008).

In addition to how individuals are valued in the community, both overtly and covertly, there are cultural differences related to healthcare. In most developing countries, access to sufficient food and shelter to achieve survival takes precedence over health and healthcare (Simons, Irwin, & Drinnin, 1987). Several developed countries view a healthy population as an asset to the community and business, and ensure that people have access to health care. Although the United States is moving toward greater provision of health insurance that will improve access to health care, it will only partially improve equity. The current situation is such that access to health care is through profit-driven health insurance companies. These companies have a profit motive to interfere with client access to healthcare. In addition, the degree of expense in obtaining healthcare has made having insurance a secondary barrier. Health insurance is prohibitively expensive to purchase as an individual so that usually insurance is only feasible through one’s job. This creates a preferential class system in which the highly-
educated that are working for large wealthy companies are more likely to have partial access to healthcare through insurance. The uneducated, underemployed, self-employed, and those who work for small companies do not even have access to insurance, much less earn enough to pay for their own healthcare.

Apart from the economic means to purchase medical care is the availability of medical facilities. In the United States, there is not an overarching, guiding plan for the provision of healthcare through facilities and personnel. In the absence of a social plan for community health, those going into medical care positions seek training that will result in the most lucrative salaries. The trend is such that care from high-risk medical sectors (such as pregnancy care and delivery), non-specialty care (such as family medicine and general practice), and care in low-population density areas (rural parts of the country) are difficult to obtain. An inadequate number and type of medical personnel and an inadequate number of treatment centers and hospitals is a continuing problem in outlying areas where the small number of clients makes medical practice unprofitable.

An issue related to available healthcare is support services for the family. When a child has a disability and requires treatment, an adult family member must either 1) give the treatment, or 2) for more complex treatment, take the child for regular medical care. During a time, and in an economic climate, where a single parent works two jobs (or more) and a two-parent household usually has both parents employed, outside assistance is critical to provide enough caring adults who have enough time to provide the care. However, little formal provision is made to provide extra time and space for parents to care for a child who has a disability. Provision of attendant care, like other forms of medical care, is expensive and seldom covered. Children are usually not provided with attendant care. Respite care, provided to give parents a break, often engenders hostility from families of children who do not have disabilities. Typical parents
may view respite care as free babysitting, despite the fact that lifting, toileting, dressing, and spoon-feeding a child over the age of one to two years old is not a typical parenting task.

Related to the family’s economic and time resources to provide ongoing specialized medical care is the family’s emotional ability to provide these supports. Necessary time spent caring for a child who has extraordinary care needs takes time away from other relationships. Other people who need the adults in the family, other children, and other family members and friends do not get the time they need from the caregivers. The parents, missing out on adult support relationships, have little emotional backup to deal with the stresses and strains of constant care, not to mention the emotional trauma of struggling to comfort and care for a loved one who may be experiencing emotional and/or physical distress.

In terms of support for families that have children who have disabilities, families are the building blocks of society. If families disintegrate under the myriad of modern pressures, one must ask, “Who will take over the family functions of support, care, education, and socialization of its members?” Families provide many necessary functions that enable society to exist. Often these functions are unappreciated and unsupported.

One of the concerns that FCDs face is care of their loved one (who has a disability) should the family become unable to provide care at home. The story of Ruth Sienkiewicz is just such a story. Her mother provided care for her until the mother’s deteriorating physical health forced the family to place Ruth in an institution (Sienkiewicz & Kaplan, 1996). However, this researcher’s personal experience, in a parent support group, indicates a more pressing concern of FCDs raising their children at home (Our Special Children, n.d.). Most of the parents expressed concern that their children were not getting a Free and Appropriate Public Education (FAPE). Difficulties that children who
have disabilities face in the educational system have been mentioned above. From the parental perspective, many parents had goals for their child that he or she would maximize their cognitive and functional abilities. Several of these parents felt the schools would rather “babysit” their children rather than help them achieve their potential. Some parents sought outside advocacy to insure that their student’s educational needs were met (PRN, n.d.).

Children who have disabilities now have a legal right to a Free and Appropriate Education, and many people in school systems and in the community philosophically support that right. However, schools do not necessarily have the funds to individualize education, provide support staff, therapy, and equipment. In addition, some parents of typical students resent the amount of resources being spent on students with disabilities (who may never produce more than they consume).

In conclusion, living in a family of a child who has a disability presents emotional and logistical stresses in accessing resources and providing care. Finding out that a family member has a disability is often a traumatic experience. Society is more accepting of individuals who have disabilities than it has been in the past. However, the number of people who have disabilities seems to be on the rise (Boyle, Boulet, Schieve, Cohen, Blumberg, Yeargin-Allsopp, Visser, & Kogan, 2011). This may be due to a confluence of improved medical technology causing more people to survive illness and injury without achieving rehabilitation (or, in the case of infants who acquire disabilities, habilitation). Whatever the cause, FCDs face the challenges of coming to emotional terms with their loved one’s care needs and trying to access scarce resources. In order for the family to adapt to this stress or trauma, they will need to display resilient behaviors. Researchers have been investigating individual, family, and group resilient responses to injury, stress, trauma, and deprivation. They continue to work to increase our understanding of
resilience processes and ways in which to support families to respond constructively to adversity.
Chapter 2

Literature Review

The organizing frameworks for this study of resilience in families comes from both the Strengths Perspective and Systems Theory. The Strengths Perspective is important in observations of resilience as they have shown that growth occurs from drawing on strengths. In the focus on deficit, there is no “material” with which to ameliorate the problematic situation. In addition, the Strengths Perspective is in philosophical alignment with the evolution of Disability Culture. Increasingly, adults who have disabilities are rejecting the deficit medical model in favor of a view that focuses on the diversity of what is normal (Saleebey, 2008).

Family Systems Theory recognizes the simultaneous dynamic existence of individuals within the family interacting in such a way as to create a unitary being. The family has a character distinct from the additive characteristics of the individuals involved. The family is also every individual’s first experience with interpersonal relationships and the ways in which different individuals have diverse experiences of the same situation (Baker, Seltzer, & Greenberg, 2011).

2.1: Resilience

Resilience is a quality of living organism that facilitates recovery from destructive forces. When encountering trauma, injury, or stress, the healing process occurs and the injured individual usually regains some measure of former “health.” These adaptive processes can be seen to operate at the micro, meso, and macro levels (Corcoran & Nichols-Casebolt, 2004).

2.1.1: Stress and Coping

Research that eventually came to be aimed at understanding resilience began in observations that some people exposed to stressful situations cope constructively and
continue on a healthy developmental path. But, others do not continue an upward trajectory. Their behavior, or their ability to access resources, decompensates and they become less functional. Researchers’ and practitioners’ observations of coping behavior and constructive adaptation led to further research in the attempt to understand why and how some people recovered from setbacks (Garmezy, 1991; McCubbin & Dahl, 1976; Rutter, 1987; Werner & Smith, 1982). Werner and Smith’s observations of children began in the late 1950s (Smith-Osborne, 2007). They observed that many children, despite living in circumstances of poverty, were able to thrive and grow into functional adulthood. The children most at risk encountered problems with health in infancy and family problems during childhood. Some children grew up in families marked by conflict, alcoholism, or mental illness. Other researchers came to resilience research through observation of adults who successfully overcame psychosis as compared to others who did not cope as successfully (Anderson, Hogarty, & Reiss, 1980; Hatfield, 1981).

2.1.2: Constructive Response

In response to trauma, resilient responses provide the opportunity for those injured to regain a previous state of more effective functioning. Hopefully, they will recover enough to exceed previous functioning and achieve even greater levels of quality of life. As introduced, above, resilience can be viewed at micro, meso, or macro levels. That is, it can be a quality demonstrated by individuals, families, and societies. Coping behaviors that foster resilience can “stem the trajectory from risk to psychopathology, thereby resulting in adaptive outcomes even in the presence of adversity” (Cicchetti & Garmezy, 1993, p. 497). Others have noted in work on childhood resilience that protective factors “might modify the negative effects of adverse life circumstances” (Luthar, Sawyer, & Brown, 2006, p. 106). Some factors are protective and support resilient responses. Other factors are risk or vulnerability factors and precipitate or
exacerbate injury, stress, or trauma. Both groups of researchers have elucidated on the importance of agreement in the research arena and reaching consensus on terminology, definitions, and measurement techniques in order for progress to be made in the study of resilience.

Since resilience is a relatively new field emerging out of earlier work on stress and coping, there is still much discussion on refining concepts and making the case for resilience as a distinct construct. Increasing agreement on definitions, terms, and measurement issues allows researchers to build on each other’s work (Werner & Smith, 2001). There is general agreement that resilient processes do not display themselves in the absence of trauma or injury. The injured party may be an individual, a family, a community, a distinct group within a society, a cultural group, or a country (Briere & Scott, 2005; Cicchetti & Garmezy, 1993; DeHaan, Hawley, & Deal, 2002; Halfon & Hochstein, 2002; Higgins, 1994; LaBoucane-Benson, 2009; Leipert & Reutter, 2005; Luthar et al., 2006).

However, J. M. Patterson (2002) makes a case for resilient processes promoting adaptation in normative/typical populations that have not experienced what some would consider traumatic events. She makes the point that stress is relative. Even those experiencing typical, constructive development encounter situations that, to them, are stressful.

2.1.3: Nature of Resilience

Resilience is generally considered to be a process, a dynamic interaction between the injured “entity” and other individuals, groups, and the environment. As such, resilience theory is philosophically consistent with the social work paradigm of addressing the “Person in the Environment” (Halfon & Hochstein, 2002; Cicchetti & Garmezy, 1993; Luthar et al., 2006; Higgins, 1994; Patterson, 2002; Smith-Osborne, 2007; Ylvén Björck-
Åkesson & Granlund, 2006; Rentinck, Ketelaar, Jongmans, & Gorter, 2006). In this process, the person/group who is injured seeks to adapt to the stress or trauma. The goal is to regain former levels of function. In the best of all possible outcomes, former levels of function are surpassed and one is able to function at an increased level of effectiveness. Resilience may also be considered as a characteristic and a goal that is observed through constructive, effective coping behavior (Patterson, 2002).

2.1.4: Risk vs. Protection

These processes display themselves through the interaction of risk factors (also known as vulnerability factors) and protective mechanisms. Risk factors may be traits, genetic predispositions, or environmental/biologic deficits. These factors create injury, place one in a vulnerable position, or are stressful. Protective factors are traits and/or contextual characteristics that are supportive in positive, adaptive responses to stress, injury, or trauma (Smith-Osborne, 2007). The same trait may be associated with vulnerability or protection depending upon the individual or the context. Stubbornness, that restricts one from changing a maladaptive behavior may, at another time or in a different context, be the persistence that allows one to strive until progress is made. Also, character traits that are normative and effective in childhood can cease to be effective in an older individual.

2.1.5: Social Networks

Another protective resource often mentioned in the theoretical literature is that of social networks. The capability to access social networks may operate in several ways to support resilience and adaptation. In one context, interacting with a social network provides emotional and educational support. Constructive social relationships can operate to reduce one’s sense of isolation. In addition, there is the potential for a social relationship to have a teacher-student component, such that parties can improve their
skills and coping behaviors. In another aspect, social networks have the capacity to provide logistical supports, as those involved learn about each other's material needs, skills, and resources. When the social network is a specialized peer support group (such as peer support within programs such as Alcoholics Anonymous), the critical mass of opportunity increases. More shared experiences exist within the members of the peer group. Not only is there greater homogeneity of experience, but those who have a greater amount of time dealing with the stressful issue can act as mentors with those for whom this is a new situation. Social competency is a protective mechanism that allows one to effectively access social support networks, as well as gain support through interpersonal relationships (Walsh, 2002; LaBoucane-Benson, 2009; Luthar, 1993; Rutter, 2006; Aldwin, 1994; Grant, Ramcharan & Flynn, 2007).

2.1.6: Response to Trauma

As mentioned above, a generally agreed upon characteristic of resilience is that it only becomes “operative” when the individual (or group) is injured in some way. If the trauma or stress is not too severe, and sufficient psychological, physical, and logistical resources exist, coping behaviors serve to reduce the destructive impact of injury. This allows those who have experienced harm to either return to former levels of function, or even grow and obtain a higher level of actualization (Cicchetti & Garmezy, 1993; Patterson, 2002; Rutter, 2006; Leipert & Reutter, 2005; Simons, Irwin, & Drinnin, 1987; Smith-Osborne, 2007; Goodley, 2005). No discussion was noted of measurement in situations where a constructive outcome is not achieved, resulting in the party either succumbing to the injury, or in the deterioration of their well-being.

2.1.7: Developmental Aspect

In addition to their dynamic nature; resilient processes are developmental, changing over the life span. Resilience manifests itself when interactions occur between
risk factors, protective factors, interpersonal relationships, and thoughts. The environment and the availability of resources also enter the constellation of risk and protective factors. As the individual or group moves through developmental stages, normative stressors change. The family’s experiences and acquired skills may act to strengthen the ability to adapt. However, if they have not been able to constructively deal with past challenges, they may have set up maladaptive coping responses. Transitional phases during the developmental process are, generally, stressful times as individuals or families are faced with new challenges. For instance, when a child goes through adolescence, he or she must deal with issues they have never faced before. With sufficient supports, most master new tasks. If supports are inadequate, or the challenges sufficiently differ from the norm, adaptation becomes harder.

The older the individual/family is, and the longer they have been “operating,” the greater their chances are to have acquired skill at dealing with stress or injury. Therefore, in most cases, an experienced family is more resilient. They have more experience in dealing with normative, and non-normative, events. However, depending on the degree of trauma they have experienced in the past and the way they have dealt (successfully or unsuccessfully) with these challenges, they could be in a weakened condition. Families that have been dealing with disability issues for a time, but in a “by the skin of our teeth” approach, may be experiencing a slow, invisible decline in their ability to keep functioning. In this situation, even a seemingly innocuous event can cause an unexpected collapse in their ability to cope. In addition to life experience with normative events, the way the family has dealt with stress in the past can act as an “inoculation” for dealing with injury in the present or future. In other words, the constructive disposition of previous trauma can confer a degree of protection in subsequent situations. However, a factor that acts as a stressor for one family may act in a protective way for a different
family. Also, situations that are stressful for some are supportive for others. One may derive support from a close knit, extended family, while another may find that degree of interaction so intrusive that it hinders its ability to function. So many factors change during the developmental span that it has become apparent that longitudinal studies of resilience are critical. A family, or set of individuals, that can adapt during one phase may find another phase of development too challenging. Previous stressful experiences may have diminished their “health” and ability to function (Cicchetti & Garmezy, 1993; Luthar, Cicchetti, & Becker, 2000; Browne, Mokuau, & Braun, 2002; Patterson, 2002; Rentinck et al., 2006; Smith-Osborne, 2007; Ylvén et al., 2006; Higgins, 1994; Grant et al., 2007).

2.1.8: Reframing

In the effort to achieve coherence in stressful situations, families may experiment with different perspectives. They will seek to reframe events to make sense out of them. Someone who is experiencing abuse will often find it has life-changing effects in how they feel about themselves and how they interact with others. One resilient way of reframing the events may be to view oneself as a survivor, instead of a victim. People may reach out for support to allay the damage caused by destructive people in their network (Aldwin, 1994; Antonovsky, 1987; Grant et al., 2007). A society that experiences an economic downturn has to make major changes in goals and how it is going to continue to function with different resources. Reframing, or focusing on different goals, helps people focus on their strengths and the good that can come from a troubling situation. Sometimes events occur that have no discernible cause. Events seem senseless and random. Resilient people attempt to understand and make meaning out of damaging occurrences that have no readily perceivable cause. Hence, resilient responses often involve reframing and working toward achieving a sense of coherence out of situations. As people search for meaning in adversity and adjust values and goals, they may improve their sense of
personal self-efficacy and find hope for the future (Brandstadter & Grieve, 1994; Dupont, 2009; Patterson, 2002; Rutter, 2000; Wagnild & Young, 1990; Walsh, 2003; Higgins, 1994).

2.1.9: Coping Behavior

When an individual or group is exposed to stressful situations, their behavior may change. Behavior that promotes constructive adaptation could be termed “coping” behavior. These behaviors can be learned and supported (Aldwin, 1994; Baltes & Carstensen, 1996; Brandstadter & Grieve, 1994; Grant et al., 2007; Orr, Cameron, & Day, 1991; Patterson, 2002; Rutter, 1999; Ylvén et al., 2006; Zeitlen, Williamson, & Rosenblatt, 1987). Some steps of coping behavior, as set forth in Hill’s ABCX Model of Stress, are “appraisal of the event, analysis of available resources, gaining social support, dealing with logistical demands and needs of other family members” (Hartshorne, 2002, p. 266).

Behavior that is adaptive reveals hope for the future and is goal driven. To be able to adapt to destructive events and still look for a path forward comes from proactive strategies. It is indicative of an intrapersonal or intra-familial core of self-esteem. The ability to evaluate changed circumstances and assess needed resources to solve problems is critical in regaining psychological, physical, and environmental/systemic health. When a problem cannot be solved or a “cure” achieved, sometimes the destructive situation can at least be ameliorated (Baltes & Carstensen, 1996; Brandstadter & Grieve, 1994; Dupont, 2009; Grant et al, 2007; Wagnild & Young, 1990; Walsh, 2006).

2.1.10: Process

As stated in the section on concepts, resilience shows itself as a process. Viewing and measuring it as such is critical in taking into consideration the complex
interactions between vulnerability mechanisms, protective factors, and the “entity” experiencing the trauma. Individuals, groups of various sizes (from families to communities), societies, cultures, and countries are susceptible to injury. The response to injury is often an effort at self-righting, or regaining stability. In addition, the interactions of stressors, the environment, and the developmental stages of these subjects argue for process analysis. Although the characteristic of being resilient and the possibility of resilient goals are cogent, the most illuminating way to understand resilience is as a process (Browne et al., 2009; Cicchetti & Garmezy, 1993; Halfon & Hochstein, 2002; Luthar et al., 2002; Patterson, 2002; Smith-Osborne, 2007).

2.1.11: Inoculation

One of the characteristics of resilience is that successful, previous experiences dealing with injury can enable the family to deal with subsequent trauma more successfully. Michael Rutter (1999) made a comparison between this kind of exposure being “strengthening” in a purely biological sense and conferring increased psychological resilience. In the medical model, a living entity can receive a vaccination against a “germ.” This exposure strengthens the organism’s rallying response to heal from insult or injury. Similarly, a family that has overcome past challenges has experience in coping and adaptation that may serve it well when dealing with future stress. The hallmark of this “vaccination” effect is that the previous exposure to stress must have either been so minor, or the protective mechanisms/supports must have been sufficient such that the family recovered from the insult (Aldwin, 1994; Browne et al., 2009; Grant et al., 2007; Halfon & Hochstein, 2002; Patterson, 2002; Smith-Osborne, 2007).

2.2: Strengths-Based

As mentioned previously, the concept of resilience works well, as used within the field of social work, to support those who are overcoming stress, trauma, and injury
because this model takes into account the constructive resources that the family has. When assisting a family in building on its constructive skills, a focus on each member’s strengths is more effective than a primary focus on the problem. This makes it easier for each member to feel competent and effective enough to address a situation that needs to be remediated. It also helps the family focus on which skills and resources to access and sets in motion a “planning” frame of mind. The Strengths Perspective takes into account the person in the environment. The family in the environment is not just his or her social network. It also speaks to his or her geographical location, the resources available to him or her in a material/logistical sense, his or her ability to produce necessary “items” or earn enough money to purchase what he or she needs, etc. Another reason the Strengths Perspective is effective is that it approaches situations from the viewpoint of what is going well, instead of what is not. This Strengths Perspective of promoting resilience facilitates practitioners’ inclusion of clients in a team-based approach. This recognizes and gives credence to the client’s position as the expert on his or her own life. It helps clients respond proactively in areas where outside resources may be minimal or insufficient. When building on strengths, the client is accepted for his or her expertise and feels like a more equal partner. When outside resources are minimal, and individuals or groups need to “make do” with what they have, the Strengths Perspective helps them build on what they have. Again, they are the experts on their strengths. Viewing the situation from this Strengths Perspective facilitates adaptive outcomes (Deegan, 2005; Goodley, 2005; Patterson, 2002; Smith-Osborne, 2007; Weick & Saleebey, 1995; Ylvén et al., 2006).

2.3: Resources

Although intrapersonal strengths and support from interpersonal relationships are crucial, the existence of those doesn’t negate the need for external resources. External resources are not only tangible and material, i.e., medicines, health care, food, shelter,
transportation, education, clothing, and adaptive devices. Other resources, such as access to services, attendant care, etc., are also important. The critical issue is that those in need be able to procure necessary resources. Problems with getting a hold of what one needs may be intrapersonal or interpersonal. However, it seems more often that the problem resides with services not being available, or families having insufficient income. Since the family is the caregiver for the children, if the adults are limited, the children suffer (through no fault of their own). Due to their developmental stage, children are more dependent (Ungar & Liebenberg, 2009). This sometimes resolves into a policy/fiscal issue, particularly in cultures that expect individuals and family units to take care of their own needs. Government and philanthropic providers are also at the mercy of economic conditions. During economic recessions, they cannot provide as much as they would during a time of prosperity.

However, like someone subject to an untreated medical condition, a family that falls through the cracks may suffer permanent dysfunction, even if there is an apparent return to functionality. It is important that gatekeepers to resources and legislators understand and accept that just because a family is surviving, it may not be thriving (Chabad-Lubavitch Organization, n.d.; Sudworth, personal communication, March 12, 2009). In fact the unseen foundations may be rotting away at the core, resulting in a future, unanticipated collapse. Hence, just because a family is utilizing current resources (those resources under the family’s control) will not negate the need for additional resources that are out of reach (Antonovsky, 1987; Baltes & Carstensen, 1996; Grant et al., 2007; LaBoucane-Benson, 2009; Patterson, 2002; Walsh, 2003).

2.4: Individual in Nature

Risk mechanisms and protective mechanisms have different effects based on the situation. And, individuals, families, or groups will be affected differently. What is risk for
one person or family is not risk for another. Even the degree of risk may be different. An example from the medical world is the condition sickle cell anemia. This condition persisted because in some environments it is protective. However, in other environments, it is a risk factor. In locations where the contraction of malaria is a risk, those who have sickle cell anemia have greater longevity because the latter condition correlates with a lower rate of malaria. However, where malaria is not a threat, individuals are at greater risk of illness from “sickle cell” (Hoff, Thorneycroft, Wilson, & Williams-Murphy, 2001). A similar, psychological situation exists for people recovering from trauma. For example, alcoholic co-dependence may help those who, for whatever reason, are in a relationship with an alcoholic. The co-dependence may serve as a protective or coping factor. However, in the typical community, interacting with those who do not have alcoholism, these codependent behaviors are likely to be maladaptive. So, when conditions of resilience are considered, observations need to be individualized and based on the specific circumstances of the individual or group under consideration. Neither the same protective mechanisms, nor similar risk factors, can be assumed to act similarly in different situations (Cicchetti & Garmezy, 1993; Luthar et al., 2000; Luthar et al., 2006; Patterson, 2002; Smith-Osborne, 2007).

2.5: Micro-, Meso-, and Macro-Levels

Resilient processes operate at the micro-/individual level, at the meso-/family/community level, and at the macro-/societal level. Individuals demonstrate adaptation in response to injury. The various analogies between healing from physical trauma, and healing from psychological trauma, are most clear at the individual level. As the number of individuals involved in the stressful situation increases, the complexity of the process increases. More resources may be available to a family than to an individual, but the risk factors for, say, interpersonal injury may increase as well. At the societal
level, there can be greater access to physical and logistical resources if the culture operates from high fraternal values. Or, there can be segregation from resources if the society holds liberty values too highly, particularly the liberty from the obligation to share one’s resources. The way interactions vary across micro-, meso-, and macro-groups presents conditions in which complexity should be taken into account, both when studying resilience and aiding others to build resilience (Corcoran & Nichols-Casebolt, 2004).

2.6: Complexity

In addition, the complexity of the mechanisms, paired with the complexity of intrapsychic processes (internal thought processes) argues for a gestalt view of resilience. The sum of factors and one individual’s responses is a very different situation from the factors and responses between three, ten, or thirty individuals. When one is looking at the factors that affect the resilience of an individual, one observes one entity’s internal psychological processes, interactions, and environments. This condition of complexity impacts measurements of resilience. Whereas reductive/quantitative measures offer a starting point for understanding, the more complex the system, the more necessary qualitative measures become. Family systems in particular (in comparison to resilience in individuals) seem more amenable to qualitative observations to facilitate understanding (DeHaan, et al., 2002; LaBoucane-Benson, 2009; Smith-Osborne, 2007).

2.7: Flexibility

When systems, even intrapsychic systems of an individual, are disrupted, former ways of life no longer work and families may have to seek out new ways of functioning. If the family has some flexibility of function and behavior, the formation of new goals is easier. New ways to achieve new or old goals or meet needs are easier to integrate. As a
saying goes, “The willow which bends to the tempest often escapes better than the oak which resists it, and so in great calamities, it sometimes happens that light and frivolous spirits recover their elasticity and presence of mind sooner than those of loftier character” (Scott, W., n.d.). When situations change, compromise is necessary to adapt. Additionally, the construction of new goals is not a one-time event. As different goals are approached, or achieved, situations change. Paths and processes may need to be adjusted or changed as well. A family who may have been functioning optimally upon the loss of one of its members has to reassess how they will move forward. Openness to different ways offers more options for continuing on, particularly with regard to the family’s mutual aid tasks. In flexible family systems, another member may be able to assume tasks that another is no longer able to perform. Or, in even better systems, responsibilities that can no longer be taken on by one can be distributed across several family members. (Antonovsky, 1987; Dupont, 2009; Grant et al., 2007; Walsh, 2003)

2.8: Self-Esteem and Self-Efficacy

Several theorists have posited the importance of self-esteem in constructively responding to adversity. Is this connected to the belief in one’s own self-efficacy, that one can make positive changes in one’s environment? Healthy self-esteem seems to be both a protective factor and an indicator of probable resilient responses. Particularly for children whose families show maladaptive functioning, self-esteem correlates with resiliency. It is probable that, in the face of destructive family or caregiver relationships, the child’s self-reliance (as indicated by intrapersonal strength and valuing one’s self) allows her or him to functionally continue development (Cicchetti & Rogosch, 2009; Cicchetti & Valentino, 2006). Similarly, high family self-esteem is often found in families that adapt well to challenging circumstances (Vega Rodríguez & De Dios De Dios, 2006).
Particularly for families that have a child who has a disability, supports within the family are more crucial when there are few similar families to act as “mentors.”

With regard to individual self-esteem and resilience, it would be logical to think that an individual with more effective self-esteem would believe that rising to challenges is worth the effort to persevere on the path toward self-actualization. In addition, individuals and groups are more likely to persevere when they believe their efforts can be effective. Sometimes taking small steps likely to result in success is more effective than trying to reconstruct a firm foundation all at one time. Another issue that may be connected to a level of self-esteem is tolerance for interpersonal isolation. Existential anxiety, although a factor in the lives of many people who have not been traumatized, could be an additional stressor for those trying to adapt to injury (Antonovsky, 1987; Grant et al., 2007; Higgins, 1994; Luthar et al., 2000; Rutter, 1999, 2000; Wagnild & Young, 1990).

2.9: Person in Environment

Long a valued perspective in the world of social work, the "Person in The Environment" view has been shown to be critical in understanding adaptation and the process of resilience. The impact of the environment on both risk factors and protective factors, and their effect on adaptation, is integral to resilient processes. The environment can be the family’s social environment, material environment, geographical environment, and intrapersonal environment. One’s intrapersonal environment is comprised of his or her mental and physical entity. Interpersonally, a family can experience destructive, constructive, or neutral impacts from people with whom they have relationships. This can extend to ease problems accessing material, such as work income, that is impacted by relationships. The group’s material environment can be marked by a sufficiency or insufficiency of conditions or material resources. Its geographical environment may
provide barriers or access to needed supports. It may also exacerbate or ameliorate conditions, such as a person who has respiratory problems having better health in a dryer, warmer climate. In addition, one’s physical and mental condition can act as a challenge or as an asset (Jahiel & Scherer, 2010; Karls, Lowery, Mattaini, & Wandrei, 1997).

The environment can be a stressor in places where needs for safety, food, and shelter are not being met. When physical survival is in question, families have little energy or resources to be concerned with growth and functioning beyond living day to day. And, the environment can act as a protective mechanism when not only physical needs are met, but the presence of a social or peer network exists. A family that lives in a relatively crime-free environment, and that has sufficient food, clothing, and shelter, has a better chance of constructively adapting to ameliorate problems (Aldwin, 1994; Grant et al., 2007; LaBoucane-Benson, 2009; Smith-Osborne, 2007).

2.10: Asymmetrical Across Domains

As an individual functions in different domains, so does a family, as an entity. An individual exists in domains of home, school/work, relationships outside the home, etc. It has been observed that an individual may experience positive resilience in one domain (for example, school or work) but that level of adaptation may not extend to other domains. The person who functions well at work may not be taking care of his or her health. Thus, the level of resilience may be uneven across domains. At the macro level, a society may recover from an economic downturn but not extend respect to minority groups. One might also assume that family resilience could be uneven across its domains. The family may offer sufficient support for members to exhibit functional behavior at work and school, but not provide sufficient resources for the family to have a social network (Cicchetti & Garmezy, 1993; Luthar et al., 2000; Smith-Osborne, 2007).
2.11: Acceptance and Problem-Solving

When trauma interrupts balance and functionality, a problem is created. Problem-solving skills assist in adaptation and the restoration of balance. Recognizing that a problem exists and deciding that the problem is one that can be addressed is a first step. Then, the family needs to identify all aspects of the problem. Next is the generation of possible ways to respond, and deciding on the most effective ways to proceed. Finally, the cycle is completed by implementation of solutions and determination of how much of a problem still exists.

Acceptance of the reality of the situation is a necessary precursor to taking action. Once the family has accepted that there is a problem, they can proceed to analysis, forming potential solutions, and ameliorating the problem. Denial can be counter-productive to realizing that a problem exists. However, sometimes hope (that a seemingly relentless problem can be overcome) can be confused with denial. Hope can be an effective coping mindset for the family (Antonovsky, 1987; Grant et al., 2007; Rentinck et al., 2006; Sands et al., 2009; Wagnild & Young, 1990; Walsh, 2002; Ylvén et al., 2006).

2.12: Spirituality

Many individuals and groups that have sustained trauma, and are pursuing resilience, find the development of a spiritual perspective helpful. When attempting to reframe one’s beliefs and find meaning in adversity, a spiritual perspective may support self-esteem. It may also facilitate a sense of self-efficacy and relief from feelings of isolation. The belief that one is not alone, and that a force more effective than oneself is present, can be empowering. These considerations may be addressed to a perceived creator that is believed to have an immense interest in one’s well-being. A spiritual perspective can be addressed, more abstractly, in terms of self-actualization. It is
interesting in the review of the literature on the interaction between resilience and a spiritual perspective that those theorists finding the most evidence for the efficacy of a spiritual perspective are researching family resilience (Patterson, 2002; Walsh, 2002).

Some practitioners, concerned with alleviating suffering and oppression, have eschewed the spiritual perspective. Many spiritual practices, formalized into religious organizations, have an unfortunate history of horrible oppression. It is important in studying resilient processes and facilitating others’ resilient responses to not project one’s own values onto another person or group. What is a protective factor to one family will not perform, similarly, with a different family. It is important to listen to what the family finds supportive or destructive as it seeks to understand and deal with the stresses it faces (Krieglstein, 2006; Poole, 1998).

2.13: Complexity of Family

Four theorists address the increased complexity of understanding resilience in family systems. Laura DeHaan, along with Dale Hawley and James Deal, wrote of the complexity of facilitating resilience when multiple interrelationships exist (2002). Joan Patterson also raised issues related to the number of people in the family and whether they relate in dyads, triads, or larger groups (2002). Family members can act as supports to each other, but they also have the challenge of managing boundaries between separateness and connectedness.

There are attendant difficulties in measuring the resilience of families as compared to measuring the resilience of individuals. It has been recommended that resilience in families be measured by assessing each individual in the family. This would be done instead of past practices of obtaining secondhand reports about family members from one or two family members. If assessments are done of each family member, it can
still be useful to obtain accounts from others that reveal interactions between members of
the group (Ylvén et al., 2006).

2.14: Organization

Also important to understanding family resilience is observing the acquisition and
maintenance of the family organizational structure. The increased complexity,
engendered by the number of individuals involved, almost requires that organizational
tools be used. Hence, to the organizational skills needed to gain some stability in
adapting to a traumatic event is added the organization necessary to allow the collection
of individuals in the family to coordinate with each other. Social networks, all the way
from close to extended family connections and to community connections, can be
supportive of adaptation but are more useful if the connections and relationships are
organized instead of chaotic. Positive patterns of organization also increase opportunities
for flexibility (Walsh, 2002).

2.15: Communication

Again, in regard to family resilience, communication patterns facilitate, or hinder,
adaptation to stressful situations. Groups that can constructively communicate can build
solutions to problems; here the “problem” is recovery from injury, stress, or trauma.
Effective communication not only facilitates logistical activities of daily living, it also
provides for emotional support as members strive to regain functionality and former
balance. Constructive communication makes collaborative problem-solving more
effective (Patterson, 2002; Walsh, 2002).

2.16: Positive Values

Constructive values, those that promote health and growth, exist within an
interactional context in the family’s environment. Values which, when internalized,
support the pursuit of constructive behavior support resilient processes. These values
also help create a milieu in which interpersonal support and teamwork can occur. Children are in the process of internalizing values as they develop. They more effectively act on values that are supported by their environmental context (Daniel & Wassell, 2002; Thompson, 2002; Walsh, 2003).

2.16.1: Hope

Uncertainty, both of the attainability of goals and temporal uncertainty (about future events), creates a space where hope can exist. As alluded to in the section on “Acceptance and Problem-Solving” above, when the future is uncertain, some may see another’s “hope” as “denial.” However, just because trauma has occurred and chronic damage may have to be lived with does not negate future, positive possibilities. Hope for constructive change is not necessarily irrational. And, although individuals or groups may not at all times be fully cognizant of the negative aspects of the situation, others should not attempt to stifle hope about real possibilities. Hope can provide emotional energy for people and groups to move forward. Henri Frederic Amiel pointed out that “uncertainty is the refuge of hope” (Amiel, n.d.; Hartshorne, 2002; Walsh, 2002).

There are many examples of unexpected progress and remarkable recovery from injury. An example is the case of a New York firefighter, Donald Herbert, who sustained a head injury in 1995. After nearly ten years in a coma-like state, he made a partial recovery that his doctors did not foresee. His improvement lasted only about one year. There are, however, other instances of people making unexpected progress and sustaining that progress. Educators now know that people who have cognitive disabilities, many in which the student has a lower than average I.Q., can make educational progress beyond what they were thought capable of decades ago (Fins, 2009; Shaw, 2005; U.S. College Search, n.d.).
2.17: Other Theoretical Constructs and Processes

The preceding issues were brought up by one or more theorists. There are other constructs and processes that, while not necessarily echoed by several writers, warrant presentation here. Some seem to have potential bearing on adaptation in individuals and groups that are at risk from injury. Matters such as “understanding” events, thinking about resilience as compared to other factors, typical populations, and other matters are touched upon in the pages that follow.

2.17.1: Sense of Coherence

One of the early researchers to seek a better understanding of response to stress was Aaron Antonovsky (1987). He found that a “Sense of Coherence” facilitated a productive response to injury or trauma. Later, theorists have extended this by introducing the terms “reframing” and “meaning making.” These activities allude to, among other things, how people come to understand events in their lives. Catastrophic events, and trauma, often seem to occur senselessly. Sometimes it appears there is little the family could have done to prevent injury or to overcome it. The “meaning making” impulse helps families recreate a feeling of order and control through their attempts to fit new, and apparently disparate, events into the schematic framework of their lives and goals. In Antonovsky’s model, three qualities were pointed out as having an effect on coherence. These were “comprehensibility — Can the presented challenges be understood?, manageability — Are resources available to meet these challenges?, and meaningfulness — Are the challenges worth investment and engagement?” (Grant et al., 2007, p. 563). This model not only addresses understanding of events, but also the planning necessary to adapt if the decision is made that active responses are likely to be effective. Antonovsky reveals some of the underlying questions that may be posed as individuals try to make sense of a “world” that has drastically changed.
2.17.2: "Resilience" as Distinct

Suniya Luthar raised several points that, while tangentially connected to previous processes and issues, bear repeating in their own space. In her articles on measurement issues and terminology, she addresses the question of whether “resilience” is distinct enough from other behaviors, and processes, to bear study as a distinct construct. She also made some points about interactions within processes. For instance, it has been noted that risk mechanisms, protective mechanisms, and intra-personal/inter-personal processes interact in the resilient response. Experience, or pre-existing factors, also mediate the response to injury and environments where risk is high. Research has shown that gender and intellectual level have some effect on the potential for resilient responses. Those who have higher cognitive abilities, and those who are female, seem to have an advantage in achieving recovery through adaptation to trauma. Luthar, as a theorist and researcher, also found that those with an internal locus of control displayed better resilient responses and that researchers in the field need to be measuring the strength of resilient responses. It is possible that the internal locus of control facilitates recovery by fostering self-efficacy (Luthar, 1993; Luthar et al., 2000).

2.17.3: A Different Perspective

Joan Patterson (2002) has elucidated some particularly distinctive theoretical particulars. She has posited that resilience exists even in populations that are “normative” in the sense of being relatively unstressed and un-traumatized. One can begin to understand her perspective when one considers the risk in developmental transitions. Other theorists have pointed to developmental transitions as being high-risk events. Patterson shows that, even in a typical family, the point where they are growing into new and untried roles is challenging simply by being new. Hence, since it is new for typical families, it is stressful. In addition, Halfon and Hochstein’s (2002) point that risk may be
cumulative also speaks to the potential for risk to emerge in populations that appear risk-free. A typical family that has not faced apparent trauma may still decompensate after several less obvious challenges have been faced.

Patterson also makes a point about strengthening relatively risk-free individuals and groups as a preventative measure. She writes that preventative measures are more cost-effective than treating damage once it has occurred. While this is, apparently, an effective way to support families, it does not work well in societies with inadequate access to resources. When it is difficult to obtain resources to address “injury,” preventative care is unlikely to be available (2002).

2.17.4: Cumulative

Before Halfon and Hochstein (2002) noted that stress can take a “toll” over time, Sir Michael Rutter (1999), in his inimitable fashion, made the point that resilience in the present situation is no guarantee against future decompensation. An individual who effectively rallies against today’s injury could later show dysfunction traceable to former trauma. This could be due to cumulative risk exposure.

He also writes of physiologic adaptation and psychological habituation as protective processes. As the body responds to chronic stress by producing hormones in reaction to that stress, the mind also (temporarily) desensitizes to a certain amount of injury. The amount of denial that a person or group can sustain varies. Denial can offer temporary respite from the situation of being overwhelmed if the denial does not continue so long that no recovery action is initiated.

Additionally, Sir Michael Rutter (2000) postulates that some protective factors may operate by interrupting a downward spiral toward increasing risk. Temporary material, logistical, or other help can allow a family to “regroup” and access other supports that would be unavailable to them while they are under extreme stress.
Challenging situations can create conditions of such intense stress that one is incapacitated from using available resources.

2.17.5: Adaptation and Disability

Little theory was found pertaining to resilience in families of children who have disabilities, compared to theory in general, as covered in the initial part of this literature review. What theory there is has mostly been adapted from the general coping and resilience theory of Patricia Deegan (2005); Michael Dupont (2009); Dan Goodley (2005); Gordon Grant, Paul Ramcharan, and Margaret Flynn (2007); Reuben Hill (1949); Patti LaBoucane-Benson (2009); Joan Patterson (2002); Michael Rutter (1999, 2000); and Froma Walsh (2002).

Dan Goodley (2005) reiterates in his work on disability that resilient processes are in response to stress, injury, trauma, or other situations that cause damage and dysfunction in individuals or groups. He also makes the distinction, for those who have disabilities, that discrimination against people who have disabilities (ableism) causes a barrier to what might otherwise be protective factors—social networking and access to resources, among others. This again argues for an approach toward the Person in the Environment, both to access resources and to reduce/remove barriers (Goodley, 2005; Grant et al., 2007). Families of children who have disabilities (FCDs) have, in the past, been denied access to the free and appropriate public education that other children in the United States have access to. The reduction of these barriers that began with the inception of Section 504 of the Rehabilitation Act in 1973 has made a positive difference in FCDs and future opportunities for these children (U. S. Department of Education, n.d.). A Strengths Perspective also emerges as a paradigm well suited to those living with chronic injury (or atypical function) as presented, again, by both Goodley (2005) and Deegan (2005). Unfortunately, lingering paternalism sometimes persuades professionals
to dis-empower those who have disabilities. Others are tempted to stymie efforts at independence by doing for PWD what they are capable of doing for themselves, atypically or not. This is a particular temptation for those nurturing and guiding children. As developing adults, children are usually unable to do all the things an adult can do. In doing for children things they cannot yet do for themselves, the “gray area” is always there. This “gray area” can be explicited by the questions, “Can this child do this process?”, “How long will it take the child to do this?”, and “Do I want to spend the time to allow the child to practice this skill?” The Strengths Perspective also leads to empowerment of those formerly oppressed and disenfranchised. And, as clients evolve into full partners with caring professionals, they take their place in the ranks of advocates—for themselves and their communities (Weick & Saleebey, 1995). Those who have the inclination to speak up for themselves work alongside and watch as others mediate for inclusion. As they learn, by watching and taking part as they learn, FCDs develop skills to advocate for their family, child, other families, and other children.

Gordon Grant, Paul Ramcharan, and Margaret Flynn (2007), drawing often on the work of Michael Rutter (1999, 2000), make several points about adaptation for people who have disabilities. Social networking and peer-to-peer support are especially important for people who have disabilities. Their specialized needs and ostracism from the society of the majority, who are “temporarily able-bodied” at times, results in a separate culture for those who are excluded. The resulting isolation makes reframing a critical process, as people try to make sense of often seemingly senseless injury (Dupont, 2009; Goodley, 2005; Grant et al., 2007). Peer-to-peer support for FCDs allows them to learn coping and adaptation skills from those who have already gone through certain developmental stages. As newer families (to the network) gain resilience, they are able to offer support in turn. Social networking, outside of the culture of FCDs in the community
of the “temporarily able-bodied,” has different but interwoven results. When FCDs resume their rightful places in the integrated community, those who were hesitant to interact learn that both communities are diverse and have more commonalities than they do differences. They learn how to sensitively weave differences into relationship in a non-discriminatory way.

The facilitation of a healthy sense of self-esteem is another way that those who are ostracized adapt to and survive in a hostile environment. This is usually an environment characterized by “-isms”: racism, sexism, ageism, ableism, and others, as members of the majority exclude those who are judged as “different.” Those who have disabilities and their families may search for alternate ways to resume a place in their communities. Individuals and families need to focus on the ways they are being “productive” and contributing back to the community as this builds self-esteem. It also helps others see people who have disabilities as differently-abled instead of disabled. Transitions in typical populations are fraught with “pot holes” as they attempt to learn new skills and take on new and untested roles. Support during development and transition is both important and problematic for people who have disabilities as there are fewer role models for constructive development (Grant et al., 2007).

There is yet another issue cogent in FCDs and that is maintenance of boundaries. This may be the psychological side of empowering others and giving them the space (and time) to accomplish things they are still learning. The more severe the disability and the more the person (who has the disability) requires assistance with activities of daily living, the more likely it is that boundaries will blur. When a caregiver has to clothe, feed, and bathe another person, it can be hard to view that person as separate and an individual. In addition, it can be difficult for the caregiver to maintain distinct enough boundaries to maintain an identity separate from the person receiving
care. This can be seen in the dynamic between a stressed family and social service systems. It becomes easy for the service delivery personnel (and system) to overstep boundaries from providing assistance to dictating how that aid will be managed by the recipient (Grant et al., 2007).

Michael Dupont (2009), in his dissertation on resilience in families of children who have an Autism Spectrum Disorder, draws heavily on Walsh's Family Resilience Framework (2002) in addressing resilience for this group. As certain family members require more time and attention, this draws from time spent on needed income-producing work, household, and interpersonal activities. This need, to fit more activities into a shrinking amount of time, requires organization and effective communication to allow flexible organization (Grant et al., 2007).

Problem-solving and the use of resources are other issues that are thrown into sharp relief in the lives of those who have disabilities. Trauma or chronic health problems result in problems in the lives of those affected. And, hence, effective problem-solving skills can reduce the stress caused by problems. Access to tangible and intangible resources, also, is protective. Intangible resources might be those that provide emotional and educational support, such as peer support groups. Tangible resources such as attendant care, help with medical bills, or accessible transportation provide compensatory help for those who have lost (or, in the case of child onset disability, never had) the ability to carry out some activities of daily living (Dupont, 2009; Grant et al., 2007).

Families of children who have disabilities often draw strength for adaptation from developing a spiritual perspective. This not only helps them reframe a situation of dysfunction more positively and provide support for a care-giving role, it also helps them maintain a sense of meaning (however abstract). This sense of meaning may be tied to Antonovsky’s Sense of Coherence as touched upon earlier. Consideration of spiritual
aspects also assists the family in maintaining hope for some positive outcomes in a situation it would be all too easy to see completely in a negative light. Families may develop a positive outcome by using their experiences to offer emotional support to other families new to the situation. Families who have dealt with inadequate resources may begin to do advocacy, so that other FCDs may have better access to resources in the future (Antonovsky, 1987; Dupont, 2009; Harshorne, 2002; Knestriect & Kuchey, 2009).

Hill’s ABCX Model of Stress and Coping, although begun many years ago, has been adapted as new knowledge has come to light and attention has evolved from coping behaviors to resilient processes (Hill, 1949). Steps four and five of this model are particularly applicable to FCDs as the steps address responses to increased logistical and relational demands in the family (Hartshorne, 2002, p. 266). These families face the logistical demands of doing, for the person who has a disability, what that person would do for themselves if he or she did not have a disability. Additionally, parents deal with trying to find time to do other activities such as caring for themselves, having a separate life, and earning income. Families face many other logistical demands other than those touched upon. In addition to these increased time demands, there also exists the need to take care of (and provide relationship time for) other members of the family who do not have a disability.

These are some of the aspects of resilient processes that have particular pertinence for those who have disabilities and for their families. These processes provide support in the face of increased demands related to maintaining relationships, making more efficient use of time, and meeting the logistical demands that arise when a family member has a disability. Families seek to achieve former balance from a time when family supports were sufficient to meet most of the needs of family members. When one child requires more time of a parent, resilient adaptation helps the caregiver find ways to
give the other children the attention and support they need (Patterson, 2002; Hartshorne, 2002).

2.18: Research on Resilience in Families of Children Who Have Disabilities

Theory informs the formulation of hypotheses, which one tests by collecting data. This is particularly important in the field of social work as we have given ourselves a mandate to provide interventions that show the greatest evidence of effectiveness. Hence, in the study of resilience in FCDs, research is important to ascertain which interventions have the best outcomes in terms of assisting families to develop constructive levels of resilience. This section of the literature review covers recent findings in research on resilience and on resilience for individuals or groups that deal with disability issues.

For those who struggle with disability issues, supportive relationships, participation in meaningful activities, and the cultivation of an attitude of hope are supportive of resilient responses (Arman, 2002). For professional caregivers and social service providers, particularly those in the medical field, it is important that they provide education to the family on disability issues. Families of children who have disabilities may have no previous knowledge of any disability issues. Even if they have a close friend or family member who has a disability, it may be a disability of a different type than the child has. Parents also need emotional, logistical, and financial support (KnestRICT & Kuchey, 2009). Peer-to-peer support, provided by other parents that have children who have disabilities, is supportive of physical and psychological health for the whole family. Support should be provided in ways that include the cultural practices and perspectives of the family. Developmental transition periods in the life cycle are challenging for any family. These periods are even more risky for FCDs because these families face untried goals with untested skills. And, there are fewer families to act as mentors for the FCDs.
Many parenting/family skills and processes were learned as current parents were growing up, in the family of their youth. But, unless the current parents grew up with a close family member who had a disability, that family experience is not as helpful. Finally, as far as the data presented by Cooley (2004) indicates, professionals should not attempt to separate the needs of the child from the needs of the family. The family should be viewed as a holistic entity, in which the whole is different from the sum of its members. The increased complexity presented by interactions between members, by itself, would present a different entity than the consideration of each member added together.

When viewed from a Strengths Perspective, Deegan (2005) discovered how hard it is for people who have disabilities to liberate themselves from the paternalistic medical model of care and to “take a seat at the table,” having a voice in their own care. What was found is that, in psychiatric settings, treatment should include a focus on solutions. Viewing this from the family perspective, the family should be included in treatment planning. Both the family’s goals, and methods they have input into, should be included in any process designed to alleviate problems. Some therapists lose sight of the fact that the family living with the trauma, despite its lack of formal training, is the part of the team best informed of internal and external challenges and resources. Therefore, the family should be empowered to have a voice in the treatment that effects it. As individuals in Deegan’s study gravitated toward, and benefited from, peer support groups, families may also derive benefit from peer support.

When doing research with families of children who have Autism Spectrum Disorders, Dupont (2009) found that one-third of the families experienced daily stress and from one-third to one-half of those families experiencing stress adapted to it in constructive ways. Qualitative analysis revealed several themes. One of these themes is “balance.” Families balance life around the child who has the disability. The extra time
needed to meet the needs of the child with a disability draws time away from other necessary activities such as earning income, taking care of household activities, and caring for other family members and friendships. However, as experience was gained, caregivers acquired skills and resources. This reduced the stress of accomplishing other activities. Other issues involve the lack of reliability in accessing supports, the positive effect of peer support for parents, and that the experience of “raising” a typical child does not generalize to aid in effective care of the child who has a disability. Families changed goals and sought reframing of world views to inculcate hope in the family. Families suffered from ostracism by others who didn’t understand the challenges of having a family member with a chronic condition, and families adapted by celebrating progress in small increments. They celebrated small successes. Those families that had a spiritual frame of reference drew strength from that world view. Professionals can support families by providing information and education, including the family as the “professional team,” and by erring on the side of over involvement rather than reaching for detachment.

A study by Gerstein, Crnic, Blacher, and Baker (2009) was unique in that it focused on daily parenting hassles for both parents involved in caring for a child with an intellectual disability. What they discovered indicates that mothers experience increased levels of stress, while fathers experience constant levels of stress. Higher levels of satisfaction with the marital relationship are correlated with improved resilience. Mothers experience decreased levels of stress when three conditions exist. These are positive marital adjustment, a state of psychological well-being for both parents, and a positive father-child relationship between the father and the child who has the disability. Fathers experience lower levels of stress under two conditions. These are positive marital adjustment and the mother’s psychological well-being. In a comprehensive view, it seems that the parental partnership exhibits more effective adaptation when the parents
experience psychological well-being, positive marital adjustment, and when there is a constructive relationship between the father and the child who has the disability.

In a consideration of whether an attitude of “hope” is realistic when a family has a child who has disability, Hartshorne (2002, p. 265) refers to Scorgie, Wilgosh, and McDonald’s (1998) variables that facilitate family coping. They found that family characteristics that facilitate coping include cohesion, hardiness, problem-solving skills, and recognized roles and responsibilities. Parental characteristics that support coping include a positive marital relationship, maternal locus of control, positive parental appraisals of the situation, and finding time to take care of duties and relationships. The only child characteristic that supported family coping was the child having a positive temperament. Hence, parental/familial characteristics were more important in adaptation than were the characteristics of the child. However, it is easy to see how “temperament” (possibly exhibited as behavior) can make a difference in how easy it would be to care for the child(ren). External variables that supported effective coping were an accepting attitude from the community, a sufficient social support network, and effective supports and relationships with professionals. Families dealing with community ostracism face additional, energy-consuming stress on top of caring for a child who has a disability.

2.18.1: Differences Among Resilience Theorists/Promoting Positive Adaptation

The section titled “Literature Review” was organized so that frequently mentioned topics were listed first. In the final part of that section were listed processes and factors less frequently commented on. These aspects are considered here from the viewpoint of families of children who have disabilities.

Looking back at that manner of presentation, one finds that the most theoretical attention has been paid to issues of access to resources through social networking/peer-to-peer relationships and the social competence to initiate and maintain interpersonal
relationships. Resources that are needed are both tangible and intangible. This indicates
that processes mentioned with more frequency are those that support interpersonal
relationships. Families dealing with issues surrounding a family member who has a
disability benefit greatly from resources that can be obtained with the help of others. Skill
at communicating and relating gives greater access to resources. There is every
likelihood that one of these resources is emotional support, in addition to other intangible
and tangible resources.

After issues surrounding relationships, the most often mentioned was conjecture
as to whether resilience manifests in the absence of trauma. Common consensus is that
adaptation is not needed, and hence not manifested, unless there are serious challenges
faced by the family. However, Patterson believes that even families experiencing
normative development will face experiences that call forth resilient responses (2002).
From the perspective of FCDs, stress is relative to the family's resources. A family
responding to demanding challenges, but with more resources, may be able to display
greater resilience than a family of a child who has milder disabilities in a context of few
protective factors.

Also touched upon were the developmental aspects of resilience. There are two
perspectives that are particularly salient to resilience viewed within this process. One is
related to outcomes. A family exposed to stress may cope, in the short term, but
experience problems related to the earlier trauma later in life. Additionally, developmental
transitions are times of increased risk as families face transitions. The transitions may be
normative but this may be the family's first time to face them. An example of this would
be when a couple has its first child. This is a typical activity in the family life cycle but it is
a new, untried experience for first-time parents.
Aaron Antonovsky’s Sense of Coherence (1987), reframing, and making meaning of events all “speak” to the inclination of families to seek explanations of why traumas occur. More often than not, the question is not “why” in terms of causation but the existential aspect of why. “Why” may be asked in terms of “Why my family? Is this a punishment resulting from something we did or did not do?” Or, the question may be asked to try to find purpose and meaning that may come from a painful experience. The family may be looking for a positive future wherein “good” comes from a traumatic experience in which the constructive results outweigh the pain. A family that was offered insufficient support may help change systems so that future families do not suffer similar deprivation.

2.19: Coping Behaviors, and Goal Oriented Behaviors Support Resilient Processes

Responses to injury may ameliorate the situation or make a bad situation worse. Families that have a child who has a disability have choices to make about what will help the family (and its members) regain former stability and quality of life. It becomes necessary for prioritizing a form of triage to take place to determine which situations to address first.

More theorists commented on topics mentioned above. Fewer theorists commented on issues such as the nature of resilience, inoculation effects, and responding to trauma from a Strengths Perspective. Questions about the nature of resilience have addressed questions of what “it” is and how it should be studied. Resilience is a process that occurs in response to trauma. During the process, the injured family seeks to regain “balance” after having been subjected to overwhelming stress. Resilience can be studied by the outcomes that families achieve and behaviors that they use to adapt to injury. This is best studied longitudinally as outcomes can change over time.
Several theorists have recognized the benefit that may accrue if a family has previous, effective experience regaining balance after injury. This has been termed “inoculation.” In effect, a family that has successfully responded to previous trauma may have “honed” resilience skills and be better able to deal with future stress (Greene, 2007).

Families come seeking help, or are observed to need assistance, after having sustained trauma or injury. The “helping response” occurs after a problem has been identified. However, the tendency is to continue to work from the “problem” orientation. Theorists have observed that resilient responses are better supported if a change in focus is achieved. More effective results are often achieved if the view is changed from the problem to the family’s strengths. The dissection of the problem is less effective than searching for family skills and strengths that can be used to adapt. A problem cannot be changed by focusing on deficit. The situation is more easily improved if it is viewed from the perspective of strengths the family possesses to improve the situation (Saleebey, 2008).

Resources are those supports that help FCDs take care of the needs of family members. These supports can be material, financial, and logistical, such as adaptive equipment or specialized child care. They can also be relational such as support groups or supportive interactions from school personnel, family, and friends. When families lack access to needed aid, family members suffer and the ability of members to carry out needed activities may be reduced. Children may be less able to obtain what they need from schooling all the children, not just the child that has a disability. Parents may be hindered in their ability to provide financially for the family (through their jobs) and to perform duties around the household to facilitate day to day family activities.
It is important that information on resilience be accumulated through evidence-based means. In order for findings to be useful to promote resilience, those findings need to be shown to be valid and reliable. Additionally, in order for results to have maximum generalizability, consensus should be sought on concepts and measurement methods.

A Roman philosopher and poet said, “What is food to one person may be bitter poison to other” (Rouse, 1975). Lucretius pointed to the observation that processes may act as risks or protective factors. One can see that what is constructive for one family may not be so for a different family. Additionally, these factors may not act similarly for the same family over the developmental path. It may be important, in many cases, to ascertain whether something ordinarily considered a support functions that way with a different family. For example, involvement of extended family is not always a good thing for the FCD.

When considering whether matters are supportive or risk-inducing, the temptation may exist to isolate issues. For example, what is the impact on resilience resulting from different family size, severity of a disabling condition, or job stress on the provider? But, as various family conditions interact, it is often necessary to consider conditions. At times, it is necessary to view conditions or interactions as a gestalt. Several factors acting together may have a different impact than any one of the factors acting in isolation.

Injury, stress, or trauma can occur to individuals, small groups (such as families), or larger groups (such as communities and societies). These could be described as being at micro-, meso-, or macro- levels. Therefore, resilience and adaptation can be observed at any of these levels. One question, then, becomes, “How does resilience occur at these different levels? And what can be discerned that will inform practitioners on ways to facilitate adaptation at different levels?”
A healthy self-esteem is one in which the family values itself, views itself as capable of meeting the challenges of life, and believes it is deserving of happiness (Campbell, Eisner, & Riggs, 2010). A constructive sense of esteem aids a family in adjusting to a life that includes a family member who has a disability. It may help them continue striving to regain former levels of function despite barriers they face. Self-esteem in the context of community and the environment can be particularly critical for FCDs. Others, outside the family, tend to focus on their deficits. Valuing “oneself” assists the family to maintain a focus on strengths.

A sense of being “different” from typical families may amplify feelings of isolation. This existential state may also be exacerbated by difficulties the family faces as they try navigating systems to obtain the help that family members need. An adequate level of self-esteem can mitigate the negative feelings associated with feeling alone.

Flexibility is also associated with effective resilience. Adaptation often involves changes in behavior and routines. The ability to more easily accept and initiate changes can facilitate resilient responses. Flexibility enables the family to integrate different options with less stress. For example, families may have to shift home responsibilities and change schedules to insure that each child gets his or her needs met. This would occur in typical families as family members go through developmental levels. When a child in the family has atypical needs, the need for the family to respond flexibly is greater.

A resilient response in one domain, one part of the family’s life, does not guarantee resiliency in other areas of the family. Adaptation may be asymmetrical across domains such as intrapersonal, health, interpersonal relationships, performance at work or school, and in other activities for which family members may be responsible. When looking at the domains in which a family functions, one would observe the family as an
entity. The family has nurturance, educational, support, and socialization responsibilities, among others. As an example, the family may exhibit resilience in the domain of nurturance but exhibit a lesser level of resilience in the area of support. The family may have the skills and will to care for itself but have inadequate income to provide for material needs.

An area that has received less attention is the family’s sense of self-efficacy. Closely tied to self-esteem, self-efficacy is the belief that one can perform adequately in intrapersonal and interpersonal areas of daily living. A family that doesn’t believe they can conduct positive relationships within the family “circle” may not try to adapt to adverse circumstances. Hence, they may not try to achieve former levels of function, displaying resilience. Likewise, in a hostile environment, the family will be more likely to try to access resources and supports from its surroundings if it feels capable of achieving some measure of success. The family’s sense that its actions can make a difference may be part of the motivational process that supports efforts to try.

A feeling of hope has been mentioned as an attitude that facilitates attempts to achieve an improved quality of life. Whereas hope fuels the family’s attempts to improve their situation, acceptance provides the starting point upon which to build. Before families can work to make their lives better, they must first understand where they are. Acceptance of barriers helps them decide what tools and skills to use to find solutions to their current situation. A family may have hope that the child, who has cognitive issues, may learn more than is predicted. Acceptance of the child’s cognitive state is a starting point to determine how the family can help the child make progress. The family should be supported to assess its situation and needs but encouraged to also access resources to build on strengths. Some families report that a spiritual frame of reference, much as a sense of hope, supports resilient responses. A spiritual outlook gives them another
dimension in which to consider what meanings their conditions may hold. Some families may seek affirmation from a viewpoint that they are especially well suited to help a child who has disabilities. They may focus, and build on, their strengths. Families may perceive their experiences as empowering. They may use what they have learned to reach out to other families that have a child who has a disability. Others, unfortunately, may view injury to a family member as punishment. They may feel in some way to blame. This paradigm is less helpful in strengthening families to improve their situations.

When the family is situated in an interpersonal environment that holds constructive values, the family finds more support to act constructively. They are less likely to succumb to continuing in an attitude of helplessness. When those around the FCD hold positive values about the importance of human life, nurturing progress, and supporting each other, the family has role models for ways to react. The family is more likely to receive emotional and logistical help as well. The environment may be as small as a circle of friends, or family, and as large as a community or society.

Observing resilient processes in groups is more complex than observing these processes in an individual. The number of intrapsychic processes and interpersonal interactions increases in a way that is more than additive. In areas of increasing complexity, such as families and groups, qualitative observation may provide a better understanding of processes. The combination of quantitative assessments, and qualitative assessments, allows measurements to be made of those processes that can be reductively measured and those that are more difficult to capture.

The organizational ability of the family has the potential to support positive movement in terms of resilience. The more members there are in the family, network, or group, the more important organization becomes to keep track of numerous abilities and needs. As the system has more individuals, the family's ability to respond in coherent
ways facilitates adjustment. In addition, the more effectively family members can communicate, the better they will be able to assess the needs of members of the family and go about meeting those needs.

Some have observed the utility of the family’s possession of a sense of hope. Although it is possible for denial to manifest itself as unrealistic hope, that is not always the case in families responding to injury, stress, or trauma. Especially in the case of families of children who have disabilities, in which the child’s medical or developmental prognosis is unclear, hope for improvement may be warranted. Also, the potential for the family to adapt and improve their adjustment/quality of life argues for the family to retain a sense of hope for a more constructive future. The maintenance of an attitude of hope may also provide psychological energy for the family to keep striving for positive outcomes.

Mention has been made in literature of the cumulative effects of stress. Although a family may have appeared to adjust to a number of mildly stressful events, that appearance may be deceiving. Similarly, an event the family appears to have “survived” with minimal adverse consequences could have unnoticed destructive effects. The family could decompensate at some time after the initial insult in a post-traumatic period. Both of these responses to trauma can mask the family’s need for support. For example, a family that loses an extended family member moves to another location, and a parent that goes back to work may find the totality of the positive and negative events stressful.

Continuing inquiry into and development of resilience theory is an important activity in human services fields. Different perspectives on resilient responses provide new questions. When these questions are reiterated in theory form, they can be investigated using research. Evidence gleaned from research allows practitioners to provide more effective supports to families who are dealing with overwhelming situations.
For example, the observation that families providing care for children face different interpersonal issues, as compared to families providing care for elders, could lead to various theories. Those theories, when developed through research, could lead to differential practice approaches.

An area infrequently mentioned is that of attitudes and responses to people who have disabilities. Devaluation of the child who has a disability or a presumption of low abilities has a destructive impact on the FCD. Some societies value their citizens only as they can produce more than they consume. In situations like this, the intangible contributions that people can make are overlooked. Additionally, sometimes a person who has a disability in one domain (physical, cognitive, or emotional) is assumed to have barriers in all domains. For example, a person who uses a wheelchair may face assumptions from those around him or her that they are cognitively less than typical. It is important that the strengths and self-efficacy of the person who has a disability be recognized in the community. Associated with that is the importance that people who have disabilities make some contribution to their community. This works to the benefit of the person who has the disability as well to the community. Related to the assumption of global incompetence of people who have disabilities is the assumption that people who have disabilities are incapable of advocating for their own needs. This attitude is particularly pernicious toward those who have cognitive and/or emotional disabilities. Fortunately, the field of social work has an ethic of including clients as members of intervention teams and treating clients as experts on their own conditions. However, it is important that professional caregivers not be lured into the paternalistic attitude that “I know what is best for you.” This attitude can also be manifested in the FCD, as they try to do for the child who has a disability what the child can do for himself or herself. True, the child may need some support, or additional time, to perform a task. But, it is in the child’s
best interest to be allowed to develop skills. The caregiver should not give into expediency and deprive the person who has a disability of growth opportunities. Allowing the child to learn new skills will enhance his or her ability to perform typical tasks of daily living in the future and reduce his or her atypical dependency. This attitude toward children who have disabilities also sets the stage for, and reinforces the expectation that, growth and skill improvement is anticipated.

There is a growing movement that acts on the fundamental assumption that people who have disabilities are capable of being full partners in advocating for what they want and need. This mindset has become increasingly prevalent in communities of people who have cognitive disabilities. Those who have disabilities are the best judges of their needs and skills and should be expected to have a significant "say" in their care. Their abilities to contribute to the community should be recognized and utilized.

A similar issue for those who need care, and caregivers, is the maintenance of boundaries. This was touched on above when it was noted that people who have disabilities should use their skills and have a voice in their lives. Also important is that caregivers not become so enmeshed with those who need assistance that they no longer have any activities that they do for themselves. It is tempting to be another’s “arms and legs” 24 hours a day, seven days a week. This drive to care can be even more pronounced when the person who has a disability is someone the caregiver has an emotional relationship with, such as a child. Unfortunately, minus the resources to hire professional caregivers, the task of providing these services continues to fall mostly to family members. Shortsighted public policies are often written with a frame of expectation that the FCD will provide this extreme level of care. Such uninformed provision of support may result in disability supports being needed, in the future, for the caregiver due to the strain of attempting such intense levels of care.
Understanding psychological processes in families is complicated by the number of members in the family. The more members there are, the more inter-relationships exist. This makes the understanding of family resilience more complex than individual resilience. However, even in individual resilience, relationships are significant supports or stressors. One way of observing family resilience is by collecting data from, and on, each member. This may be preferable to the collection of secondhand data involved in having one family member report on both oneself and other family members.

Seldom mentioned in resilience theory is the benefit of emotional communication, as well as logistical communication. In families, the awareness of each member’s emotional needs and skills is a very important part of the interpersonal networking that is beneficial in resilience of any size group. The ability of members to hear each other’s emotions without feeling threatened or criticized strengthens healthy self-esteem. Additionally, the feeling of being heard and understood relieves a sense of isolation (Hendrix, 2006; Yalom, 1980).

Some research has shown that females, those who have greater intellectual capability, and those who have an inner locus of control more easily adapt to stressful situations. It may be that the ability to think abstractly offers the opportunity to take different perspectives. Females may have a greater ability, in general, to use resilient processes if they have been socialized to nurture and heal. Those who have an inner locus of control may be less reactive to external stimuli. They may have a greater ability to hold on to their own inner perceptions of constructive plans of action.

Michael Rutter (1999, 2000), in his focus on biological responses to stress, has studied physiological adaptation. He has also noted the ways in which some become psychologically habituated in reaction to stress or injury. He additionally observed that the
potential exists for protective mechanisms to interrupt a downward cascade in vulnerable individuals.

Can resilience be conceptualized as a characteristic and as a goal, in addition to the previous conceptualization of it as a process? Joan Patterson (2002) has written of resilience in this expanded consideration. Another question she raises touches upon previous thought that resilience is only called upon in conditions of overwhelming stress, injury, or trauma. She posits that resilience can be observed in families that are relatively free from stress. This question is particularly enticing when considering the high risk encountered during transitional periods. In addition to that risk is the observation that small amounts of seemingly minimal stress can accumulate and overwhelm a family.

2.20: Summary of Literature Review Core Findings

Resilience can be viewed as a goal and a process. It manifests in the presence of injury, stress, or trauma and results in behavior aimed at reducing damage due to the stress. In addition to being thought of as a goal or a process, resilience can be thought of as a condition that a family can have to a greater or a lesser degree. Factors acting on the family can be divided into risk factors or protective factors. Risk factors are those that damage the family or inhibit its progress toward biopsychosocial health. Protective factors are conditions that facilitate resistance to the damage of risk factors or that promote recovery from decompensation. But, there is no clear delineation between what is a risk factor and what is a protective factor. What may be protective for one family may be neutral or a risk for a different family. Michael Rutter (1999) has determined that risk factors have a greater impact on the family than do protective factors. Three factors that have been observed to be protective are having a high I.Q., an inner locus of control, and being female.
Resilience can exist at the micro-level as an individual deals with stress, at the meso-level within a family or larger group, or at the macro-level within larger groups and societies. Risk and protective factors can exist within the individual at the intrapersonal level, the interpersonal level, and between the individual or group and the environment. Interactions of the family in the environment present many avenues for injury and recovery. Complexity in observing and facilitating resilient processes comes from several directions. One level of complexity derives from internal factors, interpersonal factors, and inter-relations between the individual or family and the environment. Another level of complexity in meso- and macro-entities comes from the number of individuals and the inter-relations between them. Yet another level of complexity comes from the diversity in families. No two families will find the same degree of risk, nor react the same way to similar conditions. Account must be taken of individual family reactions and strengths.

The quality of a resilient response may change over the developmental life of the family. Previous experience responding constructively to stress can confer a kind of inoculation against future decompensation. However, a family may appear to be recovering from trauma only to succumb to unobserved injury at a later time. Stress can accumulate and manifest from several smaller, stressful events. The family may even encounter a different stress later during the family life cycle that overwhelms its ability to recover, despite the fact that it recovered from an earlier injurious event. In observing complex systems, it is useful to view them from both the perspective of their components and from a gestalt perspective. Resilient responses are not even across domains. A family that may be able to successfully function internally may not be able to function in the community.
Effective social interactions both within the family and between the family and the community may be protective. Supportive interactions with others may provide emotional support or logistical support in terms of guidance and access to resources. Conditions and qualities that support constructive interpersonal relationships promote the ability to use this as a resource. Social competency, the ability to communicate, and positive values facilitate the family’s ability to deal with stressful conditions. Organizational skills help the family deal with the complexity of responding to the interactions of risk factors, protective factors, and coordinating these with adaptive behavior.

There are other capabilities and perspectives that assist the family in coping with chronic stress. Families may use a spiritual perspective and reframing to achieve a sense of coherence about their situations. Although it is necessary to identify the problem and needs, focusing on the deficit does not support adaptation. Instead, taking a solution-focused view with an attitude of hope for improvement provides a better stance to address family problems from a Strengths Perspective. Along with identifying a problem, creating proactive strategies to access supports while remaining flexible about taking action helps the family cope with stress and increase its level of quality of life. Self-esteem and a belief in one’s own capability helps maintain both motivation and a belief in the potential efficacy of the family’s efforts. As intimated in the paragraph on social supports, families need both emotional and logistical or material supports. Several writers on resilience have mentioned that supporting a family’s efforts to increase its level of resilience does not negate the family’s needs for material supports.

If these observations and findings on resilience are to be useful, researchers will need to continue to gain consensus on definitions, terminology, and measurement techniques. We should continue to gain clarity on how families recovering from stress, or learning to live with chronic stress, display characteristics, hold attitudes, and behave in a
way that fosters or hinders recovery. We should continue to gain clarity and consensus on how we describe and measure these observations. Researchers need to work toward a common numeric to quantitatively describe resilience in people of different ages.

Finally, as demonstrated by Werner and Smith, the developmental and lifespan fluctuations in resilience are best observed through longitudinal research (1992, 1993).

Resilience is a promising avenue to help families use their strengths in recovery from overwhelming stress, trauma, insult, or injury. Much has been done on individual resilience. In the face of observed impacts of positive relationships in promoting resilience, further inquiry into resilience in families is warranted. Particularly, in a social climate where external resources are difficult to access, one must help families build upon the resources they already have. And, they will likely need to seek out additional resources. The history of this philosophical and research field of resilience has led us from considerations of resistance to injury, and then on to adaptive and coping behaviors. Now the state of inquiry is looking into resilient processes. There is the promise of increased efficacy in alleviating oppression and coming closer to social justice.

This research project differed from many that were found in the literature review by its intent to compile the view of family resilience using data from each family member. Additionally, the subjects in this research were not restricted to one disability type such as “mental retardation” or autism. Comparison of the degree of need for accommodation was facilitated by a cross-disability measure of needed services using the Inventory for Client and Agency Planning (ICAP, n.d.), an instrument used by several governmental agencies to quantitatively determine an applicant's need for services. As no data was collected during the literature review of methodology in researching resilience, no comparison can be made as to whether the qualitative perspective used in this study is
typical. However, this researcher's overall sense was that more qualitative study has been done of resilience than quantitative.

David McConnell, Amber Savage, and Rhonda Breitkreuz found that extrinsic factors of social support and adequate financial resources impacted family function more than did intrinsic factors related to intrinsic, individual, and family characteristics (2014). The study focused on families whose children were experiencing behavioral problems. The findings of this study were more disturbing because the families lived in Canada, which historically has done a better job of providing medical care than has the United States. They also cited four research studies that supported the finding that a significant number of families are overwhelmed by attempts to access and navigate “fragmented, inflexible and/or poorly resourced service systems” (Browne, 2013; McConnell, Savage, & Breitkreuz, 2014, p. 834; McManus, 2011; Reichman Corman, & Noonan, 2008; Rodger & Mandich, 2005).

Consideration of the parameters of the disabling condition as a family stressor, as compared to other possible stresses, injuries, or traumas, led to a consideration of the differences between “living with a disability” compared to other destructive events. In research done on trauma experienced by children in adolescence, the types of trauma were distinguished by two parameters of 1) direct versus vicarious trauma, and 2) interpersonal as compared to non-interpersonal trauma (Price, Higa-McMillan, & Frueh, 2013). In a more recent study on associations between traumatic life experiences and physical condition, researchers categorized types of trauma as: 1) injurious, 2) psychological, 3) combat-related, 4) natural disaster/terrorism, 5) witnessing trauma, and 6) other. The “other” category included events experienced by the subject as traumatic but of a type that did not fit into any of the preceding categories (Husarewycz, El-Gabalawy, Logsetty, & Sareen, 2014). John Briere and Joseph Spinazzola, in their 2005
article, “Phenomenology and psychological assessment of complex posttraumatic states,” proposed severity, duration, frequency, and level of life threat as characteristics of traumatic events.

In considering how having a disability impacted the family, relative to other types of trauma, it became apparent that other parameters were significant beyond whether the stress, trauma, or injury is physically injurious, psychological, or because of a meso- or macro-event. Other characteristics that may be significant between disability and other types of injury include: Who is negatively impacted by the event? Are the results of the negative event essentially final, or are the destructive results ongoing? What is the potential for adaptation to former levels of function? What personal or group system was negatively impacted by the event? Are resources for adaptation available? And, what are the consequences of the destructive event?

1. The person or group impacted. In assessing who was impacted by the destructive event, one would want to know if the event impacts an individual, a family, or small group, or if the event impacted a country or was of global significance. When an individual becomes disabled, the primary impact is the individual, but there is a secondary impact on the family or close friends of the individual. When the individual who has the disability is a child, the secondary impact on the family is more powerful because relatively little independence has been acquired by the child.

2. The acute or chronic nature of the stress. Was the destructive event a discrete event in time, such as a robbery in which the negative impact has reverberations that are usually contained within a time frame? Recovery is achieved. When an individual has a disability, the need for medical treatment and/or the need for assistance with activities of daily living will be present for the rest of that person’s life. The stress could easily be seen as chronic.
3. Recovery. Is there potential for recovery? If there is potential for recovery, what degree of recovery is likely? If someone has property stolen, the time frame for replacement of property can be estimated, and considerations of emotional recovery may also allow for almost complete recovery. However, in the case of chronic disability, recovery may be partial but even that is not the usual outcome.

4. The systems affected. When assessing the impact of destructive events, one should also differentiate between the systems affected. Has there been disruption to logistical function such as might occur after a bad storm when a community might be without power, or a transportation deficit for a family that has a car that is in for repair? Is there physical injury after a sports accident or medical illness, or is it the psychic or emotional injury of the loss of a relationship?

5. Resources for recovery or adaptation. For a family that has a child who has a disability, are there people to do all that needs to be done and money to purchase equipment and medical treatments? Will the family have to sacrifice some things to buy others? Are there any resources at all in a family with single adult head of household in which the family was already living in poverty?

6. Consequences. Lastly, what are the consequences of the destructive event? Is there discomfort to the family? Is it a more significant deficit, or is it the death of an individual or the disintegration of a family or community?

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Of</th>
<th>Destructive</th>
<th>Events</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)Who is affected?</td>
<td>Individual</td>
<td>Family/small group</td>
<td>Community/global</td>
</tr>
<tr>
<td>2)Injury time frame</td>
<td>Acute</td>
<td>Chronic</td>
<td></td>
</tr>
<tr>
<td>3)Recovery potential</td>
<td>Complete recovery</td>
<td>Partial recovery</td>
<td>Living with injury</td>
</tr>
<tr>
<td>4)Affected system is:</td>
<td>Logistical</td>
<td>Physical</td>
<td>Psychic/emotional</td>
</tr>
<tr>
<td>5)Resources for adapt./recovery</td>
<td>Available</td>
<td>Partially available</td>
<td>No resources</td>
</tr>
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Table 2-1: Parameters of destructive events—Continued

<table>
<thead>
<tr>
<th>6) Consequences of failure to adapt</th>
<th>Discomfort</th>
<th>Deficit</th>
<th>Death/disintegration</th>
</tr>
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</table>

A limited search for recent work on family resilience, based on an assessment of each family member as compared to all family members as a unit, found the following articles. Curtis Cripe in a 2013 dissertation titled, “Family resilience, parental resilience and stress mediation in families with autistic children,” used quantitative instruments to measure stress in mothers and fathers. In a 2014 study on parental stress, Ashley Woodman used the Vineland Adaptive Behavior Scales and the Child Behavior Checklist to account for the impact of children’s behaviors on parents. The data were accessed from a pre-existing longitudinal study. The scales had been found valid and reliable. They were filled out by a parent. In a similar analysis of pre-existing data, Melissa Raspa, Donald Bailey, Jr, Carla Bann, and Ellen Bishop looked at family adaptation when they had a child who had Fragile-X Syndrome. Instruments measured parental factors (2014). None of the studies measured the factor of the educational system; however, every family in this study had problems with the school system. Research on the characteristics of trauma holds promise for gaining a better understanding of salient differences between adverse events and conditions. Emerging research on resilience in families revealed most assessment of resilience continues to be done on adults in the family, instead of an assessment of the adaptation of each family member.
Chapter 3
Methodology

3.1: Perspective/Design

3.1.1: Qualitative

The research perspective for this study was qualitative. A mixed perspective was considered. However, there were insufficient quantitative instruments to measure resilience in children. Of the few quantitative instruments that showed promise for measuring resilience in young children, the psychometrics for several of them had not been published in peer-reviewed journals.

From the beginning of the research planning process, part of the analysis and synthesis process was designed to be qualitative. These methods provide the flexibility to assess each member of the family, then blend those individual assessments to reveal the picture of the research topic as it affects the family as a unit. As Regina Ylvén, Eva Björck-Åkesson, and Mats Granlund pointed out in their 2006 literature review on family functioning that little research purported to be on the family actually assessed each member of the family. Instead, indirect information was obtained from one of the adults in the family (usually the mother) about others. That technique seemed fraught with potential to miss meaningful data about things a spouse or child may not want someone to know. The researchers in the 2006 study recommended assessing family resilience by measuring those qualities as displayed in each family member. This was suggested as being preferable to gathering secondhand information from parents or caregivers on other members. Family members who were too young to engage in a typical interview were engaged in a "play" activity, and the interview process flowed more naturally than that in which conversation was the only activity.
Qualitative analysis has enabled observations that have more easily taken into account the interactions between family members, and interactions between members and the environment. From what is known about resilience at this point, it is comprised of multiple and simultaneous intrapersonal and interpersonal processes. In addition, processes and behaviors that promote resilience change due to several factors such as the nature of different stressors, time in a historical sense, and the developmental level of individuals/families. These aspects also supported the choice of qualitative methods for this project.

Within the qualitative paradigm, there exist biographical, phenomenological, grounded theory, ethnographical, and case study methods for collecting and analyzing data (Creswell, 1998). A phenomenological lens was chosen as the best for the dynamic focus between individual family members and the family as the final unit of analysis (Stanghellini & Lysaker, 2007). A phenomenological methodology was the best choice for family resilience for two primary reasons.

3.1.2: Phenomenology

The phenomenological method, as described in Creswell’s book on five qualitative methods, was identified as a method to enable the researcher to understand, in-depth and in detail, the lived experience of some “phenomenon” for a research participant (1998). Sofie Davidsen defines phenomenology: “The word phenomenology is derived from the Greek phenomenon and logos. Phenomenon means appearance, which can have different forms where some are disguised or latent. Logos, or discourse, is the analytical thinking, which helps facilitate or grasp this appearing. As in qualitative analysis, coming to a possible understanding of an underlying meaning of another person’s description of phenomena depends on this analytical thinking, reflection and interpretation” (2013, p. 323).
The researcher had already suspected that her personal experience with the research topic was not typical. It was important that the results of the research reflect, as much as possible, the experiences of most families. Therefore, when the researcher discovered that phenomenological analysis provided procedures to account for the researcher’s previous experience with the phenomenon, it became apparent this method would be a preferred one for this project.

Also, perceptions of injury, trauma, and overwhelming stress are person and context specific. Often two people will respond to the same stressor in different ways. Phenomenological methods explicitly search for the meaning of phenomena for different people and groups (Wertz, 2011).

Phenomenology was considered the best of the five methods presented by Cresswell (1998) to study the phenomenon of resilience in families that had children who had disabilities. Biographical analysis was designed to analyze data about individuals so it does not have the scope to handle the “family as unit” view of this project. Grounded theory has shown facility for guiding observations on more than one individual, but many of the factors in the concept of resilience and theories related to resilience have already been elucidated.

As revealed in the literature review, the stresses on families that have a child are complex, varied, and chronic. The dynamics range from behavior problems, through the child’s need for supports for activities of daily living, and may be complicated by a lack of financial resources, social supports, and the ability to deal with fear, sadness, or grief. Even in situations requiring resilient responses in general, the responses required of families who have a member with a chronic condition are hallmarked as different. Families of children who have disabilities are in situations that display the potential to be exacerbated by the intensity of the present stresses, and the unpredictability of the
destabilizing situations that may emerge (McConnell, Savage, & Breitkreuz, 2014; Stanghellini & Lysaker, 2007; Wertz, 2011).

Although data collected from an ethnographic perspective would have handled the cultural aspect of groups living with a disability more comprehensively, this research had a more focused aim on a particular aspect of life within the culture of people who have disabilities—resilience in families of this “culture.” The case study approach was thought to be too specific to handle the diversity that exists within the “culture” of families of children who have disabilities. These families display tremendous diversity, not only in the great differences between disabilities but also in the family structure and access to resources (Cresswell, 2006).

3.1.2.1: Foundations of phenomenology

The phenomenological data analysis method first encountered during the search for a qualitative research method was that of Clark Moustakas (1994). His recommendations would probably have been used without the search for other methods, based on the “sanction” of having been presented in John Cresswell’s book (1998). However, some other issues came up that spurred the search for more information on phenomenology as a data analysis method.

Some of the terms that Moustakas used were vague and difficult to comprehend, even when encountered in the procedural context. The concept of “textural” seemed vague and disconnected, so other literature was reviewed in attempts to gain a better understanding. “Horizonalization,” with its geographical connotations, was another term that was difficult to grasp.

Clarification was needed if phenomenological methods were to be used for research in individual and family resilience. No phenomenological research on resilience had come up in the literature review at that point, so further inquiry was warranted.
Additional literature review was also needed to address questions about which topics of research investigation were appropriate for the use of phenomenological methodologies. Continuing literature review encompassed finding research done using phenomenological methods, and whether phenomenological analysis was a technique used more often in research in linguistics and language (Natanson, 1973; Perconti, 1999).

In the search to learn what subjects and disciplines had been researched using phenomenological methods, it became apparent that the use of phenomenology as a philosophical method preceded its use as a qualitative data analysis method in research. Uncovering the foundations of phenomenology was further complicated by the lack of specificity of terminology in the fields of philosophy, social science disciplines, and the psychology. The phenomenological method for human science research is considered by many to have its foundations in the work of philosopher Edmund Husserl (Giorgi, 2010). Yet, the use of phenomenology as a philosophical approach goes back to the work of Immanuel Kant (Hicks, 2004). The movement from phenomenology as a purely philosophical discipline to its use in human sciences and psychological research has been complicated by the seeming lack of specificity in terminology. The terms "phenomenology" and "phenomenological" are used in many academic disciplines, from philosophy to nursing, sociology, education, and psychology (Creswell, 1998).

Phenomenology had also been used in the fields of anthropology, economics, history, legal theory, linguistics, and political science (Natanson, 1973). There was no clear line of "demarcation" between using phenomenology for purely philosophical work, research, and to practice (Giorgi, 2011; Moustakas, 1996; Moustakas, 1997). During correspondence with Marc Applebaum of Saybrook University in San Francisco, he shared his observation that phenomenology was used in many fields (personal communication, February 27, 2014).
As introduced in the preceding paragraph, the search to find a possible confluence of phenomenology and linguistics, led me to the philosophical work of Immanuel Kant. He was developing a means to address the issue of perception as a mediator between “noumena” objects that exist outside of abstract processes and phenomena that would include abstract processes such as thought and emotion. Kant proposed that even “concrete” objects could not be adequately understood as they were perceived through senses (Hicks, 2004). This explanation of Kant’s development of phenomena versus noumena may be faulty as it has unexpectedly emerged in this research project as a necessary issue to understanding how phenomenology came to run alongside structural linguistics. Kantian philosophy, as it has come forward into the nineteenth century, evolved into the Structural Linguistic thread in which philosophers sought to connect external reality with the way it was experienced through the senses, and necessarily the way those perceptions were communicated. The Phenomenological Thread appears to be differentiated from the Structural Linguistic Thread by the phenomenological search to understand and describe, as objectively as possible, the topics of consciousness and experience that have no external, physical referent (Giorgi, 2010; Davidsen, 2013). It appears, from this cursory search for the foundations of phenomenology in linguistics, that Kantian Phenomenology is not the foundation of Giorgi’s use of the method and Smith’s use of the method as an interpretive tool (Smith, Flowers, & Larkin, 2009). However, the search for the foundations of phenomenology was drawing the researcher away from the primary objective of applying phenomenology to resilience so further citations could not be sought.

Annette Davidsen had some succinct comments about the use of phenomenology as a research method in psychology and the health sciences (2013). One issue she clarified was the dynamic nature of phenomenological philosophy as a
movement. That explained how parallel currents of phenomenological philosophy exist. In her article, she specifically pointed to the work of Paul Ricoueur and delineated his movement.

It appeared, from the one page that Davidsen devoted to the phenomenological journey of Paul Ricoeur, that linguistic phenomenology came to be a different thread than that developed by Franz Bretano and Edmund Husserl. "Ricoeur was particularly concerned with interpretation, primarily with interpreting text. He stated that human action should be understood as text and that such an approach would enable better understanding and interpretation" (Davidsen, 2013, p. 325). One of Husserl’s aims was to “study consciousness and how phenomenon in the world are constituted by human consciousness” (Davidsen, 2013, p. 320). Davidsen also did an exemplary synthesis of the work of Herbert Spiegelberg, S. Kay Toombs, Maurice Natanson, Alfred Schutz, and Amedeo Giorgi and Barbro Giorgi on the aims of phenomenology to create an analysis system that integrated philosophy, science, and the internal and external worlds that are experienced indirectly through the senses and constructed by the processes of cognition and thought. Davidsen’s article explained how researchers in psychology, healthcare, and other disciplines attempt to observe experiences and meaning (that are subjective) in a manner that is scientific.

Going back, and looking at the use of phenomenology in psychology in the United States, it became apparent that the psychological phenomenological analysis that came out of Duquesne University in Pittsburgh, Pennsylvania, did not trace its beginning to the phenomenology of Kant but to the work of Edmund Husserl and Husserl’s mentor, Franz Brentano.

Closer examination of the phenomenological analysis of Moustakas revealed he had used the phenomenological methods of Adrian van Kaam and had also synthesized
the methods of Emily Stevick, Paul Colaizzi, and Ernesst Keen (Moustakas, 1994). The Stevick-Colaizzi-Keen method had ties to the method developed by Giorgi at Duquesne, and van Kaam and Giorgi worked together at Duquesne (Colaizzi, 1973; Giorgi, 2010; Keen, 1975; Stevick, 1971; van Kaam, 1959).

3.1.2.2: Giorgi: Usage of phenomenological data analysis method

After the closer look at the methods proposed by Moustakas, a determination was made to use the analysis method developed by Giorgi (2009). The methods Moustakas used were based on researchers who had much contact with Amedeo Giorgi. Moustakas had written less on the theoretical underpinnings than had Giorgi. It is possible that Moustakas was more interested in phenomenology informing practice than in informing methodology, but the pursuit of that idea was beyond the scope of this project. Another deciding factor was that Moustakas was no longer writing on phenomenology. He died in 2012 and his last publication addressing phenomenology was released in 2000 (Blau, Bach, Scott, & Rubin, 2013; University of West Georgia, n.d.). A search of Moustakas’ publications indicates his last publication related to phenomenology was in “The Handbook of Humanistic Psychology: Leading Edges in Theory, Tresearch, and Practice” published in 2000 and edited by K. J. Schneider, J. F. T. Bugental, and J. F. Pierson.

Concepts pertinent to phenomenological inquiry are lived experience related to a phenomenon, and the meaning constructed by the individual integrating the encounter with that phenomenon within the context of his or her life. Edmund Husserl was the original proponent of phenomenological philosophy from which the research method is drawn. In phenomenological philosophy, objects are more than an external objective physical reality. The object also is a creation of how it is perceived and the meaning that is assigned to it (Giorgi, 2010).
Before going on to the steps of analysis, most recently updated by Giorgi in 2012, several characteristics of his Descriptive Phenomenological Method in Psychology will be specified (Giorgi, 2009; Giorgi, 2012). He wrote about the goal of understanding the meaning of a phenomenon for the research participant, bracketing or assuming an attitude of phenomenological reduction, and identifying meaning units from what the participant shares with the researcher. When one identifies meaning units, this is done from an attitude related to one’s discipline, and then, using free imaginative variation, transforms the units into sensitive expressions. After transformation, the researcher searches for the essential structure of the experience of the participant. More detail on these characteristics is in the following paragraphs.

*The goal of phenomenology.* The goal of the phenomenological analytic method is to gain an understanding of the underlying meaning of a lived event (phenomenon) for someone who has experience with the phenomenon being studied (Davidsen, 2013, p. 323). In the effort to understand the lived reality of an experience for another person, the researcher is sensitive to the parameters of the phenomenon, and sets aside their personal experiences, judgments, and preconceptions in order to understand the event from the point of view of the participant (Giorgi, 2009).

*Bracketing.* The researcher sets aside their previous experiences of the phenomenon in an ongoing process that is called “bracketing.” Another term used for this is “assuming an attitude of phenomenological reduction” and it calls for the researcher to be aware of, but set to the side, his or her past knowledge of the phenomenon (Giorgi, 2009, p. 118). This “setting aside” of the researcher’s previous experience with the phenomenon is not an assurance that researcher pre-judgment will not cloud accurate perception of the participant’s experiences; however, it is a necessary first step toward
that goal (Giorgi & Giorgi, 2003, as cited in Davidsen, 2013; Natanson, 1974; Spiegelberg, 1978; Toombs, 1992; Schutz, 1967).

In this process, the researcher maintains an awareness of his or her experience with the phenomenon. A conscious effort is made to hold the researcher’s experience as distinct and separate from the experience of the participant. This is to allow collection of data from the participant, and analysis of the lived experience of the participant with minimal distortion, which could occur if the researcher projected their lived experience on to the participant.

Meaning units/significant statements. The identification of meaning units within what the participant has shared is common to much qualitative analysis. However, in phenomenological data analysis, the researcher is looking for parts of what the participant has shared that touch upon the phenomenon being studied, that touches upon the perspective of the researcher. The researcher keeps in mind that the ultimate goal is the meaning of the phenomenon for the participant in a dynamic way, a way that encompasses the phenomenon as an experience. The meaning units, or significant statements, are kept as close to the original words of the participant as possible.

Phenomenological scientific reduction. One of the attitudes that needs to be held during the identification of significant statements is the focus on the participant’s experience—holding in abeyance the experience the researcher may have had with the phenomena. Another attitude is a disciplinary one, related to the perspective of the researcher. This appears to be what Giorgi meant when he wrote, “Since the analysis is also meant to be psychological, then meaning units sensitive to that perspective are also required” (2009, p. 129). He also wrote, “Again, the attitude that has to be assumed is that one is in the phenomenological scientific reduction, within an overall psychologically
sensitive perspective, and finally, one is mindful of the specific phenomenon being investigated…"

*Imaginative variation.* Having identified statements that are significant within the frame of the phenomenon and within the disciplinary perspective of the researcher, one starts to transform the statements into sensitive expressions of the lived experience of the participant with the phenomenon. This has to be accomplished using free imaginative variation as a tool. When using imaginative variation, the researcher “mentally removes an aspect of the phenomenon that is to be clarified in order to see whether the removal transforms what is presented in an essential way” (Giorgi, 2009, p. 69).

*Sensitive expressions.* What one hopes to accomplish in this process is the revelation of the intentions in what was said. For example, a participant may say, “It’s different, living in a small town.” Does that mean one of the following? “Nobody cares about us, nobody offers to help, there is no sense of community,” or, “I’m so relieved that people aren’t looking over my shoulder every minute, offering constructive criticism or judgments.” The sensitive expression of the statement may not be overt within the conversation. However, a view of the communication as a whole will usually reveal "a strong background presence” of the implied expression (Giorgi, 2009, p. 134.).

*Essential structure.* After the transcribed conversation has been mined for significant statements (meaningful units) and those statements have been transformed into sensitive expressions that reveal the participant’s experience in greater depth and meaning, the search begins for the essential structure (or structures). The structure clarifies the relationships between constituents in a holistic way. Giorgi referred to Gurwitsch in defining constituents in relation to elements (1964). On page 102, Giorgi writes, “…an element is a part that is independent of the whole in which it resides, whereas a constituent is a part that is mindful of its role in the whole. This means that if
one makes a triangle consisting of three black dots, calling the top dot a ‘black dot’ would be considering it as an element, but calling it the ‘apex of the triangle’ would be considering it a constituent because its position in the whole is taken into account” (p. 102). Free imaginative variation allows the researcher to mentally manipulate parts of the structure to determine whether the parts are “expendable” or integral to the structure. Other terms for essential structure are “invariant meanings” and “eidetic reduction.” Giorgi identifies “eidetic reduction” as “…a process whereby a particular object is reduced to its essence” (2009, p. 90). The goal, in relation to the structure, was to find one that unified the statements and expression of all, or most, of the participants. However, it is possible that an essential structure can only be determined for one individual. It is acceptable that a study of a phenomenon as experienced by three participants could reveal three different structures (Giorgi, 2009).

One critique of Giorgi’s method is that it does not allow for interpretation of findings. Interpretive Phenomenological Analysis, developed by European researchers and widely used in human, social, and health sciences, has explicated the interpretation of phenomenological findings. However, Giorgi makes the point that much of phenomenology is descriptive but interpretation is not out of place (Applebaum, 2012, p. 63).

3.1.2.3: Variations of the phenomenological data analysis method

Clark Moustakas (1994) proposes two adaptations of phenomenological research methods. One is the method proposed by Adrian van Kaam (1959). The other is a synthesis of the work of Emily Stevick (1971), Paul Colaizzi (1973), and Ernest Keen (1971). Moustakas identified the steps in van Kaam’s analysis method as:

Using the complete transcription of each research participant: 1. Listing and Preliminary Grouping: List every expression relevant to the experience. (Horizontalization) 2. Reduction and Elimination: To determine the Invariant Constituents: Test each expression for two
requirements: a. Does it contain a moment of the experience that is a necessary and sufficient constituent for understanding it? b. Is it possible to abstract and label it? If so, it is a horizon of the experience. Expressions not meeting the above requirements are eliminated. Overlapping, repetitive, and vague expressions are also eliminated or presented in more exact descriptive terms. The horizons that remain are the invariant constituents of the experience. 3. Clustering and Thematizing the Invariant Constituents: Cluster the invariant constituents of the experience that are related into a thematic label. The clustered and labeled constituents are the core themes of the experience. 4. Final Identification of the Invariant Constituents and Themes by Application: Validation. Check the invariant constituents and their accompanying theme against the complete record of the research participant. (1) Are they expressed explicitly in the complete transcription? (2) Are they compatible if not explicitly expressed? (3) If they are not explicit or compatible, they are not relevant to the co-researcher’s experience and should be deleted. 5. Using the relevant, validated invariant constituents and themes, construct for each co-researcher an Individual Textural Description of the experience. Include verbatim examples from the transcribed interview. 6. Construct for each co-researcher an Individual Structural Description of the experience based on the Individual Textural Description and Imaginative Variation. 7. Construct for each research participant a Textural-Structural Description of the meanings and essences of the experience, incorporating the invariant constituents and themes. From the Individual Textural-Structural Descriptions, develop a Composite Description of the meanings and essences of the experience, representing the group as a whole” (Moustakas, 1994, pp. 120-121).

In another suggested method, Moustakas combined the methods used by Emily Stevick, Paul Colaizzi, and Ernest Keen. The actual publications of Stevick and Colaizzi were reviewed. The Keen work that Moustakas used was an unpublished manuscript dated 1971 and done at Bucknell University. It was not possible to get a copy of the unpublished work but another work of Keen produced in the same year was reviewed (1971). The steps of what Moustakas called the Stevick-Colaizzi-Keen Method are:

1. Using a phenomenological approach, obtain a full description of your own experience of the phenomenon. 2. From the verbatim transcript of your experience complete the following steps: a. Consider each statement with respect to significance for description of the experience. b. Record all relevant statements. c. List each nonrepetitive, nonoverlapping statements. These are the invariant horizons or meaning units of the experience. d. Relate and cluster the invariant meaning units into themes. e. Synthesize the invariant meaning units and themes into a description of the textures of the experience. Include verbatim examples.
f. Reflect on your own textural description. Through imaginative variation, construct a description of the structures of your experience. g. Construct a textural-structural description of the meanings and essences of your experience. 3. From the verbatim transcript of the experience of each of the other co-researchers, complete the above steps, a through g. 4. From the individual textural-structural descriptions of all co-researchers’ experiences, construct a composite textural-structural description of the meanings and essences of the experience, integrating all individual textural-structural descriptions into a universal description of the experience representing the whole group” (Moustakas, 1994, p. 122).

The difference between the Stevick-Colaizzi-Keen Method and the van Kaam Method were the degrees of self-disclosure of the researcher. In the Stevick-Colaizzi-Keen Method, the researcher writes about his or her lived experience with the issue under phenomenological psychological analysis. Adrian van Kaam’s method does not include researcher reflexivity. Deeper exploration of the development of the two analysis methodologies revealed all four researchers had ties to Amedeo Giorgi. Adrian van Kaam was at Duquesne University eight years before Giorgi arrived and suggested Giorgi take a closer look at phenomenological applications in psychology. Emily Stevick and Paul Colaizzi were students at Duquesne, where the Phenomenological Psychological Method was developed. Ernest Keen cited Giorgi in his work.

The first step in data analysis, according to Moustakas’ adaptation of the Stevick-Colaizzi-Keen Method, is for the researcher to describe her experience of resilience (Creswell, 1998, p. 147).

As more literature on phenomenological analysis was reviewed, the researcher became aware that, besides Moustakas’ adaptations and Giorgi’s Descriptive Phenomenological Method, another set of analysis procedures had been proposed by Jonathan Smith and developed with the assistance of Paul Flowers and Michael Larkin (2009). This method, the Interpretive Phenomenological Method, was identified as more explicitly interpretive. The steps of this method are: 1. Read and re-read the data. 2. Make descriptive, linguistic, and conceptual comments. The authors noted deconstruction
of the written data (for example, reading a paragraph backwards) may help the researcher gain different perspectives. 3. Develop emergent themes. 4. Search for connections across emergent themes. 5. Move on to the next case requiring analysis for the phenomenon under consideration.

3.2: Research Purpose: Exploration

3.2.1: Purpose

The exploratory purposes of this study are to understand the essence of how families that include a member who has a developmental disability experience resilience. A definition of developmental disability obtained from the Prader-Willi Syndrome Association, as defined in the Developmental Disabilities Assistance and Bill of Rights Act (42 US C.§ 6000), is a "severe, chronic disability of an individual 5 years of age or older that is attributable to mental or physical impairment or a combination of mental and physical impairments, is manifested before the individual attains age 22, is likely to continue indefinitely, and results in substantial functional limitations in three or more areas of life activity classified as self-care, receptive or expressed language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided" (Prader-Willi Syndrome Association, n.d.).
3.2.2: Research Question

Joseph Maxwell goes into great detail about qualitative research questions. The most pertinent parameters for the research question for this exploratory study involved explication of what the researcher was attempting to learn, what the focus of inquiry was, and what conceptual context was involved in the area of inquiry (Maxwell, 1996). Additionally, the research question in qualitative studies is often influenced by the method chosen. In this case, the descriptive, phenomenological analysis method directs the researcher attending to the participant to drive the question. The researcher chooses the phenomenon of which understanding is sought. The participant guides the researcher to an understanding of the meaning of that phenomenon for the participant (Englander, 2012). The exploratory purposes of this study are to understand the essence of how families that include a member who has a developmental disability experience resilience. For the purposes of this study, the research question is, “What is the lived experience of the phenomenon of resilience for families with children who have disabilities?” According to Amedeo Giorgi, in psychological phenomenological analysis the research question should address the researcher’s search for the meaning of a phenomena and/or the desire to gain a sense of the particulars of the experience (2009). The focus was resilience; the context was resilience in families facing a particular kind of stress.

3.3: Participants

3.3.1: Criterion and Sampling

The research question drove the criterion for sampling. As the goal was to explore resilience in families of children who have disabilities, the criterion for participation was that research subjects be family members of children who had disabilities. The age criterion for “child” was that the child who had a disability be below the age of 22 years old, the age at which a child is no longer eligible for educational
services. That is a stage at which resources, supports, and goals change. The experience changes from that of being in a family of a student who has a disability to that of being in a family of a young adult who has a disability and is no longer receiving services from a secondary school system. This study was designed with the intent of obtaining information on meanings from each family member, and those who expressed an interest in participating were told that the researcher would want to talk with, or observe, each family member. The criteria for disability was that the child have a diagnosis by a physician of a disabling condition. The goal was set to interview members of five or six families with the realization that this could result in anywhere between 10 to 30 individuals enrolled. There was no restriction on the composition or number of people in the family. It was assumed, during the planning process, that these parameters could result in participant families ranging from a child with an adult caregiver to families with extended kinship or friendship circles. The sample size of five to six families was kept at that number to allow study of the issue in depth and detail (Creswell, 1998; Tuckett, 2004).

Sampling was purposeful to contact families that met the criteria. This was accomplished by having two parent support groups disseminate the contact message. One group was based in the southeast area of the state, and the other support group was state-wide. Since “peer support” is a factor supporting resilience in individuals, an attempt was made to contact parents through four local school systems. One school system did not respond to the researcher's requests for an appointment to discuss possible collaboration; a second school system declined to participate based on its belief that the families’ confidentiality and safety was not sufficiently protected. The second school system refused to review the IRB guidelines that the research project had already met. A third school system initially agreed to assist in contacting families but did not submit the
required letter to the IRB stating they would be willing to help the researcher contact families. A fourth school system did cooperate and sent out letters of invitation to 294 families. Two families contacted the researcher to obtain more information but declined to participate in the study. Five families in the sample came from contacts with the local support group, and one family learned of the study through the state-wide support group. Since the family was the unit of analysis, the sample size was determined by the number of families.

3.3.2: Sample Demographics

Seven families initially agreed to participate in the research. One family, composed of a mother and her pre-teen son, began the interview process then withdrew before the son could be interviewed. The mother said she had become too busy to schedule a time for the researcher to interview the son with either her or the child’s respite caregiver present. Of the six families in the final sample, the total number of individuals interviewed equaled 20. Three of the families were headed by two parents. Two of the single parent families were headed by grandmothers, and the other single parent family was headed by a mother. Nine adults, four siblings, one cousin, and six children who had disabilities were interviewed or observed. One young adult sibling declined to be interviewed. The sibling would not communicate with the researcher at all but family members offered their opinions on reasons she may not have wanted to participate.

Information on the specific ages of the siblings was not collected as their cognitive level and ability to converse was more pertinent to the study than was their physical age. However, of the five “siblings,” two were over 22 years old, one was in his/her late teens, one was a pre-teen, and one was under ten years old. Three of the “siblings” were female, two were male. Of the six children who had disabilities in the
sample, one was under ten years old, two were between 10 and 20 years old, and three were over 20 years old. The age range was nine years old to 22 years old. The median age was 20 years old, and the average age was 17 years old. Three of the children in the study had Autism Spectrum Disorders. One child had an intellectual disability, one child had an intellectual disability with significant cerebral palsy, and one child had Rubenstein-Tabi Syndrome. The child who had Rubenstein-Tabi Syndrome had severe learning disabilities and moderate coordination problems compounded by a severe visual deficit.

Four of the children had disabilities significant enough that it was apparent upon initial meeting that they each had a medical condition. All children who had disabilities, by preset research criteria, were still of an age eligible for public school services. They were under 22 years old as of September 2012. Four of the children who had disabilities were male, two were female. Children met the criteria of having a disability if their disability had been diagnosed by a physician.

Table 3-1: Demographics on research participants

<table>
<thead>
<tr>
<th>Sample Participant</th>
<th>Age</th>
<th>Primary Disability: (other issues/mild, moderate, or severe)</th>
<th>*Care Need</th>
<th>CWD lives at home=H</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAMILY 1</td>
<td></td>
<td></td>
<td>1=↑ need</td>
<td></td>
</tr>
<tr>
<td>Grandmother</td>
<td>na</td>
<td>na: data not collected</td>
<td>Average=4</td>
<td></td>
</tr>
<tr>
<td>Child with Disability (CWD)/male</td>
<td>18 y.o.</td>
<td>Mental Retardation (cerebral palsy)</td>
<td>5</td>
<td>H</td>
</tr>
<tr>
<td>--------------------</td>
<td>-------</td>
<td>-------------------------------------------------------------</td>
<td>------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>FAMILY 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>na</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>na</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. Sib. (adult sibling)/female</td>
<td>25 y.o.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. Sib./male</td>
<td>24 y.o.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CWD/male</td>
<td>22 y.o.</td>
<td>Mental retardation (cerebral palsy)</td>
<td>1</td>
<td>H</td>
</tr>
<tr>
<td>--------------------</td>
<td>-------</td>
<td>-------------------------------------------------------------</td>
<td>------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>FAMILY 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>na</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3-1—Continued

<table>
<thead>
<tr>
<th>FAMILY</th>
<th>Member Type</th>
<th>Age</th>
<th>Condition/Description</th>
<th>Need Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>CWD/male</td>
<td>21 y.o.</td>
<td>Mental Illness (Autism, Tourette’s)</td>
<td>7 H</td>
</tr>
<tr>
<td></td>
<td>Grandmother</td>
<td>na</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>na</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>CWD/female</td>
<td>21 y.o.</td>
<td>Rubenstein-Tabi Syndr., vision/severe, IQ: 30, mobility/mild</td>
<td>3 H</td>
</tr>
<tr>
<td></td>
<td>Cousin/female</td>
<td>~23 yo</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A.Sib./female</td>
<td>~19 yo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Mother</td>
<td>na</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>na</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>CWD/female</td>
<td>8 y.o.</td>
<td>Autism</td>
<td>4 H</td>
</tr>
<tr>
<td>5</td>
<td>Sibling/female</td>
<td>6 y.o.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Mother</td>
<td>na</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>na</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CWD/male</td>
<td>10 y.o.</td>
<td>Autism</td>
<td>3 H</td>
</tr>
<tr>
<td></td>
<td>Sibling/male</td>
<td>~14 yo</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Care Need: ICAP Service Level (n.d.)
Numbers Assigned to Care Need Levels

(1= high need [↑], 9=low need [↓])

1: Total personal care and intense supervision
2: between total-extensive / intense-constant
3: extensive personal care and/or constant supervision
4: between extensive-regular / constant-close
5: regular personal care and/or close supervision
6: regular-limited / close-regular
7: limited personal care and/or regular supervision
8: limited-infrequent / regular-infrequent
9: infrequent or no assistance for daily living
3:4: Interview Guide and Procedures

3.4.1: The Interview Guide

In qualitative data collection, especially that which uses interviews, the researcher is considered to be the “collection tool” (Chenail, 2011; Patton, 2002). Conversation prompts were used to encourage participants to share, first, resources, behaviors, and responses that supported family adaptation. The research question was broached before the researcher and participants met as potential participants contacted the researcher to find out what participation would involve. As the term “resilience” is not one in popular usage, the researcher explained to potential participants that the project involved getting family member input on how they successfully “adapt” to having a family member who has a disability.

All research interview were done by the researcher. The Research Conversation Guide for Adults began with information on the research project for those who had not spoken with the researcher before. The research information was presented with a statement similar to this: “This project is intended to get information from family members on what helps your family adapt to having a child who has a disability. We will be covering both the things that work and the barriers you face. I would like to focus, first, on strengths, the things that work for your family, because a better understanding of strengths is more useful in building more strengths. We will cover things that are barriers to your family before we finish. What resources, groups, or things do you do that help your family adapt to having a child who has a disability and helps you take care of everyone in the family? What things are barriers to your taking care of your family? What else do you want me to know that I haven’t asked you about? If you think of anything else you want to share with me, you can call me, write to me, or we can schedule another visit. Thank you for your help.”
Questions for children were framed differently. “What happens in your family that helps your family work, and for everyone to take care of each other? What kind of problems do you or your family have, and what helps your family fix those problems? What would you tell other kids to help them live in a family that has a child who has a disability? What do you want me to know that we haven’t talked about yet? If you think of anything else you want me to know, your mom or dad can call me and we can talk on the phone or I can come visit again. Thank you for your help.

3.4.2: Context

Interviews were conducted from November 2012 through November of 2013, and member check interviews were conducted from July of 2013 through March of 2014. In the member check interview, the researcher assesses the validity of the analysis by getting feedback from the research subject whether the analysis was accurate (Koelsch, 2013). As five of the six families interviewed had not previously met the researcher, every effort was made to have the interviews take place in a location where participants felt safe. Participants were offered the option of meeting in a public place, at their home, or any other setting that would work for them. One participant interview was conducted at the participant’s office and interviews with other family member were conducted at the participant’s home. Another participant from another family requested to meet at a restaurant close to his or her job for convenience. All other participants chose to be interviewed at their homes. Part of the reasoning of families for their decision about interview setting may have been that they would have a place with relative privacy to talk freely, and care of children who had disabilities would be easier at home than in a public setting.
3.4.3: Procedures

The researcher chose phenomenology for data collection and analysis because the method has explicit procedures to account for possible researcher bias, guide the researcher to be aware of their personal biases, and guide the researcher to refrain from projecting her own experiences onto the participant. In this way, the likelihood is increased that the researcher will receive the meaningful experiences of the participant.

The local family support group disseminated information about the research project in its e-mail newsletter. The invitation to participate contained information about how the researcher could be contacted. In this way, potential participant families had information on how to become involved with the study, but the researcher had no information on families unless they chose to contact the researcher. The same IRB-approved invitation was posted at the annual conference, and the researcher gave several to conference attendees that expressed an interest in the project. Prospective participants were given information they requested. Information was usually requested during telephone contact. If the family wanted to proceed with the interviews, a time was scheduled for the researcher to meet with the members.

One of the processes used to establish rapport was for the interviewer to model openness and honesty about her experiences as the mother of a child who had a disability. Participants were given as much detail as they asked for so they could trust that what they had to share would be honestly reported. When the participant asked why the research was being done, as the researcher had her own personal experiences of the phenomenon, the bracketing process could be explained. One of the foundational recognitions of the process is that no one person’s lived experience is “the truth” and the participant’s lived experience has equal validity alongside the experiences of others.
Research prompts were designed to encourage participants to tell their lived experiences of successfully adapting to being part of a family that had a member who was a child under the age of 22 years old and had a disability. During the interview, the researcher redirected the participant, as necessary, back to the topic of the lived experience of successful adaptation. If the participant wanted to focus on barriers, they were redirected to focus on protective factors first and reassured that their comments on risk factors and barriers would be needed later during the interview.

All interviews were audio recorded with the permission of the participants. The reason for the audio recording was explained to the participants before recording began. The reasons explained to the participants were that audio recording would insure that no important information was missed, and the recording would also allow the researcher to give the participant the researcher’s complete attention. All participants allowed the researcher to record the conversations.

3.4.3.1: Pilot interviews

A conversation guide was used to conduct two pilot interviews with a couple who was interested in the research purposes and had a son with a developmental disability who was 23 years old. Since their son was outside the age parameters for this research project, the parents asked if they could facilitate the research by helping with piloting the conversational prompts. The pilot interviews or “conversations” went smoothly, with the unanticipated response that one of the parents became somewhat sad during the interview. Both persons had signed, and been given copies, of the informed consents. They had telephone numbers for counselor and support group contacts should they have felt continued distress. During subsequent contact, they evidenced no continuing emotional distress, said that they did not feel unduly sad, and expressed an interest in helping with future research.
3.4.3.2: The research interview

The interview can be viewed as a tool in the same way an archeologist uses shovels, screens, and brushes to uncover what is hidden (Patton, 2002). Both Giorgi, and Smith, Flowers, and Larkin propose that interviews are the most effective processes to obtain data on the meaning of lived experiences for research participants (Giorgi, 2009; Smith, Flowers, and Larkin, 2009; Patton, 2002). Although interview prompts were used, the Interpretive Phenomenological interview suggestions made the prompts secondary to the recommended procedure of conducting the interview as “a conversation with a purpose.” This allowed an interaction that facilitated the participants sharing their experiences in their own words with the aim of obtaining concrete, detailed, and rich descriptions of family members’ lived experiences in a family that includes a child who has a disability. The questions in the research prompts were responsive to the process of establishing rapport and to the cognitive level of the participant (Giorgi, 2009).

Ongoing analysis, beginning with the first interview, made little difference in the interview prompts but did change the procedures in communicating with younger children or participants whose cognitive function was significantly less than their physical age. It was quickly learned that young participants could not communicate during a traditional “adult” two-way conversation but felt much more comfortable (and established rapport more quickly) during a shared activity such as a board game. The interview prompts allowed sufficient flexibility to accommodate unanticipated findings.

Field notes were kept of researcher personal responses and emerging analytic thoughts around the times of the interviews. This journaling, in phenomenological research terminology, allowed for the comparison of emergent findings and helped reveal whether these were idiosyncratic or part of a pattern (Groenwald, 2004, p. 13-14). The researcher did the transcription of the first two interviews. It then became necessary to
turn transcription over to a professional transcription company because of time constraints.

As transcripts were prepared, coding proceeded and alerted the researcher to the same issues emerging in subsequent conversations. The ongoing coding built a “library” of statements that reflected a growing consensus of ways in which families were experiencing the adaptation to stress. Before coding began, it had been the researcher’s intention to be sensitive to factors that had already been found to impact resilience. However, as the researcher continued to look into, and learn about, phenomenological methods, it was realized that looking for statements and expressions linked to pre-existing knowledge of resilience factors would be a breach of bracketing. The researcher quickly began to attempt to bracket even academic information about resilience.

Other researcher thoughts, insights, and observations were recorded at the end of the analysis section for each family. The researcher used Giorgi’s data analysis steps with some changes in terminology (2009, 2012).

The researcher attempted to read each transcript several times to achieve a holistic memory of the conversation before attempting to read through the transcript to note significant statements. Co-coding was done by a graduate research assistant at the University of Texas at Arlington. It was used to assess the reliability of analyst observations. However, it is likely that the analyst who conducted the face-to-face interviews with the family had an advantage in coding over the co-coder who had not met the family members. The researcher who was present at the interviews not only had body language to guide them to ascertain meanings received from the participant but also the ability to ask clarifying questions.

Significant statements were identified that had importance for the participant in terms of the phenomenon, resilience in families of children who had disabilities, and
showed connections to the researcher’s disciplinary attitude. For Amedeo Giorgi, a psychologist, his disciplinary sensitivity was psychological. For this researcher who was observing from the social work frame of reference, the sensitivity was bio-psycho-social.

However, one of the most meaningful observations to come from the analysis was produced by attending to the Strengths Perspective (Saleebey, 2009). As the researcher was asking the participants to focus on what was working, constructively, for them in adaptation, the researcher was also looking for strengths in the data. As the researcher continued to dwell with the information provided by participants, she also began to look for any strengths or constructive possibilities present in the barriers and the hardships faced by families.

As families continued to share experiences of struggle, the researcher began to wonder whether the persistence to overcome barriers was a strengths aspect that had been hidden in the overwhelmingly stressful event. While this factor was emerging, the researcher was continuing to use imaginative variation to transform statements into significant expressions. In addition to the “resilience sensitivity,” the “bio-psycho-social” sensitivity (and now the “strengths sensitivity”), the analyst was attending to what might be present, covertly, behind the overt statement. In addition, the researcher continued to look for expressions unrecognized but emerging.

After sensitive expressions were collected, the analyst began looking for essential structures that would show how expressions, both overt and discovered, were interrelated, if, indeed, any of them were. After seeming structures were discovered, they were taken back to the data of statements and expressions to find out if there were other constituent, unrealized in the data pool, or if other structures could be discovered.

One alteration in the use of the phenomenological method that had been noted before in the activity-based conversations with children pointed to a weakness in the
universal use of phenomenology to understand the meaning of the lived experience of phenomena. Phenomenological observations are geared toward gaining data from people who are conscious of a phenomenon and able to verbalize their experiences. This required some communicative adaptations in trying to access the thoughts of younger subjects who lacked experience in responding to stress, the ability and experience to think about their situation, the relative experience to realize their family is different, and the ability to verbalize what thoughts they have had on stresses in the family. Additionally, gaining information from participants who lacked the cognitive ability to communicate required accessing secondhand information from caregivers. The same problem would have occurred with other qualitative methods that depend on the ability of the participant to communicate verbally and be able to think abstractly.

Despite this weakness in the method, as it was used to observe resilience in families by gaining views from each family member, the researcher gained a better depth of issues that affected the children and other family members. If only the mother had been interviewed, the research understanding of the lived experience for the whole family would have been much shallower.

Since the interview meeting was usually the first face-to-face meeting between the participants and the researcher, the establishment of rapport included some information that the researcher had been the mother in a family that included a child who had a physical disability. Establishing rapport with a child participant would have the information shared in a statement similar to “I had a son who used a wheelchair.” After establishment of rapport and answering any other questions the participant had about the purposes and procedures of the research, the research question was framed in such a way to elicit information about the lived experience of resilience.
Although the Strengths Perspective directs one to focus on adaptations and actions that are constructive (rather than on problems) that would have been counterproductive with families where so much of resilience is aimed at overcoming barriers. Participants were encouraged to begin the “conversation” (Smith, Flowers, & Larkin, 2009) by sharing what was working for the family and assured that we would also be talking about barriers. When the research conversation appeared to be going off track from experiences of resilience, the researcher redirected the conversation to areas of adaptation.

At the end of the interview meeting, participants were asked if there was anything else that was important to the family maintaining quality of life that had not been brought up at that point. Almost all participants had something else that was important to them to offer. Participants were asked to contact the researcher by phone, e-mail, or letter if they had any other thoughts after the interview.

One participant sent some additional information after the interview. Participants were assured at the beginning of the first interview that subsequent interviews would be conducted if they wanted one. However, the member check process appeared to meet most participants’ desire to share additional information (Koelsch, 2013). Member check interviews were done after the first round of data analysis, when the researcher assessed the validity of the findings by sharing them with the participants and getting feedback on accuracy.

3.4.4: ICAP: Inventory for Client and Agency Planning

The ICAP was another tool used in the research process. The Service Level on the Inventory for Client and Agency Planning (ICAP) was used to assess the level of severity of the disability of the child in the family. This was necessary to allow the comparison of severity across different diagnoses. The instrument was not used to
assess whether the children met the criteria of “having a disability.” It was used to compare the level of disability by comparing the level of care needed. The parents were told about the need and purpose of the ICAP assessment before the study started, and they filled it out in conjunction with the researcher at a time of their choosing.

The ICAP is an adaptive behavior assessment used by Texas state social service programs that serve people who have disabilities. Other states that use this inventory include Alaska, Delaware, Idaho, Indiana, Utah, and Wyoming (R. Befort, personal communication, August 22, 2011). The Inventory is a 16-page booklet used in assessments to determine the type and amount of care that people who have disabilities may need. It will be used in this research to help assess the amount of supports that people who have different disabilities may need. For instance, it will help compare the amount of stress facing a family who has a member with cerebral palsy (a primarily physical disability) as compared to a family who has a member with mental retardation (a primarily cognitive disability). Additionally, use of the ICAP allowed the comparison of families whose children may have different types of disabilities by gaining a measure of level of supports needed.

The Service Level ranks individuals on a scale of one to nine according to the level of personal care they need, and how closely they need to be supervised. An individual who needs total personal care and intense supervision would need a level care of one.
Table 3-2: ICAP service levels (ICAP, n.d.)

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Total personal care and intense supervision</td>
</tr>
<tr>
<td>2</td>
<td>(no description on the response booklet)</td>
</tr>
<tr>
<td>3</td>
<td>Extensive personal care and /or constant supervision</td>
</tr>
<tr>
<td>4</td>
<td>(no description on the response booklet)</td>
</tr>
<tr>
<td>5</td>
<td>Regular personal care and/or close supervision</td>
</tr>
<tr>
<td>6</td>
<td>(no description on the response booklet)</td>
</tr>
<tr>
<td>7</td>
<td>Limited personal care and/or regular supervision</td>
</tr>
<tr>
<td>8</td>
<td>(no description on the response booklet)</td>
</tr>
<tr>
<td>9</td>
<td>Infrequent or no assistance for daily living</td>
</tr>
</tbody>
</table>

This assessment is a proprietary instrument distributed through Riverside Publishing. The information on the web site indicates it has been normed on a population, aged birth to 50 years old who did not have disabilities (ICAP, n.d.). It contains 181 multiple choice items and is designed to be completed by a parent, teacher, or care provider in 20 to 30 minutes. The 181 items cover areas of descriptive information, primary and additional diagnoses, functional limitations, adaptive behavior, maladaptive behavior, residential and daytime services, support services, and social/leisure activities. Habilitative activities are covered under residential and daytime services. The service score (0-100) is calculated using a weighted combination of 30% of a maladaptive behavior score and 70% of an adaptive behavior score. A lower score indicates the need for more external support. The Test-retest and Inter-rater reliability for six to eighteen-year-old, nondisabled subjects was 0.94. The Construct validity, correlated with subjects aged zero to eighteen years old, was 0.91. The Criterion validity, correlated with an Intelligence Quotient (g), was .29-.91. According to contact with the publisher, statistics on reliability and validity with populations who have disabilities is only available by purchasing the ICAP Examiner’s Manual (R. Befort, personal communication, July 18, 2011; Bruininks, Hill, Weatherman, & Woodcock, 1986).
The ICAP Examiner’s Manual indicates that the Inventory was normed on 1,764 individuals drawn from 11 of the 50 United States to access a representative sample from the four census regions. Of the 1,764 individuals assessed, 593 were aged three months to five years of age, 655 were aged six to twelve years old, and 516 were aged 14 to 29 years old or older (Bruininks et al., 1986). The ICAP norms were comparable to those of the Scales of Independent Behavior (SIB) (Bruininks, Woodcock, Hill, & Weatherman, 1985). The independent variables that were found to significantly add to the predictive value of the ICAP were “diagnosis (mental retardation, mental health, physical health), mobility and arm-hand use, recent hospitalization, medication usage, vision, hearing, adaptive behavior domain scores (motor, social and communication, personal, community, and broad independence), and the maladaptive behavior indexes (internalized, externalized, asocial, and general)” (Bruininks et al., 1986, p. 55).

Internal consistency reliability was calculated using Mossier’s Formula and ranged from $r_{cc} = .81$ to .92 for broad independence. Split-half reliability for samples that had been identified as having disabilities was $r = .93$ to .97 for children, .88 to .98 for adolescents, and .97 to .98 for adults. The test-retest reliability of a sample of non-disabled elementary school students was $r = .87$ for broad independence, .86 for the general maladaptive behavior index, and .89 for the ICAP service score. Test-retest scores for 30 adolescents and young adults who had cognitive disabilities (mental retardation) revealed a $r = .98$ for broad independence, .92 for the general maladaptive index, and .95 for the ICAP service score. Test-retest scores for 159 adults who had cognitive disabilities and were between the ages of 18 to 44 years old showed $r = .94$ for broad independence, .85 for the general maladaptive index, and .92 for the ICAP service score. Inter-rater reliabilities in two different samples of adults who had cognitive disabilities were $r = .94$ and .83 for broad independence and .94 and .88 for the ICAP
service score. Inter-relater reliability for two samples of individuals in residential treatment was $r = .94$ and $.80$ for functional limitations (Bruininks et al., 1986, p. 66).

Construct validity was achieved by comparing adaptive behavior to developmental norms and indicated strong validity for social development and for adaptive behavior but not maladaptive behavior. Adaptive behavior domains of motor skills, social and communication skills, personal living skills, and community living scales intercorrelations ranged from $r = .40$ to $.80$ (Appendix A). Intercorrelations for the domains measured for maladaptive behavior (internalized maladaptive index, asocial maladaptive index, externalized maladaptive index, and general maladaptive index) ranged from $r = .32$ to $.91$. More than half of the values were $r = .60$ or more (Bruininks et al., 1986, pp. 69-70).

Criterion validity was determined by comparing the adaptive behavior and maladaptive behavior scales of the ICAP with the Scales of Independent Behavior (SIB) (Bruininks, Woodcock, Hill, & Weatherman, 1985). Since much of the adaptive behavior portion of the ICAP was derived from the SIB, the correlations were high, in the .80s and .90s. “The first analysis involved scoring the ICAP test items imbedded in the SIB test protocols gathered as part of the standardization study and then correlating the ICAP and SIB scores. The median correlation was .96 between the two measures of broad independence. The high correlations between these scores are due, in part, to the common test item content and to the fact that the scores were derived from a common test administration” (Bruininks et al, 1986, p. 80).

The adaptive component of the ICAP was also compared to the Adaptive Behavior Scale-School Edition (ABS-SE) (Lambert, 1981) and the Woodcock-Johnson Broad Cognitive Ability Scores (WJ). Although the ICAP Examiner’s Manual doesn’t mention which version of the WJ they used, the third version was reviewed in 2007
In comparison to the ABS-SE, the ICAP achieved correlations of $r = .40$ to $.84$, with most correlations occurring between $.50$ and $.80$. There were 52 subjects in this comparison, only 5 members of this group had cognitive disabilities. In the comparison to the WJ, children with disabilities showed a correlation of $r = .91$ and adolescents and adults had a correlation of $r = .77$. The maladaptive behavior component of the ICAP was compared to the Quay-Peterson Revised Problem Behavior Checklist (Quay & Peterson, 1983). The ICAP Asocial Behavior rating correlated with the Quay-Peterson Conduct Disorder rating at $r = -.66$. The ICAP Externalized Maladaptive Behavior score correlated with the Quay-Peterson Conduct disorder score at $r = -.58$. The ICAP Internalized Maladaptive Behavior measure correlated with both the Quay-Peterson Anxiety-Withdrawal measure and the Psychotic Behavior measure at $r = -.39$.

Although the ICAP psychometrics were measured using, mostly, only those individuals without disabilities and those with cognitive disabilities, it is an instrument used by Texas government social services to measure intensity of supports needed by individuals with an array of different disabilities. Its use in this research project is to allow comparison of families whose children have different disabilities. By providing a quantitative measure of the level of supports needed by the individual who has a disability, it has been possible to compare the challenges faced by a family who has a child with a mild cognitive disability juxtaposed to a family who has a child with a different level of another type of disability.

The data collected, which was in the form of interviews, was analyzed using the analysis steps. Listed below are some of the more significant statements and the sensitive expressions that came through transformation. They are presented for each
family. After the statements and expressions for all families are presented, the essential structures are presented.

After essential structures were revealed, member checks were done with the families to ensure that what the researcher saw was accurate and what the family meant. All families agreed with the structures. One family wanted to make sure the importance of each child getting individual attention was recognized. Another family wanted to emphasize the challenge that behavior problems could present.

Although Giorgi did not believe that measures of validity and reliability were applicable to phenomenological analysis, even measures designed for qualitative methods, an analysis of co-coder agreement was done for this study (Beck, 1994; Giorgi, 1988; Marques, 2005). The true agreement rate, using Hamilton, Gurak, Findlater, and Olives’ Confusion Matrix (as presented in Marques & McCall, 2005, p. 455), gave a true agreement rate of 87% with an acceptable lower limit of 66.7%.

3.5: Results: Families One to Six

In the data analysis, the significant statement labels, representative significant statements, and sensitive expressions are presented for each family. The labels, statements, and expressions are categorized according to whether most of the meanings fell into the category of risk factors or barriers to the family, whether they were so mixed between risk and protective that they should be placed in the mixed category, or whether they had more of a protective effect (in which case, they were placed in the protective factors category). At the end of the results section, the essential structures that emerged during analysis are presented.

3.5.1: Family One

Family One was a family unit that included a grandmother and a young adult in his late teen years who had a disability such that he needed a care level of three as
measured on the Inventory for Client and Agency Planning and recorded as the “Service Level” (ICAP, n.d.). A service/care level of three indicates the individual has an extensive need for personal care and/or constant supervision. The care levels range from one to nine, with a care level of one being the most extensive level of care for an individual who can perform very few (if any) activities of daily living. All care levels listed for the children who have disabilities in this results section are care levels recorded on the ICAP as “Service Levels.” Listed below for Family One are some of the significant statements and supporting quotes. Labels for significant statements are followed by a section that pairs a quote from the family member in support of the significant statement. Risk factors are presented first, followed by factors that have been both risk and protective, then protective factors are given. The summary for the family contains the significant statements transformed into a sensitive expression. The essential structure that reveals the relationships between some sensitive expressions is in the Discussion and Interpretation section.

3.5.1.1: Statement labels, statements, expressions

Table 3-3: Significant statement labels

<table>
<thead>
<tr>
<th>Family One Factors</th>
<th>Risk/Barrier Factors</th>
<th>Mixed/Risk and Protective Factors</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hard to get information</td>
<td>Past behavior problems now lessened</td>
<td>Balance is better in sports activities</td>
<td></td>
</tr>
<tr>
<td>Family fights for school services</td>
<td>&lt;&lt;Family fights for school services</td>
<td>Funding support for medical care</td>
<td></td>
</tr>
<tr>
<td>C.W. began to regress age: two to three and a half years old</td>
<td></td>
<td>Family support</td>
<td></td>
</tr>
<tr>
<td>Waiting list for Medicaid program that will transfer to adult services</td>
<td></td>
<td>Planning for the future for C.W.</td>
<td></td>
</tr>
<tr>
<td>Support services are given in a way that is convenient for the provider; not what the family needs</td>
<td>Religious beliefs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The transition services (childhood to adulthood) inadequate</td>
<td>Family supports C.W. to continue to develop skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A lack of cohesion/little sense of community among FCD</td>
<td>Support from friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with disabilities treated as second class citizens</td>
<td>Interests of C.W. are supported</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Background on emergence disability</td>
<td>Acceptance</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Advocacy for others</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Conversation with C.W.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

N. C.W. = child who has a disability, FCD = family of child who has disability

**Significant statements that reflect risk/barrier factors.** Hard to get information:

The grandmother said, "We got C.W. when he was two weeks old and I just assume—I mean I went work at a private school, so I just figured everything just school just comes with bills and listens to everybody. (C.W. is a pseudonym for the child who has the disability.) My children, my youngest was like 15 when we got CW, so that was, like, just everybody was excited and whatever, but it doesn't work out that way. And, I found that out when I started to need things for him. It was, I mean, it's amazing and you talk to a lot of people and, for whatever reason, to me this is just my opinion, that this community of people with disabilities is almost secret to me. People don’t tell other people things or don’t tell other people about other services. It’s been really, it’s been an eye opener for me and suddenly to have had seven kids and you know they kind of went to the public school system and you kind of, you fought a little bit but nothing in comparison to which
you have to fight for, for a child with a disability. Yeah it’s been a real eye opener for me.”

Waiting list for Medicaid Waiver programs that will transfer to adult services:
“…last year we were number 2,200 on the waiting list, so we don’t know when we will get picked up for it and when we run out of MDCP (Medically Dependent Children’s Program) when he’s 21, and if he was eligible to come over in to CLASS Medicaid Waiver (Community Living Assistance and Support and Supports), then I figure they will pick him up then, because, when you are trying to transition from these programs they make you stay in the other program until you are 21.”

Support services are given in a way that is convenient for the provider, not what the family needs: “…if you’re needing this, like I work a flexible schedule, so if you’re needing these people at that time, they set up a time and say you can do this between this time and this time because that’s when we’re going to be there. So, it makes your life even harder, but you have to work within their limit…” … “I mean, you learn to just persevere, man, I mean you know and I learnt this—you can’t just say no to me, you know that was the first thing and it took me a long time to get, to get Medicaid for CW.”

The transition services (childhood to adulthood) are not adequate: “So this is probably going to be my ongoing battle—one you turn 21 or, actually, once you turn 15, the bottom kind of just falls out, you know there is nothing. Before that there are times organizations are kind of concerned about the grouping, and then when you turn about 14 years old, then the grouping changes a lot.”

A lack of cohesion/little sense of community among families that have a child who has a disability: "And there’s not a lot of support between families; it’s like a hidden society. Nobody is sharing information. Teachers and home help, it’s like they stay hidden.”
People with disabilities treated as second class citizens: “So, that was kind of another eye-opening thing, so some people just don’t see people with disabilities you know what I’m saying?” … “I don’t want to say they don’t consider them, but it’s like you don’t have to include them because he’s got a disability. And, I don’t think it’s because they’re being mean, he just doesn’t fit in to their life.” …”But my question is, is that the people that worked on the line with them, that were just regular people they knew? You had to know because they worked there, that the people they worked with were living on the farm in these ragged and falling down shacks, there on the farm.”

C.W. began to regress when he was two to three years old: “…we got C.W., he is my daughter’s son, when he was two weeks old. He started to walk late, about 16, 17 months, but he was riding his bike, and the skills that he already had, like riding a bicycle, he started to lose those skills and so he just started to kind of slide backwards. He started falling at school and stopped riding his bike at home. Yeah, you get them all, get them all there and then, whoops, there goes one. Then, one day he just kind of hit the floor, I mean he just—they say he just fell, I mean, he just lost, like, his legs just gave out on him and he fell. He didn’t lose conscious, he was just kind of a little glazed over more or less, and this started to happen just kind of frequently; well, we took him to the emergency room and by the time we got to the emergency room, he was pretty much fine and there was nothing going on. We started with the neurologist to run some tests and some different things. And, they saw some spikes, but nothing serious. Later, about three years, three, four years later, we found out that he was having seizures at 3 or 4 in the morning. He had been losing skills all along and we never knew.

Significant statements that reflect mixed risk and protective factors. Behavior problems: “He started to get really aggressive. He did a lot of hitting, we thought maybe because his speech wasn’t so good, that maybe was because he couldn’t hear so again.
We did it all, we did the eyes the ears, we—C.W. has had speech O.T. and P.T. since he was 18 months old (O.T.: occupational therapy, P.T.: physical therapy). So we were putting everything that we saw in place; he—so, we just saw different sectors of what's going wrong with C.W. And, so from that, we went into another school, because they were not able to accommodate him at my school. He was kind of doing good, he still had the kind of aggression and the hitting and his memory, or, I want to say sometimes his long-term memory was better than his short term: what happens right now and he is there right now. And, so, he, just—like I said, he regressed.. And, so, we have not, we make a step and we make 10 back and two forward and, so, yeah.”

Family fights for school services: “At school now, he's in a life skills program, he gets an opportunity to kind of participate in conversation or hear a lot conversations and other social skills, yeah, so he's in that, and then he does a team sports gym. He has a motor problem, but he can play basketball and he never falls, not one time.” … “And it's whatever I fought for, for C.W. would benefit the whole. You know, everybody would benefit, if he had to have an aide, then that would free up the aide that they had in their class to help somebody else.” … “But the ones (the students) that are more severe or more—needing more are getting less. And I've filed with TEA (Texas Education Agency) and, you know, it's like the school system just does not get it. And, I mean, I go to the school, because my job is a little flexible, I have an opportunity to go to school, but it's been fighting tooth and nail to get the school to even do that, even though it's there, it's in your IEPs (Individual Educational Plan) and…” … “So it's—I think where the parent is concerned it's just the lack of, I mean, you have to go, you have to stay there. It's like having a senior in a nursing home, and you have to go every day or every two or three days and you have to fight, you literary have to—I call it a fight, it's a battle, because they tell you one something and they do something else, you know. The kids are not getting
what they need and the parents are being led to believe that they're doing what they should be doing and so everybody is missing it.

“They never know when I'm coming. I peep in, they used to have the windows papered and you know they were saying that the kids were passing by and knocking on the windows or meddling and I thought, well, my say to the principal was, ‘I said if you have that many kids out in the hallway being able to knock and lean on doors and windows, then there’s something wrong with your school.’ And, so, they made them take the paper out of the window, but that was because they weren’t doing anything and they didn’t want anybody to pass by and see that they weren’t doing anything.

“You still don’t get it (educational services). You fight for it but you don’t get it, you fight that battle and they agree, yes. You need a tutor, yes, we’re going to give you a tutor, yes, you need an individual aid, yes, he deserves this, this is due to him. They say that the IEPs are legal documents, but you don’t follow them. We write them up all the time, but nobody is following them and, guess what, nobody is making them follow them. TEA I filed in 2008, I think, I filed 29 counts about the same thing that I’m about now. And, they agreed, okay, they document them nicely taped and that was it. And I just figured this out, like you launch a complaint or you find you an advocate that will fight with you against this process. But they want you to pay out of the wazoo. We used an advocate one time and I paid her $25 an hour to go and sit at the school. I was thinking, okay, maybe I’m just asking for something that’s just, it’s really—maybe somebody else needs to go into this meeting and see you’re not doing it.

In order to get it I don’t know what it’s going to take, to get the appropriate education that the kids need. Not even the other kids. I’m not just saying for my grandson, I mean, you see kids that are in special education right now, that are there, and I know because I started volunteering and that was another means for me to go to
see what was going on, so that there are kids that are blind that no one has taught Braille or have even considered giving Braille lessons to.

“...if you have a kid with disability you have to, there’s a, it’s a whole ‘nother fight. It’s an ongoing fight, you know, when you go to school and your kids are functioning normal, you talk to the teacher, you go on, and you say, okay, ‘Fred you’ve got to start doing so and so and so.’ Whereas the kid with the disability, you have to remind the teachers, you have to keep up with the teachers, you have to keep, you know, on them.” ...“and so schools offer nothing for kids in Special Education, as far as I am concerned. It is a place, I believe, a place to warehouse them. I mean, I think that is exactly what’s happening to children in Special Education because the teachers are just not teaching them. I had a teacher a few weeks ago say that if the parents don’t care, why should we care? How do you have this attitude, how do you—I’ve always thought teaching was a calling, kind of, you know. You had to—and certainly of even work in Special Education, you had to care something about the kids. “

“I’ve been trying to communicate with his teachers by sending a spiral notebook to school with him, so I can send notes and the teachers can send notes back. This is everyday—this notebook has been lost three times, since we started school in August. Okay, so these are Xerox copies, okay, I learned to copy everything, okay. So, this week when we first went to school and the teachers were supposed to sign in on this every day. This is how it comes...nobody signs in and this is an ongoing issue.

So, what do you do as a parent, to get what you need for your child? You can’t sue, you can’t afford it, so what do you do? You keep going to the school and, yes, I see you coming and you’ve been red flagged and so what is it for the school? Because I believe it’s going to take us, the outside people, or the parents, to make the schools recognize that these children are due this. They are due an appropriate education.
The law says that they are due on appropriate education, but once they get them all in and they just warehouse them and they’re just sitting up in there, you can probably go into most special education classrooms, if you just go in at the drop of the hat. The kids are probably doing nothing in most schools today. So what do we do? What do we do?

Persistence in seeking services or adequate services: “Like I said, I learnt a long time ago to, you know, just not taking off. You know, if I call and ask you about your services and you tell me no you don’t, you know, you didn’t feed me, then I will go back and have another look at your services and see what I can find in your service. No, we came here for this service and your material says you serve these children. Now explain to me why you’re not doing that. So when they say, ‘No, we don’t.’ you have to say, ‘Yes, you do, and you’ll keep seeing my face until you do what you’re supposed to do.’ … Yeah, you know, you just—because they say no all the time.”

Significant statements that reflect protective factors. Balance is better in sports activities: “Not one time, (falling) but we’ve—no, once a bit we say that it’s something that he wants to do. More than anything he likes that and he never falls, well, yes, every now and then, but nothing in comparison to, you know, how his motor is just on a, you know, on his way through here, but if he’s playing basketball, he fell very seldom.”

Funding support for medical care: “We get—C.W. is on social security and we get our Medicaid, is it—I think it’s Medicaid and, I mean, he’s been on it a long time and we are also receiving MDCP” (Medically Dependent Children’s Program). … “They pay for a provider for C.W. for while I’m at work, there’s a provider…attendant care, and medical bills.”

Family support: “I guess family support, we are a close knit family. I have seven kids so, you know, everybody just kind of jumps in and I thank God and, you know, for
the strength, I call it grace, I think C.W.—it took me a while to kind of come to the, you know, you should try everything you know, speech you do, or you need to do everything to make his life better. Well, my daughters have children now and before they didn’t have kids, they still, C.W. was still like our baby. They would take care of him, they would take him with them when they went out. Because, and they still do that even with their kids now, you know, like my daughter picks them up and keep them for the weekend or something or if they’re going to a football game or, you know, there is something going on, you know, and they’re taking the other boys. That doesn’t happen and so, yes, everybody, my other grandsons, say that when they get ready to go to college, they are going to build a school here and they are going to all be roommates, you know. This may change but, you know, that’s something to think of. My son-in-law works with ___ and so he has been kind of that person, you know, take him to the games and he is another mentor to his C.W. You know, he takes him to the sport malls and, you know, they’ve been getting him to, you know, good things, so they have been kind of working with him, following up on speech services.

Religious beliefs/sense of coherence: (Repeat of family support above) “…I thank God and, you know, for the strength, I call it grace. This is what God intended; there’s a path and a purpose for us all. And I say that had it not been for C.W., where would I have been at this point? I could have been—this was something that He intended because I had plans. I could have been big and gone on the road. But, he gave me C.W. and I counted it as a blessing, because who knows where I would have been, I don’t say that it would have been something bad. But evidently this was the path that He chose for me, because had it not been, I could have turned him back over to child protective services. I could have called in 30 days and said, “Hey, look, here I’ve been having him over here for too long. You all need to come and get him.” … “Because
raising another kid was not the thing that I wanted to do, like I said, I was going to travel. So I believe that He put C.W. in my life to stabilize me.”

Planning for the future for C.W.: “C.W. has a non-profit organization set up in his name. It’s called C.W.’s Choice, which is the kind of thing that once we leave MDCP we will be able to use his funding from them or, whoever the next provider person is, we will be able to put that funding into that non-profit organization and pay for C.W.’s services, and this is something that he can have for the rest of his life. He has a board and, you know, that kind of thing, so we can do fundraisers and build funding for him and he can do some kind of work, like this paper shredding project. And we thought he could work at a movie theatre, a lot of options we’ve been considering. I won't say everything's just fine. You know, you just have to keep trying. You just cannot, you have to not let them say no to you. You know you just, you cannot, you know? And I know a lot of people say, well, you know, eventually you just have to. But you have to stay strong.”

Family supports C.W. to continue to develop skills/hope for a better future:
“Yeah, yeah, to work and then, you know, when you come to that point that you have to accept him for who he is and if there’s going to be a change then it will, you know, it’s just, he is who he is, but that doesn’t mean that you stop doing or you making things available to kind of help him along the way, but you kind of have to come to that conclusion. But you still keep giving him the things that you think will make a change, because those things are going to be things that you need, anyhow, you know, just like you would do the other kids, you just keep bringing him some more stuff. You keep trying to make that happen for them. You give him a pencil and he’ll take that pencil and start to doodle, but it’s not writing, you know, it’s scribbling and has no meaning, no basis, but yes I can, if they are writing I can do it, so...” … “I would rather them have that perspective than ’I can't, I can't, I can’t’.”
Support from friends: “I guess friends because our friends have been around. My kids kind of grew up and their friends or the friends they had, they’re some of my friends and other friends I’ve had my whole entire life. So, we, you know, we… there’s just a lot of support we have for each other. So, I’m going to say more, so, I would think the family support and I guess I say it may not be we are kind of a unique little group. Because I feel on the outside I know people that have kids that have disability but don’t have this much family support, and I say that because of the stipulation in certain things and the way that the system is set up. Sometimes, and even in foster care type of situation, it is because those people are not vested in that person. It’s just the process so that why there’s always a struggle there and then sometimes some family just don’t or are not able to deal with the kind of the process.”

Interests of C.W. are supported: “He likes basketball, he likes fear-provoking movies, he likes scary movies. He likes playing on the computer and, I mean, playing he can open about 700 pages in just a matter of seconds. He—and he likes outside, you know, he likes movies, he likes going to the movies as well as, you know, watching the videos, he likes playing video games. We’ve never been able to actually decide whether he’s actually playing.

Acceptance: “Yes, and you are—and for a long time it took me to realize that he is his own person, no matter how many times I give him therapy, how many times I—this is—he is who he is and you have to accept that. And, so we kind of, you know, “Yeah you did good, man, and what does it say.” He may give you an explanation for it…” (What he’s “written.”)

Advocating for other children: “I was asking the teachers about the kids, because we do my grandson’s class for Christmas. My kids and myself and we have a Christmas party for my grandson’s class, so we take on two kids a piece. And so we
shop for them—size, shoes, clothes, you know, just Christmas. And so, but this year we took on the whole 46 kids in his life skills program.”

Conversation with C.W.:

Interviewer: “Okay. Tell me what else you like to do besides basketball.”
C.W.: “I write papers.”
Interviewer: “Do you ever play baseball at school?”
C.W.: “I play baseball with my friends.”
Interviewer: “Okay, at school or here in the neighborhood?”
C.W.: “At school.”
Interviewer: “Does someone help everybody get together? Because you need more than one person to play baseball right?”
Interviewer: “My papa.”
Interviewer: “What do you like to do when you go out?”
C.W.: “Eat.”
Interviewer: “What kind of food do you like to eat?”
C.W.: “French fries.”
Interviewer: “Okay, where is the best place to get French fries?”
C.W.: “Burger King.”
Interviewer: “Tell me about classes at school; what are you learning to do at school?”
C.W.: “Write.”
Interviewer: “Okay, what else do you, what else are you studying at school?”
C.W.: “Cutting.”
Interviewer: “What’s more fun, writing or cutting?”
C.W.: “Cutting.”

Interviewer: “So writing is a problem, it’s something you are working on getting better at?”

C.W.: “Yeah.”

Interviewer: “Who helps you with your writing?”

C.W.: “My sister.”

C.W.: “I play soccer ball.”

Interviewer: “Okay, do you do that by yourself or with friends?”

C.W.: “With friends, with my cousins.”

Interviewer: “Your cousins?”

C.W.: “Yes.”

Interviewer: “Who helps you get together with your cousins, do they come pick you up or does your grandma takes you or does someone else get the…”

C.W.: “Grandma takes me to (Cousin’s) house.”

Interviewer: “(Cousin's) house?”

C.W.: “Yeah (Cousin).”

Interviewer: “You’re smiling. Do you like playing soccer with your cousins? Would you rather play with your cousins or would you rather play by yourself?”

C.W.: “Playing with my cousin.”

Sensitive expressions. The sensitive expression of the lived experience of the family members of Family One reveals an outrage that necessary resources, including information and services, are being withheld. The outrage is felt, not just on behalf of this family, but on behalf of other children who are seen also to be underserved. The
matriarch of the family takes it upon herself to not only stand up for her loved ones but to also speak up for others who have no influence. This thought cannot be completely attributed to the researcher. Rick Warren, the author of *The Purpose Driven Life*, was heard to say during a television interview, “The purpose of influence is to speak up for those who have none.”

3.5.1.2: The researcher’s notes on data collection and analysis of data contributed by

Family One

I noted with interest my impulse to help the family with issues that touched me. In the case of Family One, I identified with the grandmother’s desire to make changes that would help other families as well.

3.5.2: *Family Two*

Family Two was a family unit that included the children’s mother and father, two young adult siblings, and the young adult who had severe physical and cognitive disabilities with a primary diagnosis of Mental Retardation. The child who had the disability was in his early 20s and had a care level of one. He needed total personal care and intense supervision. The two siblings of the C.W. were also interviewed. (C.W. is the pseudonym for the child who has a disability.) They were in their early to mid-20s and no longer lived in the home. To reiterate, in the research conversations sharing began on strengths. The invitation to share barriers was offered at the end of the conversation. Additionally, before the conversations ended, the researcher asked the participant if there was any other issue, or event, the participant wanted to share that had not been asked.

The report of significant statements, below, is organized with the risk and barrier factors first, the mixed risk and protective factors, and ending with the protective factors. Initials are used as pseudonyms for the family members; they are not the initials for the participants’ names.
Table 3-4: Significant statement labels

<table>
<thead>
<tr>
<th>FAMILY TWO FACTORS</th>
<th>Risk/Barrier Factors</th>
<th>Mixed/Risk and Protective</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty in addressing adaptation to having a child who has a disability (complexity)</td>
<td>Parent had search skills to find services (Researcher note: time consuming)</td>
<td>Logistical care supports to care for CW</td>
<td></td>
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<tr>
<td>Trouble getting medical services</td>
<td>Schools create additional stress</td>
<td>Peer support</td>
<td></td>
</tr>
<tr>
<td>Physical strain on family</td>
<td>Searching for services/inadequate services/ not being given information</td>
<td>Searching for a diagnosis and treatment</td>
<td></td>
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<tr>
<td>Sibling worried about intense care needs of CW</td>
<td>Access to services</td>
<td>Previous experience with children who have disabilities</td>
<td></td>
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<tr>
<td></td>
<td>The non-disabled siblings’ experiences [from the parents’ point of view]</td>
<td>Access to quality medical services</td>
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<td>Spiritual perspective</td>
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<td>Gratitude</td>
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<td>Team work w/coordinator</td>
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<td></td>
<td></td>
<td>Family members contribute their skills</td>
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<td>Sibling felt their needs were taken care of</td>
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<tr>
<td></td>
<td></td>
<td>Contributions of siblings who did not have disabilities</td>
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3.5.2.1: Significant labels, statements, and expressions

*Significant statements of risk/barrier factors.* Complexity of adaptation in families of children who have disabilities: “You know, your question is a pretty broad question, and this is an extremely multi-faceted situation. And, we’re kind of focusing, more or less, on the medical stuff ‘cause that’s what you focus on first. ‘Cause it’s through the medical community. But, then once you get that hopefully squared away, then you’re
going to have to go into social services, and activities, school…. Which is, school is a whole ‘ball of wax’ by itself, which is very, is extremely difficult to deal with…schools.

Trouble getting medical services: W.I.: “Oh, attendant care. Just getting somebody in the house to help us take care of C.W. (W.I. is the wife and mother; C.W. is the young adult who has a disability.) That’s what really set me on the course of finding out on my own what those services were. Because I didn’t get any help from my E.C.I. program (Early Childhood Intervention). I had to fight them tooth and nail for a lot of stuff for C.W. Well, they had me down for occupational therapist but they didn’t have anybody. And they just kind of let it go for nine months, without any occupational therapy, which…they were in violation of their own plan. . . . “ . . .sometimes the speech therapist would cancel on me because she needed to catch up on her paper work. And I was just like, ‘You guys are dedicated to the minimum and I’m dedicated to the maximum and there’s a problem and I’m out of here!’ I started talking to other parents. Then when I started bumping into someone I said, ‘Honey, you’re on Medicaid. Why are you here? Your E.C.I. program charges your Medicaid, why don’t you take it to (the children’s hospital) or take it to the care group, or, and, you know they’ll assess him and…see how much therapy he needs, and if they agree with your doctor that he needs this many that’s how many he’ll get.”

Physical strain on family: H.U.: (The husband and father in the family is talking about the flexibility his employer was willing to give him.) “…because they knew I wasn’t necessarily getting a regular night’s sleep, as far as support, that was huge, for me, both financially and psychologically.” . . .”because we’ve never gotten normal sleep patterns, ever since he was born. He’s being fed during the night and so that alarm’s going to go off at 4:00 in the morning, and it can’t start until 11:30 at night, so you know you’re going to be going to bed at 11:30 to 12:30 at night, at best, and at best, if there’s nothing that
occurs during the night, then you’re going to be getting up at 4:00. And, normally, you’re going to get up one or two times in there to do something with him, adjust him in a different position in bed or things of that nature, or probably, I guess I’m going into a completely different area there…but that’s my life with this.”

Sibling worried about intense care needs of C.W.: “…my mom said it was really …I don’t mean it, I truly believe in God’s plans. I mean, not everybody is spiritual and that’s understandable but, like, my mom told me one day when I was talking to her about how, I just don’t think I could have your life. I don’t think I could do what you do. I don’t want to do that. And, I know I was being really honest with her and she was accepting of it.”

Significant statements of mixed risk and protective factors. Parent had search skills to find services: “I think being able to do the research on getting the services that I needed. That’s something I really focused on, was getting access to state services. That was probably the number one thing that helped us. It teaches you you’re just a number and you’ve got this whole bureaucratic system to figure out. I had to figure out which services I could get from D.A.D.S. (Department of Aging and Disability Services) on the physical disability side and what services I could get for C.W. on the M.R. (mental retardation) side and which one did I want to choose. And talking to other parents helped also because it is a daunting system.” … “Well, the waiver programs, we were just at the day back when I first found out about the Katie Beckett Waivers. It’s called ‘Medically Dependent’ here in Texas.”

In reference to having their home and family assessed to qualify for medical services: “Do I really want people in my house? Gee! I was raised Southern. If somebody comes into your home, you have to entertain them, serve them tea. You’ll have to clean your house. But, he was probably two when we got onto the medically
dependent program and that’s back when it was nothing but nursing, twenty hours of nursing. We started at six and then we went all the way up to twenty-one hours [of nursing care]. He started school at three years old, so we had a nurse in the afternoon that helped us into the evening, and then we were on M.D.C.P. for a while until he was like seven or eight, and then I was just able to find out here’s the CLASS Medicaid Waiver you got to get signed up for it [Community Living Assistance Service and Supports]. Oh, here’s the Home and Community Based Services Waiver, you need to get signed up for that.”

Different programs only service children with specific diagnoses: “I had a deal with my pediatrician…And I did the research. I did a lot of research on what are these programs? What are the qualifications? Is it under Department of Human Services, Community Care Aged and Disabled, or is it under M.H.M.R.A. [Mental Health and Mental Retardation A.]? And we had so many, C.W. had so many diagnoses, mental retardation, that’s M.H.M.R.A., legally blind, that’s Texas Commission for the Blind. So we had so many diagnoses that I learned how each one played, each one would work, which one did I want to use, and I looked at it like here’s the services. Which one has the shortest waiting list; that’s where I’m going. And I had a deal with his pediatrician, I told him I’m going with physical disability ‘cause they have the shortest waiting list so I don’t want to see any paperwork that leaves your office that says C.W. has mental retardation because I’m not going down their road. I’m going down the road over here with physical disabilities so it’s developmental delay not mental retardation and he agreed. The schools put M.R. on him number one and we said, ‘Unh, unh, unh! Put it down number three or four, it’s not his primary diagnosis. We never denied that he had a diagnosis of microcephalic, I mean, you can’t deny M.R. and we knew that M.R. would play, at some
point, take over, but it was about services, it was about what the services, and it was
about waiting lists, which one can I get now, or which one will best meet his needs.”

In the search for services/inadequate services/not being given information: W.I.: 
“Once I found out they [E.C.I.] were charging his Medicaid, I was like, ‘Wait a minute,
guys, you’re not giving me quality therapy. I’m out of here.’” … “Once I got the Medicaid
card for C.W., I just went to [the children’s hospital] and got there and then we started
getting in the home services. That was a real slap in the face at the very beginning,
finding out that, ‘Oh, you mean I got to fight for this stuff! Jeez!’ Well H.U. did support me
having to go down that road of finding the resources on my own because nobody was
really helping us. And doing the parent support group he kind of warned me, ‘You know,
are you sure you want to do this because it’s going to take time.’ But he supported me
and we’ve benefitted from it greatly because that’s how we’ve gotten all these services
for C.W. because I went out and found out what they are. And, I’ve got a whole career
based on it.”

Geographic access to services: “And we were fortunate that we lived in inner city
so it was easy to get therapists, it was easy to get the nurses because we were
centralized. We weren’t way out in, or way down in, it was easier. And we had every
intention of moving out to the rural part, but once C.W. came along, and H.U. was into the
Arts at the time, so it was really kind of crucial for him to stay in the city. But we always
wanted to move back out to the rural, but we got so connected with [the children’s]
hospital; we weren’t about to be more than fifteen minutes away.” H.U.: “And he was in
the hospital frequently those first 10 years or more, maybe 15 times? “ W.I.: “The first
year he was hospitalized 8 times that year so we had a lot of surgeries.” (Researcher’s
note: The negative side is that families don’t have as much freedom to move or change
jobs when they need to live in a large city.)
Schools create additional stress: “Well, the school was a barrier, a barrier to education, a barrier even to our mental health. Just a huge fight pretty much daily, the whole time. He went on homebound for scoliosis, we were just like…screw y’all, we’re keeping him on homebound. We’re not returning him to school. There is nothing but childcare. And we don’t need childcare. You’re not, academically you’re not doing anything with him.”

“Yeah, when we experienced homebound he also didn’t get sick as much. It made our lives a lot easier with him getting what he…now, he didn’t get the socialization aspects, but we found other ways to do that through our church or through different programs, sports programs…”

“But, just anecdotally, about the school, when the school bus would come, we had a school bus driver that was real fond of ‘taking off’ because she felt like we were taking too long to get C.W. out, in his wheelchair, to the bus. She only gave us the three required minutes. We would literally be, like, getting him out the door, trying to get him out there, and she would just dri…she would just drive off. One time, I had to change C.W.’s diaper, but it took 45 minutes because he got too big for me to put in and out of the bed by myself. I mean, I coul…it would be a lot…it would be really hard for me to get him out, change his diaper, change his clothes. And then the bus, which is only going to stay for three (minutes), is gone. And then I’ve got to load him up in the van and take him to school by myself. And then calling the bu…actually, I would call the bus barn and say, ‘Get back here!’ The bus barn hated me. We’d run down the street after her sometimes. ‘What are you doing?’...get her to back up. WI: “I did chase them. One time I threw my shoes off and I ran down, and I caught that bus, and I was like, ‘See!’ And I had that bus driver thrown off that route. ‘Cause I’d been calling the school and said, ‘See!’; they’re
just, I mean, she was there. I've been telling y'all that she's been there and she just
takes off. Because I was able to catch up with her.”

“But, that to me is the epitome of…That’s what I would describe as the attitude of
schools, of the schools that we dealt with, for the most part. And there were definitely
exceptions with some people in the schools. But that describes our experience with the
school district…a constant fight….It wasn’t about helping us. So, once we had him in
homebound, we kind of discovered, and I really encouraged W.I. to keep him on
homebound.”

Communicating with C.W.: “You know, he’s nonverbal, but he does
communicate. If he’s uncomfortable, he starts making noises and sounds, that, like, I’m
kind of keeping my ear on him right now to see if he’s getting uncomfortable in that chair.
He’ll start squirming around and making noises and you can kind of tell he’s
uncomfortable.” … “He kind of hums and makes noises, different types, and you can kind
of tell, you kind of pick up on it, he’s just being a little ‘mouthy’ or something, you know
he’s wanting to…”

The non-disabled siblings’ experiences from the parents’ point of view: “Well,they [the siblings] were young enough to where they were really resilient. M.S. was two
years old and F.S. was barely, what, about three and a half, or four, so they were young
enough to where, I really think, they don’t remember it being any different.” (M.S. is
C.W.’s brother, and F.S. is his sister.)

“We saw the difference with our friend, E.F., her oldest was like 11, when F.F.
was born. Well, F.F. was diagnosed at age 3, so everything changed for D.F., their
oldest. Because there was such a long time where everything was normal, just like any
other family. And then F.F. gets diagnosed and everything changes. And she really
struggled more with it than any of the other kids that were close in age to F.F. because they were younger, their demands weren’t that much, and they just kind of ‘rolled’ with it.”

“And I think F.S. and M.S kind of ‘rolled’ with it because they were so young. We had some interruptions. In fact, now that I think about it, we had just gotten F.S. potty trained and were on the way to getting M.S. potty trained and it threw them both back into diapers. So, we did see some regression.”

“We did see that they were tired of us being gone a lot. They got shuffled a lot. I think F.S., whenever she saw them phone, us moving in a particular manner, she was just kind of looking at me, like, ‘Okay, where are we going next? Who are we staying with now?’ It was probably hard on MS because he was just so young. And he got shuffled at a much younger age than F.S. F.S., being the first child, and she’s just the typical, typical oldest child; she had our time. She had that time with us, by herself. So then, M.S. came along, it was still normal. So, I think M.S. didn’t really have that….he’s the poor middle child, typical middle child.”

As the siblings got older: “I believe that their attitude about C.W. seemed to, they didn’t have resentment. That was one of the things that I certainly was extremely concerned about, that they would be resentful of that. And I think they do, in a way have some latent, possibly latent, resentments that we weren’t able to focus on them the way that maybe we should of…But, as they’ve gotten older they’ve kind of worked through those things. We get along with our, with them. And, in fact, M.S. helps with C.W. a tremendous amount now. And, he’s totally devoted to him. But that was something we were real sensitive about.”

Significant statements of protective factors. Logistical care supports to care for C.W.: “…getting the services that I needed for C.W. in the home so I can have someone take care of him while I shared in that caregiving, but also had time for our two other kids
and for my husband. That’s something I really focused on was getting. So, getting access to state services helped, was probably the number one thing that helped us.”

Family seeks out peers: “…H.U. and I both decided very early that we were going to find other parents, that’s who we really, mainly wanted to talk to, other parents, and, ‘How did you get this and how did you get that.’ I would chase parents down if they had a kid in a wheelchair. I would approach them ask them how they got services ‘cause I wanted to know, ‘cause it is a daunting system. So I guess that was number one.”

Previous experience with CWD and hospitalization: “There was a family in our church that we were good friends with, when their third child was diagnosed with a terminal brain tumor attached to the cerebellum that could not be removed two weeks after she gave birth to her fourth child. I would go over there and take care of the three kids while she would be in the hospital with F. who had the brain tumor. And I stayed for several days while she would come in and out. My friend would spend the night at the hospital at night, she would be there during the days and then she would come home during the day. And she never wanted to come home to an empty house. She asked me to, please, come to her house and bring my kids with me. That was my function so we had this example of and she dealt very well with the doctors, very well with the nurses; she was quite literate. And I was meeting doctors, I was meeting pediatricians, well, we met our pediatric surgeon I didn’t have to meet in the future, our pediatric surgeon, because I was with her, not knowing that a year later I’m going to be in front of him and he’s going to be doing surgery on my son. And, just by her example on seeing what she had to go through, we had a little window into at least the hospitalization, the hospital part of it.”

Previous experience with CWD, living with a disability: WI: “There was a horse ranch I worked for in another town; their foreman had two adult children, he and his wife,
severe, severe cerebral palsy. This was back in the sixties and seventies, this was back, like, in seventy-nine. And they were young adults at that time, so they were, like, they were the old where they would be just be really contorted and stuff and we were around them a lot. ‘Cause E.F. would always bring J.P.F. and L.F. up at lunch just to be around the place, and while we were training horses and stuff. And everyone had a lot of respect for E.F. and J.F. because they took such good care of their kids.” HU: “Yeah, everybody admired them. Of course, they had two grown children in wheelchairs and they would bring them out to the horse ranch all the time. It was really impressive. It was really impressive.” W.I.: “It was. So we kinda had some good role models before we even had C.W.”

Searching for a diagnosis and treatment: "And when we got the diagnosis, when C.W. was six months old, then for us the process started right then because we were already looking for answers for why we were having the seizures and the different problems that he was having in development. So, the immediate thing was research. The adaptation was first, the realization that you’re going to need to adapt, we were going to be different, we’re not going to be doing what we thought we were going to be doing. We’re going to enter this world, and we were both very much prepared for that at the time."

(Researcher note: This is related to geographical access to services above. However, the repercussions are different, and significant enough, to warrant mention in both places.) Access to quality medical services: "Yes, certainly the hospital side. And getting services out of the hospital, and a ‘leg up’…I kind of contribute our success to the fact that we had Children’s Hospital. I mean, we had the best. We did not have to spend a lot of time searching and arguing with our private insurance or Medicaid to pay for us to go out of state, to go to the best, to specialists; I mean, it was all just down the street."
I’ve always felt like that freed us, that we had the time to put into getting the services that he needed and talking to other parents and trying to get that down.”

Financial qualifications for services: “And I stayed home. I was already home with F.S. and M.S. We had already taken a huge hit with our income with me staying home. We actually qualified for and didn’t even know it, qualified for Medicaid, qualified for TANF [Temporary Aid to Needy Families], Food Stamps, all that stuff, and didn’t even know that we did until right before C.W., when I was pregnant with C.W. So, one of the ways we got kind of got prepared for when C.W. came.”

Spiritual perspective: “…for us, the underlying thing, this whole thing was our faith. We’re Christians, and we were, really, as a result of the support of our church, going something that traumatic, we had a lot of support of a lot of friends, a lot of understanding, and a lot of babysitting for F.S. and M.S. while W.I. and I were busy in the hospital. ‘Cause early on I would go, I was there in the hospital a lot more. Later on, W.I. pretty much handled it on her own. She didn’t need me as much so I could go to work or stay at work. But, the faith that we had that there was purpose in this. But, to really understand our perspective, you have to know that underlies everything.”

Advocacy for other families/spouse’s admiration for what the partner is doing: “It evolved into charity work for W.I. because during that time she was doing this research, she was developing and compiling all this information, and began disseminating it to others. You know, she started her own parent group because she wasn’t getting the information that she needed from the support groups and so that’s why she got into that. And so it kind of just evolved into, well, this is going to be your job. And you can do charity for others by providing information for them about these programs. And that’s essentially what she did for many, many years and really still does.”
Gratitude: H.U.: "And my role in all this was I would have the 'freedom' to go to work and not to be burdened except for those times when it's critical, when we were in the hospital and that sort of thing. We got used to that. We got used to being in the hospital. We just figured, 'Well if this is the way it's going to be, it's the way it's going to be'."

(Researcher note: This issue is mentioned, above, under the physical strain section. It is mentioned here as the employer supports the family by providing flexibility.) Flexible employer: "Fortunately I got a job that, they were very understanding about me being gone at critical times. I could pretty much come and go as I pleased. That flexibility in the workplace lent a tremendous amount of support. Just the moral support they gave me at work, and it was a small company, it was only 20 employees. I was working as an (___) and once we moved into this neighborhood, we bought a house about 2 blocks from here that had a separate studio and I could work out there and they knew I would work at home and still get my work done, so I could be right there in the backyard and I could work late at night or whatever, and if WI needed something, I was just that far away as opposed to just being off at work. I didn't have to do that a lot, but I could do it whenever I wanted to. They knew that I would, that I didn't have to show up on time because they knew I wasn't necessarily getting a regular night's sleep. As far as support, that was huge, for me, both financially and psychologically."

Team work/coordination/skill: H.U: "We had a division of labor going on right away that she just alluded to a minute ago—I would be the support money. We were going to forego what everybody else gets to do where your wife goes out and works and hopefully paying the taxes on whatever I'm making."

Team work/coordination: "There was delegation. We did do a delegation of who did what. Why I went to all the doctor's appointments, handling the doctors, the notes for
the treatments was because it was ‘in my head.’ And I dealt with all the therapists, the home health provider, and H.U., he worked, he worked actually a job and a half. I mean, his primary job, and a secondary job, and then his own doing ____ for people. But he would always diaper C.W. as much as I would, get him in bed…as much as …It was a shared responsibility with C.W. at home but we did have our delegation.”

Team work/skill: “And I expected that, I mean, really only one person can keep up with all that medical history so we didn’t do the 50-50. Like, I go to 50% of the doctor part and you go to the other 50%. It was just like, ‘I’ll do all that.’ And, I wasn’t working, I was at home. I was already at home with F.S. and M.S., and it just naturally flowed to me.”

Family members contribute their skills: “Well, it was a naturally occurring process for us too because W.I. has a degree in zoology so she could talk all the medical stuff. Like I was telling you earlier, I think that’s a real critical thing to be able to converse in the language of these doctors, and therapists, and all these different people. Talk about support, education, about the terminology that you’re going to have to use; it just enables you to communicate better and naturally if you communicate more effectively with these professionals you’re dealing with. You’re going to get better services out of them. For one thing, they’re just going to have more respect for you. So, that was kind of, I think, a natural occurring process in terms of how we supported one another.”

Sibling felt their needs were taken care of: “I commented on how I had more independence but my parents were always there when I needed them and they managed to do all that, I don’t know how, but…”

Sibling was able to help someone else because of experience with CW: F.S. told her friend when they found out their baby had a disability, “Okay, well, I know that it can be like this. I know that your life can be normal with a child with disability normal, in
what in my eyes is normal.” … “Because I’ve been there and my mom knows how to get it. My mom knows what to get, what questions to ask, what things you need to know and what you have to push for. I don’t know and I wanted to be so involved because I wanted things to go just like it did for me, but it didn’t because hydrocephalus must just be ten times worse, I don’t know. But baby ended up not being able to make it. And I know that my friend is now struggling why, why did that happen to me? I was strong enough. I was ready for this, and I knew she was and I was going to be there right by her side. And I was like, ‘We had all the tools, why did you take her, why? Why?’ and that’s something, now, we’re both having to deal with as 25-year-olds who don’t know and are so young.”

Family contributions of siblings who did not have disabilities: H.U.: “Both W.I. and I are extremely strong-willed people, and so are our children. And I think as a result of that, those kinds of personalities, that both F.S. and M.S. possess… the situation required a real kind of independent mindset, that I think they fared probably better than they otherwise would have. And the fact that they kind of learned how to take care of themselves, without causing a lot of stress for us that we would have to focus attention on them. Now, don’t get me wrong, we’ve had the normal problems that families have with their what I call ‘Profoundly and Severely Normal Children’ with problems in school, problems with… But because they were so independently-minded about it at a very young age, and had the opportunity through this situation, where we kind of flung them out there sort of on their own with these other families. Now, they knew these other families, but sometimes they did not, in our church. But we’re talking about four and five-year-olds, six-year-old, seven-year-old children, as they’re growing up and they could’ve, they sort of got used to that, but I think that just brought out those talents and particular proclivities of their personalities already and that was a big help to us.” W.I.: “Well, I think later on, though, it kind of bit us in the butt.” H.U.: “Yeah, true.” (laughter) W.I.:
"As they became teenagers, they were so used to being on their own and being a little bit independent and by the time we followed through, we could tell 'em what to do but following through with what they did was a little bit difficult because our attention always got so interrupted with what was going on with C.W. So, as they got to be pre-adolescent and teenagers and even older adults, they haven’t, they're real independent and that …” (W.I. dramatizes what she imagines was going on in the heads of the siblings, M.S. and F.S., as the parents started following up on the siblings activities.) “….less willing to follow directions,…having to do it on their own and getting out there and it was kind of like, ‘Oh, now you’re going pay attention to us?! Geez, we don’t want you to pay attention, NOW. I mean, what? You want to know what WE'RE doing?!”

Sensitive expressions. The sensitive expression of the lived experiences of the members of Family Two reveals the power of commitment backed by a unified group of people. As pointed out, persistence on behalf of a family member is not denial of the reality of disability (Hartshorne, 2002). It is the courage, in the face of that reality, to seek the highest level of well-being and the highest level of quality of life for a loved one. The family values each and every family member and seeks to meet each person’s needs and maximize the potential of the family and its members.

3.5.2.2: The researcher’s notes on data collection and analysis of data contributed by Family Two

I was still experiencing strong emotions during conversations with families. I felt admiration that the family had done so much work to provide the best possible care for their children. I also felt pain and anger at the mammoth indifference of bureaucrats and school systems to the needs of these families. The parents in this family wanted to do a joint couple interview, so that was done first. At a later date, I did separate interviews with each parent, explaining that I wanted to make sure I got everyone’s complete
experience (including issues they may not have felt free to share in the presence of the other parent).

As I began to look at the data through the resilience lens, I was struck by constructive world view of both resilience theory and the ways social work tries to impact our communities. As I dwell with the data, I was trying to reconcile the Strengths Perspective with the trauma, stress, and injury that calls forth the resilient response. I kept returning to the risk factors that families were sharing and realized that, for families of children who have disabilities, risk is an inadequate term. The presence of a family member who has a chronic disability or illness is a risk factor. In addition to falling into a risk category, these families are facing barriers to education and barriers to medical resources. I began to observe these families struggling, in a perseverant manner, to overcome the threat of inadequate resources. It seems that the perseverant response became active in response to the threat. And I began to look at some issues as neither totally risk/barrier, nor totally protective because the struggle to take care of each other was mobilizing the persistent response (what I consider a protective response).

3.5.3: Family Three

Family Three was a family unit that included a mother and a young adult in his early 20s who needed a care level of seven, limited personal care and/or regular supervision. The risk factor statements are presented first, followed by statements that reflect mixed risk (or barrier) and protective factors, as well as protective factors. Sensitive expressions are presented after statements.

3.5.3.1: Significant statement labels, statements, and expressions

<table>
<thead>
<tr>
<th>FAMILY THREE FACTORS</th>
<th>Mixed/Risk and Protective</th>
<th>Protective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk/Barrier</td>
<td></td>
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Table 3-5: Significant statement labels
<table>
<thead>
<tr>
<th>Difficulty finding appropriate medicine:</th>
<th>Elementary school supportive, middle school not supportive, high school supportive</th>
<th>self-esteem in the face of difficulty, and interpersonal support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some disability/medical issues for which there is no effective treatment/intervention:</td>
<td>Financial difficulty affording specialized school</td>
<td>academic/career interests</td>
</tr>
<tr>
<td>Transition to college did not go well</td>
<td>Parent’s medical problems, but family and protective services intervened in a constructive way</td>
<td>Financial/logistical support for college/career preparation</td>
</tr>
<tr>
<td>Problems obtaining correct diagnoses</td>
<td>Mixed quality of day care</td>
<td>Ability to bounce back from an unsuccessful experience and persevere</td>
</tr>
<tr>
<td>Could not afford medicine</td>
<td>Concern about the future/independent living</td>
<td>Transition to college did not go well</td>
</tr>
<tr>
<td>Problems finding peer group</td>
<td>CWD’s disability is borderline (subissue: Which problems are disability related)</td>
<td>Parent and school support, parent had previous experience obtaining services/knew systems</td>
</tr>
<tr>
<td>Grieving over loss of typical child</td>
<td>Family tried to help with care of CWD but some tension is present</td>
<td>Open communication between parent and CWD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sought and found therapeutic interventions for behavior</td>
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<td></td>
<td></td>
<td>Family member’s previous experience working with children who had disabilities</td>
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<td></td>
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<td>Family support</td>
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<td></td>
<td></td>
<td>Family focuses on strengths</td>
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<td></td>
<td></td>
<td>Family supported religious practices of CWD</td>
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<td></td>
<td></td>
<td>CW’s hopes for the future</td>
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</table>

Initials Used to Identify Participants
CW: Child who has a disability
MO: mother
GR: grandmother
Significant statements of risk/barrier factors. Difficulty finding appropriate medicine: “I took him to a child neurologist and he was diagnosed when he was, I think, 3 or 4, with ADHD. And I chose not to give him medication until he actually began school. Because, you know, I didn’t wanna…I knew of the pluses and the minuses…” ...Then when CW was in college: “Yeah, he was on a big new medicine and we didn’t want to mess with that because it took so long to get him on the right mix for him, so anyway, and he started, he ran in a huge problem and I was out of town for my job. And I got a call from him pretty late one night and he was, like, want to jump out of the window.” “It’s also an ADHD medication and he’s tried it before and he really liked it, but the doctor that he was going to at the time, a physical doctor, said that it blew up his liver enzymes and so they kicked him back off of that.”

Some disability/medical issues for which there is no effective treatment/intervention: (Researcher’s note: The reduced quotations don’t fully reveal the strain of trying to help someone whose disabilities are nearly invisible. Yet the disability prevents full function, and there is no treatment to remediate the disability.) “But it’s been motivation, and it’s been responsibility, and it’s been all the things but we didn’t work on for years, when he wasn’t living with me, that just went out the window and the school. The high school wasn’t like a regular school—they would be more concerned with a child’s emotional and executive functioning things than they were with structure and responsibility and all that, so that’s been a hard part. What can I do? You know I can’t treat him like a kid. He’s not a kid.”

Problems obtaining correct diagnosis: “But we still haven’t found the right mix of stuff. We figured it out that he’s depressed, we figured it out that he’s Asperger’s. The child tried to function for years. It wasn’t until he was almost an adult that the Asperger’s was diagnosed. I said I think he had Asperger’s…” “…went to an Asperger’s specialist."
… “…yes, he does have it. And that’s, like, entirely out of the blue for me.” … “I realized about ADHD, knew a lot about ADHD and through my work with the clinics I knew about Autism, but not Asperger’s. It was really a relief to find out about this ‘cause there were things about him that I thought was a lack of my parenting, his lack of empathy and consideration.”

Unable to afford medicine: ”He was hooked up with the psychiatrist there on campus, and everything’s good to him to get medication. But when he turned 18 the disability stopped, so he didn’t get that anymore, so he didn’t get medications anymore, and I wasn’t on my insurance yet, but he had to pay for his own medication, which ranged over a thousand dollars a month.”

Problems finding peer group: “…he fell in with some disruptive students…” “But in the family, he didn’t quite fit in, he didn’t fit with the boy, he didn’t fit with the girl. He just had no interest in the same stuff. He’s always been a loner. He felt different. His mother was getting better and had been doing quite well on that occasion.”

Grieving over loss of typical child: “I didn’t see this coming, I didn’t realize the extent to which his handicaps were gonna get in his way, you know, until I’m just going through the grieving process. I’m just now realizing, you know, he may not grow up and get off on his own, he probably won’t want to get married, he probably not want to have kids, that kind of way, you know those kinds of thing…and it’s, it’s resilience…not really, not right now (laughing).”

Significant statements of mixed risk and protective factors: Mixed educational services (parent and school support, parent had previous experience obtaining services/knew systems): “Well, my mum was a social worker and back then she worked in MHMR. She knew how to get me the help I needed and she knew what thing she needed to say and she knew who she needed to talk to because she’s done it for kids
other than her own and advocated for them and so I always had the help I needed. " . . . ". . . she was willing to fight and everything to make sure I got the help I needed. If I had not had someone who was so dedicated to my success behind me all the time, I don't think I'd have gotten most of the help I had."

Mixed educational services (prior adequate supports are no guarantee of future supports): "But that change when I moved into middle school. Not just my medication, the school they were less cooperative and...well, the principal and the authority figures were less cooperative and they didn’t coordinate with each other or with my family as well. Like, for instance, there were days I’d have meltdowns at school, like, in public and they’d send me the counselor and they’d have her talk to me and everything, but my mum wouldn’t even know unless I mentioned it. They wouldn’t call her or anything, whereas when something terrible happened at any of the other two schools I attended there she would know. They would call her at work and say, ‘This is what happened, you can come down here, you cannot, it’s up to you what you wanna do about this.’"

Financial difficult affording specialized school: “A very, very small school, very exclusive, very expensive, and the only reason I was able to go was because a benefactor who was a friend of my grandparents who otherwise chose to remain anonymous put up most of the money that wasn’t paid for by scholarships; we had to pay very little of it ourselves compared to little and other than my grandparents my whole three years of high school was here in [large city] and just their approach to education was revolutionary.”

Parent’s medical problems, but family and protective services intervened in a constructive way: "Well, yeah, she had to be in the hospital a lot, and there was no one else to take care of me.” ... “Well, I need to give the context for that. The first time my mom had to go in the hospital. . .so when my mum sensed that stuff was going to go
down, she called my grandparents and they came and took me for about half a year and I
lived here in [large city] and then I returned to [the small town]. The second time my
mother became sick. . . the state got involved through various contrivances and things.”

Mixed quality of day care: "Some of them were better than others. At first, he
was staying with a lady and she didn't have air-conditioning . . . So I did take him to
another lady and a kid bit him and so she tried to get him to bite the kid back. That did not
work. Then we had a really, you know, a perfect situation for him, a mother, she had her
child and I think another child and Robert and he loved it, it was perfect, and then she
moved, so . . . he went to another day care and there was a kid that was, like, bit him up all
the time and I tried to work with the day care about it. And the kid was the day care
owner's grandson so they had a problem with that” . . . "The last day care he was at, they
were great, they were called [name of day care center] and they tracked what's going on
and let me know what's going on with him.”

CW's disability is borderline: “And then you get to the point because he's not
severely any of these things except for ADHD.”

An associated issue with borderline disabilities: "Which problems are disability
related? What can he do and what can't he do and what can I expect of him and what
would it be wrong to expect of him. That's kind of where I'm at now, that's where I need
help.”

Planning for the future: "As far as adapting, I mean, that's constantly what it is.
You are having to follow the track of whatever you are on and trying to find whatever you
can to help you. He's also applying for disability right now, I've gone to things with him
before but I want him to be as independent as he can be so I try to get him to do it by
himself. I think I might have to get involved in the disability thing with him but I want him
to work it out because I'm not always going to be here. He's not going to be able to
depend on me forever. And I want him to start making some steps to make him more independent. He’s not so involved, meaning that he doesn’t have so many serious diagnoses that he can’t ostensibly someday be on his own, you know. It’s way different because people expect more from him than he’s able to give. We’ve talked about him moving into a group home. He might be eligible for something because Autism is considered a related condition in MHMR so he’d eligible on the MR side . . . it’s structure, and he really needs the structure. . . the other thing that’s really hard, you know, what happens to him if something happens to me?"

Family tried to help with care of CWD but some tension is present: GM: “When she was pregnant with CW, they took her (MO) off her drugs . . . they didn’t put her back on enough of the dose and my heart was just broken because she never slept after he was born. In the hospital, she never slept. So we decided it would be better if I cared for CW. There was a deep, deep attachment. But there was a lot of tension in the family about who would take care of him. We tried to learn what was out there for us to learn and we started talking to the people involved. We got ourselves involved.”

*Significant statements of protective factors.* Self-esteem in the face of difficulty, and interpersonal support: “For a while, I was pretty depressed. . . also, the fact that I felt kinda worthless because I had lost two jobs over the course of two years. I felt very good about myself talking to my psychiatrist, talking to other people about stuff facing me. You know, I realized that I’m far from worthless because I have talents, I just haven’t found a job to put those to use yet and I’m growing more able to, um, handle a job like situation and I’m going to try again pretty soon… is the fact that I’m not alone and I know that I’m not alone and I know there are people who want to help me because they realize that though I may be outwardly intelligent, but I have some issues and that they understand that.”
Academic/career interests: “I was really a political science major but I’m probably going to change to something else, something more practical…”

Financial/logistical support for college/career preparation: “Well, a little bit of both, uh, I am working with a department called DARS, Department of Assistive and Rehabilitative Services. Started working with them in my second year of high school, I believe, and they’ve been immensely helpful, made sure I had the things I needed to succeed in high school, help pay for counseling, books, my computer, tuition, and job coaching. And the great thing about DARS is that they don’t have like necessarily a framework that they try to fit you into.”

Ability to bounce back from an unsuccessful experience and persevere, and academic/career interests: “I may take some courses on creative writing or history or something of that nature because those are fascinations of mine, just curious of time or places that I know very little about and educating myself. They (DARS) let me pick what I wanted to study but some of them were not very good choices. Like, I tried to take math with a lot of weaker subjects, I ended up getting a withdrawal from that and I tried to study Chinese. Studying any other language would be easy, but not one that uses an entirely different alphabet and putting a lot of emphasis on syllable, creating a totally different word and it was crazy. I just piled too much on myself my first year, like right after high school, and a very nurturing high school at that, to going on my own and living in a dorm and all that stuff.” . . . “I’m probably going to change to something else, something no . . . more practical.”

Open communication between parent and CWD: “There’s nothing because we talk about things like that a lot. She’s always asking me what she can do to be a better mom or ‘Am I a good mom?’, stuff like that, but the answer is nothing under her control.”
Sought and found therapeutic interventions for behavior: “But you know, I know he was difficult to deal with ‘cause he was difficult for me to deal with as a single parent, and even after because he’s just a… I went to a counselor ‘cause I didn’t know what to do with him. Spanking does not work at all. And, with the counselor, he taught me some ‘one, two, three magic,’ which is awesome. He said, ‘All right, tell him one time,’ says ‘Son, I want you to pick up your toys,’ then you know, he said we’ll explain this to him before we do it. And he said the second time you just say his name and say, ‘Son that’s two,’ and the third time he goes into his room and then he’s not going to come out and he’s going to stay in this room. Well, I did that and I was surprised the neighbors didn’t call the police because he was screaming, yelling, and beating the door. It was really hard to go through but I had to do it once. The second time that he actually had to go into his room, he calmed down, he said, ‘Mom, I want to come pick up my toys,’ you know whatever it was and I would say, ‘No,’ I had to do it again until he would do whatever he’s supposed to do. Yeah… it worked real well, you know, I had to have help because I couldn’t figure out how to respond to his behaviors.”

Family’s previous experience working with other populations of children who had disabilities: M.O.: “Actually, one of the things that helped was I had worked so much with the head of the special education group. She and I had formed very close bonds so she was so easy to work with and she was the best I’ve ever seen and then when she retired things changed.” G.M.: “You know, I worked in the system for 25 years in different areas. I did occupational therapy at a children’s hospital. I started all the programs in the small school district we lived in many years ago.” … “I was always attracted to the care of children who had medical problems. And I just felt like I wanted to do something with my talents or responsibilities, something in caregiving.”
Family support: MO: “So, I called my parents come get me and they did and he stayed with some students at school that semester. And he came back during the summer and, I think, about a year later, that time I was having some physical problem, I went to the emergency in the hospital and CW went with me ‘cause I was the only one in town at that time. I was still married but my husband travelled to work so the social worker at the hospital called child protective services and they took him. So, he was in the system for a little while and then my parents got him out and he lived with them for 4 years.”

Family focuses on strengths: “Like you said, he’s a great kid, he really is. He’s a neat person and I’ve told him that too, I said even if you weren’t my kid I’d like you. He’s got a lot of enthusiasm and a lot of interest and I think his medications, not too long ago they increased his antidepressants and they put him back on Intuniv, which was his favorite med he ever had, so the meds make a big difference and him being on…” … “But I think he’s getting to a place now where he is really wanting to make a difference in his life, he’s really wanting to dig in and get started with his life. And that’s something that I’ve kind of been waiting for. That’s one and some of the other thing is his hope and his strength…his beliefs, I guess that’s what….Yeah, if he believed in something he’s like a dog with a bone, you can’t get it away.”

Family supported religious practices of C.W.: "After he came to live with us, I went to his church, a Baptist church. He didn’t want to go to a catholic church, it’s a really good country church, but he didn’t want to go to a catholic church. There weren’t a lot of kids in the neighborhood his age and there wasn’t a lot for him to do, so when we looked for a church we looked for one that had a very good youth program so he could meet people and then engage in something. And one day he came home, and I asked him, ‘Do you want to try it?’ and he said yes. We did and he had a thousand good friends
there and they had a good time. The kids and he had something to hold on to and then we had enrolled him in this school for kids with special needs and he started making friends there.”

C.W. on his hopes for the future: “And all kinds of different families, all kinds of different people, and if this is going to be studied by anyone who has the authority of a physician to do anything, I just want them to know that these are families that are almost at as much risk of breaking apart even statistically as families that are affected by drugs or alcohol or violence, you know the only difference is—main difference I should say—is that nobody has any control over the (neurological) disability. I'm not saying that everyone who is alcoholic or drug user has total control over their actions because they could open a can of worms. Yeah, basically there are definitely at-risk families and they should be treated delicately and they should be treated with, you know, all the care and all the concern that a family…otherwise at-risk family will be treated with. And that's pretty much all I have to say…lots of families have had to relocate or, you know, do entirely different things because there are things that the government simply cannot or will not provide that families need, especially in (the specialized school). You know, people are being sent to school, some of the families who went there are pretty wealthy…”

Sensitive expressions. The sensitive perception and expression of the lived experience of Family Three is reminiscent of several science fiction movies in which supports appear to characters who have been forced into dire and necessitous circumstances. In our world, beyond the camera lens, sometimes resources appear when acute need (a need that could not have been planned for) emerges. That is not to say that this family experienced a “happily-ever-after, fade to credits” outcome. They still
struggle with vulnerabilities related to nearly invisible disabilities and untreated
disabilities.

3.5.3.2: The researcher’s notes on data collection and analysis of data contributed by
Family Three.

Conversations with members of Family Three familiarized me with the risk issue
of living with a borderline disability. It raised my level of awareness that people facing this
struggle can’t function without supports, but often supports are denied to them because
they sound, and seem, to have sufficient abilities to take care of themselves. As I
continued to think about the persistence I had seen in all three families, I started to
consider why I could not label this covert finding “love” or “commitment.” As I did a
member check interview with Family One, I asked them about the part persistence played
in their life. The grandmother in Family One responded by saying, “Yeah, you have to
have that, man. If you don’t, it beats you down and will definitely beat you down.” The
grandmother went on to add that behavior problems are an additional significant issue in
her family.

3.5.4: Family Four

Family Four was headed by the paternal grandmother and included the CWD
who was in her early 20s. The father, one or two cousins, and the younger sibling of the
CWD were regularly in the home and involved in the care of the child. The CWD had a
diagnosis of Rubenstein-Tabi Syndrome. She had significant cognitive, expressive
communication, and vision problems, and moderate balance and ambulation problems.
Her care level was three, which indicated she needed extensive personal care and/or
constant supervision. The results section lists the most significant statements that
reflected risk factors or barriers first, followed by factors that were mixed risk and
protective, and the last category of statements are those that reflected protective factors.

After statements, the sensitive expression is delineated.

3.5.4.1: Significant statement labels, statements, and expressions

Table 3-6: Significant statement labels

<table>
<thead>
<tr>
<th>FAMILY FOUR FACTORS</th>
<th>Mixed/Risk and Protective</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Burnout</td>
<td>Educational services</td>
<td>Family support</td>
</tr>
<tr>
<td>Caregiver loss of typical resources</td>
<td>Information on Services/Support Services</td>
<td>Skills, behaviors, care needs, potential of child who has disability</td>
</tr>
<tr>
<td>Family member sacrifice/misunderstanding</td>
<td>Sibling refused to be interviewed</td>
<td>Problem solving</td>
</tr>
</tbody>
</table>

N. G.M. = grandmother, F.A. = father, C.W. = child who has disability, C.O. = cousin, F.S. = female sibling

Significant statements that reflect risk/barrier factors. Caregiver burnout: "...she [the mother of CW] detached emotionally, immediately. She did just the bare necessities and stayed in, just stayed in. She was experiencing such disappointment and even depression that she just continually went downhill. Finally she said, 'Come and get her, I can do it anymore.'"

Caregiver loss of typical resources: "Like, my grandma can't spend a lot of time with her friends, because when she's not at work she has to come back here and let the person off work, because they already done their hours. So I know my grandma can't do as much as she would like and even when she comes to our houses—even when she brings CW, she still isn't being able to interact with us as much as she would like, because CW is there for all of us to still attend to, but if she has a different baby sitter here, she would be able to spend time with us."

Family member sacrifice/misunderstanding: "Yeah. She—the adults in our family had to help her more. So, when we were younger, we might have been wondering
why she had more attention but that’s because she needed it, and maybe—I mean, I’m just her cousin so I wasn’t living with her, but maybe her sister felt left out, because CW got more attention because they had to focus on her and help her and—but I’m not sure.”

*Significant statements that reflect mixed risk and protective factors.* Educational services: “Yes, less flexibility, LT, the last teacher, she had been there forever and everybody knew she walked on water; nobody gave her any flack. And we’re close and I developed a relationship with all those teachers and the aides and because they need to know how they are appreciated too. And he was thinking he had to stay in control, right and he was trying to use the standard things that they teach him about restraining children who don’t cooperate. But I have known he had to have some training, and he had to have some direction and I called an ARD meeting and with all the powers that be, that this is what I want him to do to help CW. And this other step will not work and I don’t want any, I don’t want your expectations. I want your expectations and mine to be the same.” (An ARD meeting is an Admission/Review/Dismissal process in which a student’s services are either begun, continued without changes, continued with changes, or discontinued.)

“She responds—the best thing you can do for CW is, when she starts getting out of control, she starts acting out, is bear hug her—you got to gather her up and give her a big firm bear hug.” … “And scratch her back, remain calm, just tell her you know you are okay, and just you know be a sweet girl and typically that will, that works. This is what works for CW, it’s a really the best thing for her, it will be the best thing for him [the teacher] and enable him to provide effective behavioral support.” … “If you all got an issue with that was, let’s talk about it. But nobody did, I mean…”

Information on services/support services: “Because the family just can’t do it. And financially or physically or emotionally, if you don’t—if there’s not a bunch of you,
you’re not going to be able to pull it off.” … “Just that you know the thing that families need, want, if the professionals would tell us about services and supports, how to get help. You cannot make an informed decision if you can’t get any information, and I’ve not been able to get it.” … “And I was trying to find an answer so that I could take a job because I knew I wouldn’t have the same salary and benefits that I had when I started to have her with me. I had to have some way to pay for her care and the camp when, thank goodness, that I asked enough people and made them listen to what I was trying to get. Because there is this language and every industry had its own language. There is a language in the health industry and, if you don’t know it, you don’t get the answer that you are seeking or if you get them, you don’t understand them. So how many people don’t get what their children need because they give up? I have to say you know I had to find a job, I had to go to work, and I know that I will not be able to pay somebody to care for her. And I said, ‘Oh, I think we have been told that.’ No. Yeah, yeah. You know it was a very frustrating moment. I was thinking, thank you God, I am just so glad, when we finally got attendant care for her. We had been doing by ourselves for 18 years.” … “Well one thing that finally helped was when she turned 18, then she could get Medicaid, which opened the door for her to be able to get, I think it’s called PCS (personal care services) so it’s—she could get like attendant care, she could get services through Medicaid or someone to come to the home and care for her, so that we could work. And we didn’t find that out, she was 18 in July but we didn’t find it out, until February or March of the following year. It took us that long and we kept—we continually looked for supports and then they said, ‘You’ll got to be able to have somebody to come into the house and get...’ But everything we tried while she was living with her dad, we were told he made too much money, which is asinine, excuse me, but nobody on a regular salary can pay for the care of a child like CW.” … “Then she turned 21 and that mess started all
over again, when she turned 21 the benefits for adult Medicaid are far different from the
benefits for pediatric Medicaid.” … “But every time you think things are going to be okay,
then somebody pulls the rug out from under your feet! You cannot, you cannot take a
breath. So you can't plan, you can't depend on the ground underneath your feet!” …
“They told me, they said, ‘They do not care if she falls.’ I said, ‘Well, it is not an issue of
her falling, it is an issue of, if she were here alone, it's like leaving a two-year-old at home
alone, or actually more dangerous because she is taller, she is bigger, she can get out of
the house and wander off, get lost! If she were able to get food…she had a choking
issue and last spring they had to call EMTs to the school because she was choking and
they couldn’t get it out.” … “There is a huge mistake in her level of need and level of
services so I’m contesting that.” … “We are low maintenance if we can just get enough
hours to have her cared for. She cannot be left alone period, so she cannot be left
alone.”

Sibling issues were not done for this family. Researcher note: CW’s sibling, FS,
refused to be interviewed. CW’s cousin [see family member sacrifice/misunderstanding
section above] guessed that FS might be feeling have felt left out when the sisters were
younger. GM said maybe FS felt sad about the whole situation of CW’s disability. The
researcher asked GM to give FS the researcher’s telephone number and e-mail, in case
FS changed her mind. The family members were left with a copy of the informed
consent, which contained contact information should FS need help dealing with emotional
distress.

Significant statements that reflect protective factors. Family support: “What
makes it possible for us is, as I say, that’s where we draw our strength. And we’ve all,
like, been a very close family and as far as my family, her dad is out of the family, that’s
my family, and we are a large family.”
Skills, behaviors, care needs, potential of child who has disability: “She’s made a lot of progress. She has become more interactive by far because of all those years she was locked in that room she didn’t know anything but isolation. But now she’ll come and you see there’s some blocks in the floor, she’ll come in here and get in the floor and play for blocks in here while she’s here with Jessie in the afternoon. She’ll do it when she’s here with me in the afternoon. She’ll come get on the couch with me now. She never did that in the past. She stayed.”… “A lot of catching up to do, a lot of making up to do. But, you know, that’s what keeps me so persistent and so determined, is that I see progress being made in her skills and interaction.” … “So progress, you know, when you can see her evolving, you don’t want to quit.”

Child expresses affection: “She’ll come get on the couch with me now. She never did that in the past.” (This is also quoted above in the section for skills, behaviors, care needs, potential of child who has disability.)

Problem-solving: “A lot of catching up to do, a lot of making up to do. But you know that’s what keeps me so persistent and so determined is that I see progress being made in her and if she had to just be—and I know that [the director of the Adult Day Care Center] has a real good thing going, a positive environment with affection and laughter and he’s told me, he said I want you just to go look. And he said they have a place here in [town near metroplex] that is females only and he said I was over there the other night and we’ve got one little person there who she was nurturing to the staff, she was going around giving them kisses. Because that’s my thing. I said. you know. if CW were in a residential facility, where would she get her kisses?”

Families provide intangibles that institutions cannot: “…Nurture, Nurture …”

Sensitive expressions. “We can only give so much. When you have a person who needs 24 hour per day, seven days a week care, you can’t put that on one person.
They can’t take it. But at the same time, we can’t ship our child away. So we sacrifice any personal life, and therefore sacrifice our personal and emotional health, and we take time away from other family members, because what is the alternative? To abandon our child?”

“An additional point that needs to be explicated between support services and developmental transition points in individual/family life is that such transition points are high risk factors in and of themselves. When systems do not provide for smooth transition, the risk that the family will disintegrate under the burden increases. The very systems that are supposed to support and protect cause injury.”

“When the teacher ‘gets it,’ they can do wonderful things for our child. They can maximize her growth and help her reach her highest potential and her highest level of independence. And we try to let them know how important they are, what a great job they are doing, and how much we appreciate them. But, when they try to make the child do things the child can’t do, school becomes hell on earth, and my granddaughter comes home damaged, and the whole family suffers. I try to tell them what we have found works to help her fit in at school but they treat us as if we don’t know anything.”

“We carried the whole burden, by ourselves, for years…..the medical care, the child care for a thirteen-year-old who functions like a two-year-old. We searched for help and couldn’t find anything. There’s help out there but no one gives that information to parents. Finally, we got some supports for medical care and attendant care (she can’t be left alone, she’s functionally a two-year-old) and it was like the weight of the world was lifted off of our shoulders. And then the sky came crashing down. One day she’s 21 years, 364 days old and can get attendant care so I can work. There’s no one to pay the bills if I don’t work. She turns 22 years old and all of a sudden they cut her supports in half.”
“She’s a part of our family and we love her. We see the progress she’s making, and that she knows she’s loved, and she loves us in return. The family pulls together to take care of her. When we run into problems, we will keep looking for solutions. She’s our daughter and granddaughter, not a piece of trash we can throw away into an institution. There is also, in this family, the emergence of the ‘Advocate’ role that this family is just now realizing and assuming.”

3.5.4.2: The researcher’s notes on data collection and analysis of data contributed by Family Four

My previous experience with families of children who have disabilities was one of the reasons I had chosen the phenomenological research method. From what I had seen in the past, the biggest barrier FCD (families of children who have disabilities) face is getting a free and appropriate education. I knew the phenomenological analysis would assist me in bracketing my own experiences so I could get a more accurate picture of the lived experience of FCDs. It was an emotional jolt to meet a family who was facing the same issues my family had faced: families cannot provide 24 hour a day, seven day a week care for a family member. Family Four and my family had faced a similar issue about another factor, support systems that change supports without warning and without any attempt to help families prepare or destabilize an already shaky system. I felt elated at the peer connection, and horrible that I was happy when another family was in distress.

3.5.5: Family Five

Family Five was composed of both parents, a CWD who was eight years old, and her six-year-old younger sibling. The CWD had a primary diagnosis of Autism and a care level of five, which indicated she needed regular personal care and/or close supervision. The risk factor/barrier significant statements are listed first, followed by mixed
risk/protective factor significant statements, followed by protective factor significant statements. After the significant statements is a section offering the implied sensitive expressions.

3.5.5.1: Significant statements, statement labels, and expressions

Table 3-7: Significant statement labels

<table>
<thead>
<tr>
<th>FAMILY FIVE FACTORS</th>
<th>Risk/Barrier Factors</th>
<th>Mixed/Risk and Protective</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavior problems of CWD/rejection of her sister and father</td>
<td>Stress: dealing with diverse needs</td>
<td>Flexibility/meeting diverse needs</td>
<td>Problem solving flexibility</td>
</tr>
<tr>
<td>Financial difficulty paying for medical treatment</td>
<td>Early signs of disability</td>
<td>Caring for the needs of each family member</td>
<td></td>
</tr>
<tr>
<td>Mixed support from school system. CWD is now home schooled.</td>
<td>Some respite with a private sitter but still cannot leave both children with a sitter</td>
<td>Key partner</td>
<td></td>
</tr>
<tr>
<td>CWD receives no social security, Medicaid or Medicare</td>
<td>Child’s disability may not be severe enough for her to get supports</td>
<td>Sibling is academically advanced</td>
<td></td>
</tr>
</tbody>
</table>

\[ N \] W.I. = wife/mother, H.U. = husband/father, C.W. = child who has disability, F.S. = female sibling

*Significant statements that reflect risk/barrier factors.* Behavior, academic, and other problems of CWD: HU: “I try to explain CW’s behavior to FS. I tell FS, ‘Yeah,
CWD does love you, she just doesn’t know how to show it. And I’ll hear FS tell CW, ‘CW, you love me, you just don’t know how to show it’ type of thing but you know there’s a point where it hurts FS because she wants to love her sister. CW is very ‘I like my things the way I like my thing.’ I don’t expect her to be an outgoing child or anything but at least to be helped with activities and in different therapies and stuff trying to get, so that at least she and FS can play together once in a while, or at least they can interact and don’t have these battles all the time. Usually kids with behavior problems and social issues have their social issues across the board, but with CW it’s only with her sister. We don’t go out to dinner any more. FS had an event—she was in Christian Youth Theatre. I guess WI had taken FS to the rehearsal and then the performance was after. So, CW had to be in the car riding there and back. I guess it was just a battle the entire way there and back. And so by the time I get home from work to go to this performance, WI’s had this battle with CW and threatened to take away her iPad and all this other stuff to get CW to go. And CW went, and everything was good and we got through it but it was having to have this battle between CW and FS. It seems like CWD has gotten worse about not wanting to get out of the house. I guess you have to learn to adapt to your situation. And that’s a difficult thing. I would like her to be able to get away, go, do something, get away from both of them for a while, especially CW because it’s feeling a cons—she is constantly there with CW because she is home-schooling CW. And CW won’t let me do stuff for her and WI really needs time to for herself.”

Financial difficulty paying for medical treatment: “Health becomes a resources issue, it’s like how much can you—families that have children with special needs, it becomes incredibly taxing of resources.” … “I guess when you spend money on trying to do therapy or something, you just hope that it’s okay. Something is going to work. I don’t know, I think it would be nice to have some way of finding something that will help CW be
able to cope with getting out. I’ve got a friend that was using a therapist at night. I don’t know if she’s going through her insurance company. He works at one of the schools, he’s working during the night with her daughter and charging $50 an hour. I don’t know if she was going through her—I don’t know. So I was going to contact her so we’ll see. I’m hoping that, because I know a lot of the ADA stuff isn’t covered through insurance. We have [private insurance company] for the moment but it’s probably going to change."

School services inadequate: “CWD got really lucky at her first grade, I almost figured out in kindergarten. I homeschooled her, she wasn’t connecting with her teacher and they took away all her services. That’s when I hired a child advocate for the school system and got her services reinstated because she had an Autism diagnosis but they weren’t giving her the services she needed. They were giving her speech therapy and her special education services were listed as speech impairment. It was under speech not under Autism even though everything said Autism. I mean all the, we had friends that taught PPCD [Preschool Program for Children with Disabilities] and taught at the School District even though, like, everything I had written and all the stuff indicated Autism. They never did an Autism screening, which I didn’t realize, and I mean, our friend that read it was, like, this all says Autism, I don’t know why, you know, all these things are indicating Autism so, like, I don’t know why they put it under a speech therapy.” … “…and not recommending—well, they could have suggested doing Autism testing at school. I mean, what’s sad is they had indications that Autism was there. They just like buried their head in the sand and hoped it would go away…” …“They set it out so that the next school could take her services away. I mean, by diagnosing her under speech instead of Autism they set it out so that her services could get taken away.” … “So in the fall they had, she had an aide for writing in the fall semester. Well, when we got to the first semester and her annual IEP [Individual Educational Plan] came out, they took away her specialized
education and that’s when your writing requirements significantly increase in the kindergarten’s spring semester. Well, and her teacher starts punishing her by taking away her recess and also other times administering ADHD medicine. Then she started, like, refusing to go to school, hating school, and, yeah, I almost pulled her out, though I ended up hiring an advocate, getting her services reinstated, but I started looking at home school groups and researching homeschooling. So, at the start of the first grade, I already had an option of being homeschooled or going to first grade. She tried going to first grade but I was completely prepared to pull her if it didn’t go well. We got really lucky and she adored her first grade teacher; I mean, I just fell in love with her and her first grade teacher loved her, developed a relationship with her, constantly checking on her still, and then she moved to a different school, second grade not so lucky, which is kind of what I figured would happen. And then the workload increased. So when her, she has [a fall and a spring IEP left]. So October comes up, we’ve got an IEP meeting, it shows that she’s more distracted and she’s paying less attention like she did last year, and she told me she hates school, or don’t like the school or don’t like the teacher and, you know, the homework, if she actually do all the homework it’s like an hour of work each night, I’m like I don’t want to do this, you know, and I don’t want to fight with her, if I want to spend an hour doing work, I’d rather just do it during the day, get it over with, and then my evening just spend with CW. So, I just decide to pull her out.” … “I knew we were going to have to home-school her. We were already planning on home-schooling her by middle school anyway, before her fifth grade. I’d never wanted her to go to middle school, just the environment and the other students. So I started home-schooling her earlier than I had planned.” … “Even on ADHD medicines she was bouncing off the walls. She is not behind in the system but she hates school.”
CWD receives no social security services: “No. I’ve never looked into social security. A friend of mine, he’s got a daughter who she’s homeschooled, she’s a little more severe than CWD. I mean I guess she’s Autistic. She looks like she has Downs Syndrome but she doesn’t have Downs Syndrome. Well, he’s home-schooled her since kindergarten but she qualifies for the, I don’t know if it’s Medicare or Medicaid, but her husband doesn’t make a lot of money and we looked into that one and Dad makes too much money. I don’t know if we—if CWD would qualify for social security.”

Significant statements that reflect mixed risk and protective factors. Stress and problem solving/ flexibility: “You know it puts a lot of stress on your family.” ... “...CW didn’t want to go out and go do, and FS and I went in to the parks and did things.” ... “And just like, you know, I just got to be calm because it’s—she’s going to tense and cry and stuff.” ... “CW is FS’s polar opposite.” ... “So, yeah, putting them in the car together is a nightmare, because you need to put noise cancelling headphones for CW...”...“...FS wants to constantly be moving and talking and making noise and wants the constant stimulation and if you’re not going to give it to her, she’s going to do it to herself, but that kind of stimulation is more than CW can deal with.” ... “It’s always a challenge trying to figure out how to interact with her, when she will let me interact—it’s like you try to use different things. You try this counselor, that counselor there.”

CWD is gaining increasing awareness of sensory issues and able to adjust her environment: “You know CWD has sensory issues.” ... “Sometimes she’ll go to her room to get away from everything.”

Early signs of disability: “Trying to change her foods was the first indication we had that she was having problems. When we tried to change her to more textured foods as a baby, she couldn’t handle the change. Her preschool suggested we get her tested at three at this PPCD [Preschool Program for Children With Disabilities]. They tested her
and diagnosed her with anxiety disorder but they did not put her in the program. Then, at three and a half, that’s when we were like we think there’s something else wrong but we didn’t know for sure. So that’s when we started suspecting there was something else wrong and we took her back at four to have her retested and that’s when they put her in the program. It was really at four that we knew it was Autism.”

Some respite with a private sitter but still cannot leave both children with a sitter: “I’ve found a sitter—I’ve got a home school sitter like I—CW is fine with the sitter if it’s just her. FS was playing softball and CW didn’t want to attend. So there’s a homeschooled girl down the street just about 15. I found her on the home school sites and I hired her a couple times for CW. But CW has gotten worse with FS, and right now I’m not comfortable with leaving both of them with anybody except their older step-sister.”

Child’s disability may not be severe enough for her to get supports: “CW’s kind of weird in that way. In some way, she’s socially immature and in other ways she’s fine. I mean, emotionally, she’s kind of a typical ADHD kid in that, yeah, socially though immature but just like a normal kid with ADHD who tends to act, you know, socially immature. But, in terms of like common sense, intelligence, I think she’s above average. She’s always been above average in common sense stuff, she’s actually pretty responsible.”

Significant statements that reflect protective factors. Problem-solving: “Problem-solving is a continuous learning process—learning what works and what doesn’t work. It’s been a balancing act trying to meet both CW’s and FS’s needs because FS is so outgoing and that drives CW to distraction. I’m about to hire a behavior therapist for CW because she’s becoming more and more reclusive and less and less tolerant of her father and sister. But you have to accept that sometimes things are going to be nice and smooth, and other times when things are just not. The internet has been an invaluable
support for me. When CW was first diagnosed with Autism, the internet provided a wealth of information to educate us about Autism. And through the years, it has also been a social network. I’ve been able to learn from sharing with other parents who have struggled with similar issues.”

Caring for the needs of each family member was not performed all at once. Researcher note: There was no one conversational thread where meeting the needs of each family member was addressed. This factor appeared in conversations with WI in which she talked about home schooling CW, and about trying to ensure that FS attends various activities. It also emerged during conversations with HU when he, also, spoke about concerns about CW’s withdrawal, how CW’s behavior impacts FS, and his concerns that CW rejects his help, placing most of the caregiving responsibility on WI.)

Key partner/caring for the coordinator/leader: “To me, WI shouldn’t have to do everything. I would like her to be able to get away, go, do something, get away from both of them for a while, especially CW because it’s feeling a cons—she is constantly there with CW because she is home-schooling CW. And CW won’t let me do stuff for her and WI really needs time to for herself. Yeah, because emotionally and mentally it cannot be extremely difficult unless I—I want you to have some other time, I just don’t know how you do it, how do we do it, how do we get it. We need to go, take an afternoon and go—I don’t care just get away from home let me deal with them. And, I think some of her hobby would be a change of pace at least, but it’s difficult for her to get away for even that. That is difficult to say, I wish—I should just go on. I don’t know because I wish that CW was at least more of receptive to letting other people help with things…not having have her mom do everything. And the other thing I keep track of is making sure that each kid gets separate alone time with Mom.”
Sibling is academically advanced: “I've been able to teach her concepts and she'll apply that concept, I mean, a simple concept, she is in first grade and they are doing addition and stuff. But even before she was in first grade, in kindergarten I was teaching her addition and then over the summer we got in and she had a workbook, it was at a first grade level, she’s now going to second grade type things. And I had double digit addition, double digit subtraction, and other stuff and just taught her how to do the double digit addition. You know, they do your right side, do your left side, and if you’ve got to carry something, carry something. And so there was double digit subtraction in it and I was, like, ‘Hey, FS you want me to show you how to do that?’ She’s, like, ‘No dad you’ve already shown me how to do this, you do the right side first and then you do the left side.’ And, I mean, if you are having a ball [decimal] you have to work with that, but this was simple enough that you move them to borrow from one another.”

Searching for and valuing the strengths of the CWD: “Yeah, and that’s the thing I have a hard time figuring out is what does CW easily do or easily learn?”

FS has multiple sources to meet social needs: “You know, mama can you set up play date with ‘this and that person,’ I want to go to the park and play.

Other family member pursing disability related career: “So, it’s kind of interesting she chose genetics, that she’s [CW’s young adult stepsister] chosen that field, but she always loved science and stuff.”

Planning for future: “And, I don’t know how, as she gets older, how that will be. You know with school she would—recess, she wouldn’t really interact with the other kids in the playground.”

Cultivating patience and being aware of limits: “You know, having a child with disabilities, it’s having to make sure that you just got to have total patience and at times I’m like, ‘I have had as much as I can stand.’ Because I don't like yelling at my kids, I
don’t like—you try to be as calm and reasonable and there’s points where it’s just like you just have a hard time of like, look, ‘Listen to me’ or just patience is a tough thing. You have so much and then there’s a point where you can lose your patience like, ‘Okay, step back.’"

Medication and medical treatments for CWD: “All right, definitely medication for anxiety and ADHD.” … “When she started kindergarten she had just started getting the ADHD meds, it really took the whole kindergarten year, you know, bouncing around to find the right one. And, of course, there is no perfect one and everyone’s got side effects where you kind of have to choose something and give up something. Right now we’re all concerned of, which have kind of a nasty downfall when you come off of it, you’re grumpier but it does help her. And she’s not ‘off the wall.’ … “ Really, in the early years, we did occupational therapy to assist with her hand tremor, which helped with her writing, you know getting her writing to where she could—she started therapy before at kindergarten and then through kindergarten she developed two and a half years which helped to get her to where her writing, you know she’d be grade level with writing so she did speech services, up until I just pulled her out of school…”

The doctor prescribing medicine for the CWD was with the family from early in the child’s life: “She was born in December and I had probably started seeing him maybe in—I don’t know maybe September or something.”

Peer support: “I think that the key for the parents is that there’s a support system of friends that also have kids who have the same sort of disability your kid has. Having other friends that have similar disability issues to deal with because parents with normal kids don’t understand. So it’s just, I think, that’s like probably the biggest support, it’s just being able to call somebody with the same kind of kid, even if their kid had another form of disability. One of my friends has a kid with Asperger’s, her son, you know, mostly acts
differently than Hailey but she can still relate sort of, yeah. As opposed to the ones that have normal kids don’t, can’t know at all. When CW was in PPCE, she got really close to two of her classmates, and I met their parents and we became friends. We got lucky because we lived in the same neighborhood. We happened to live close together. Now they just moved to [another town] 45 minutes away but we talk often.

Sensitive expressions. The sensitive expressions begin to reveal a pattern of persistence in struggling to access information, resources, and services that appear to be hidden, withheld, or offered only if the child fits in an arbitrary, exclusive box. Additionally the extra stresses a family faces when part of the disabling condition is behavioral is evident for this family (McConnell, 2014). This family was one of the three families that had two adults in the home. This family also evidenced the key partner function where one of the adults monitors the health and happiness of the parent who acts as the coordinator.

3.5.5.2: The researcher’s notes on data collection and analysis of data contributed by Family Five

The essential structure of persistence was coming together. As I continued to dwell with the data, I came to the conclusion that “love” was necessary for these families but apparently not sufficient. I had seen families or spouses who loved each other but were not able to hold their relationships together when face with adversity. I had also thought in the past that commitment was sufficient. But, when I applied imaginative variation to the construct, it seemed that I knew people who loved each other and had commitment to each other but fell apart in the face of injury, trauma, or overwhelming stress. That is when it became apparent that the persistence to overcome the almost daily challenges that FCDs face did entail, for my sample, persistence/perseverance. As I continue to apply imaginative variation to the structure, and use the structure to review
the initial data, the structure seems to hold. However, I still have questions about the utility of persistence and about issues such as, “If a family member ‘burns out’ and for a time cannot be persistent, how does that effect the resilience of the family?”

I also began to see another emerging construct to which I could only put a label on after interviewing members of Family Six. But, it was teasing me with persistent parental behaviors in continuing to seek educational, therapeutic, and medical services for, what are at this point, incurable, chronic disabilities. I achieved more clarity after interviewing Family Six.

3.5.6: Family Six

Family Six had four members—the mother, father, an older sibling, and the CWD who was 10 years old. His primary diagnosis was Autism. His care level was three, which indicated he needed extensive personal care and/or constant supervision. The risk/barrier Factors are presented first, followed by the mixed risk/protective factors, followed by the protective factors. After the statements, the implied “sensitive expressions” and notes on the researcher’s experiences are written.

3.5.6.1: Significant statements, label statements, and expressions

Table 3-8: Significant statement labels

<table>
<thead>
<tr>
<th>FAMILY SIX FACTORS</th>
<th>Risk/Barriers</th>
<th>Mixed Risk and Protective</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fractured system makes it very difficult for families to have a parent be a coordinator and make it difficult for families to find services</td>
<td>Paying for medical care without Medicaid is almost impossible</td>
<td>Persistent and committed that her child would get the care he needed</td>
<td></td>
</tr>
</tbody>
</table>
The child is not treated in a holistic, integrated way | The teachers in the school system are good but the administration is a stumbling block and a barrier to getting a child the services he or she needs | Spouse is partner/friends are supportive:  

| Services are withheld due to words on paper | Family members work together to care for C.W. | Family members agree on priorities  

| The adaptive skills of C.W. are low. It is difficult to find out how he is feeling because his expressive communication is not typical. | For a few years C.W. had sleep problems which caused considerable stress until a solution was found. | Parents take care of themselves, take care of their relationship, and spend individual time with both children. Attempts are made to meet each person's needs  

| Finding services and supports is a struggle | Appreciating progress wherever it occurs | C.W. initiates topics, communicates, learns  

N. C.W. = child who has a disability

**Significant statements that reflect risk/barrier factors.** Fractured systems make it very difficult for families to have a parent be a coordinator and to find services: "I would, one thing that I encounter that is a huge hardship, but I don't know what the solution, even though there is a solution kind of on paper, and that's case management, so case managements exists and that's great, but in general I feel as a mother, I don't know how my husband would answer this, but I feel as a mother that I am the CEO of CW, I'm CW's CEO, and why is it my job to make sure that his pediatrician, that the specialist communicated all the information to the pediatrician, why is it my responsibility to make the physical therapist did their assessments on time and got it to her who can be in the know. Everything is so completely fractured that I think that that is very difficult and I find that other friends of mine who have children with disabilities find that as well, is that nobody is really in charge, so the mom has to learn a whole other medical language, the mom has to learn—and the dad too, no disrespects to dads, but generally moms are
managing many, many things.” … “For me and my family and this is what I hear from other people is the fractured nature of it, the huge amount of time that you have to spend managing and I if were a disorganized person, I mean, it would be a nightmare. I just find that hugely time consuming.” … “…Providers are so focused on the disability they don’t focus on things that are the real issue, in this case, medical problems that are not disability related.” … “, treating the label and the label isn’t even really accurate because the label is two-dimensional and people are like four-dimensional.” … “The Down syndrome is secondary. It’s all these other medical things that are a problem, that are more problematic I would say, for him in particular. I know kids with Down syndrome who are perfectly healthy. You know, I have a friend, her child I only think has hypothyroid, I mean, he—I think he even tests about 70.”

Needed services are withheld if the child does not meet a criteria on paper, but the exclusionary criteria makes no sense in reality: “And I just had this conversation in yet another meeting where I said just because he doesn’t meet the state eligibility, for the state definition of having a visual impairment, every single evaluation you see mentions his visual issues, his optometrist said he has some visual issues even after correction, so just because we didn’t tick your box does not mean that this doesn’t and they’re just, like, ‘Well, that’s what they said, we have to go by what the state says.’ Oh my gosh.”

The adaptive skills of the CWD are insufficient for independence: “So he is probably 5 to 7, 4 to 7, but adaptively incredibly low, like, self-help stuff, but because he is hyperlexic, like, he can read the New York Times and that’s also kind of a disability, where if we go somewhere in the community he has to read everything, so if he is walking, you can’t ever, like, go on a walk so we use a wheelchair for him because he has low endurance and he reads everything. Yeah, on the whole he is pretty good, he has the problem, our main problem with CW I would say are, is his inability to
communicate adequately to us feelings and physical needs and so, when he is hurting, you know he has got enough physical issues, he has got, you know, he had sleep issues that when he has got a headache or something or a stomachache and or bloating or whatever because he has got some...Yeah, exactly, and so he is—it's hard, it's hard to figure out what's wrong and so it's harder to help them, so you know we have kind of followed some clues sometimes and sometimes we think he may have headaches that are migraines or similar to migraines.”

Finding services and supports is a struggle: “… just been a line from when he was born and, like, these little spikes that I see off the line. Someone tells me one thing and somebody tells something else, somebody tells me something else. Even in the hospital, I was amazed because then I became, not really a parent advocate, but I served in a role when, for example, if a woman just gives birth in the hospital and she has child with Down syndrome and the person who goes in and meets with her is another parent, and I was amazed, of all the places that I went in Houston, the medical capital of the world, where not even a social worker had been sent or they hadn’t even gotten the lists, the interest lists, like, they didn’t even know about them until the kids were old, like, in their teens and then, you know, you have another 10 years to wait. So, there was no, again, even in the hospital, and that was part of kind of our mission in some of the parent groups that I belong to is to get that information and say, ‘I’ve got to go tell this family what they need to do, what ECI [Early Childhood Intervention] is.’ There are people leaving the hospital who had not even been refereed to ECI, so --.”

Significant statements that reflect mixed risk and protective factors. Paying for medical care without Medicaid is almost impossible: “For me and my family and this is what I hear from other people is the fractured nature of it, the huge amount of time that
you have to spend managing and I if were a disorganized person, I mean, it would be a
nightmare. I just find that hugely time-consuming."

"The teachers in the school system are good but the administration is a stumbling
block and a barrier to getting a child the services he or she needs: administration won’t
provide what isn’t on checklist, teachers just want to do what works" ... "...which is what I
mean about they don’t understand—the administration. The teachers are, like, yeah.
And it’s just the top-down that’s just ridiculous." ... "...which is placing stress on our
family. We adore the school. He is thriving at the school. Teachers love him at the
school." ... "He is getting what he needs in one sense, because the teachers are caring
and, you know, they’re not specially trained, but that’s okay with me. We’ve partnered
and worked together and because I wanted him in an inclusion They’re willing learn." ... 
"For example, in most public schools, positive behavior support is kind of, it’s not by law
but part of it I think are kind of mandated by law that you, for certain behaviors that are
related to disability, in other words, the whole campus should be trained in positive
behavior support. No one is trained in positive behavior support. They don’t know when
you can touch a kid, when you can’t touch a kid. When you can redirect, when you, you
know, for specific things, just in general, even for typical kids, but more importantly and
CW is not the only kid with a disability, not the only kid with an IEP, he is probably the
most severe, but they don’t have, they’ve never had training even though we’ve asked for
them to be trained. They’ve never had—what else, collaborative planning time. Again,
it’s fractured. It’s like, okay, the OT comes on this day, the speech therapist comes on
this day, never throughout the year do they collaborate and talk to each other except in
an IEP meeting. How easy would that be? How easy would that be to have a consult
time once a week for 45 minutes, or a half-hour? It would make all the difference.
Everybody would be on the same page. That doesn’t happen now, very, very common.
And that’s in a good situation, many of my friends, again, in some other schools don’t even, number one, have to fight to get services at all and it’s also very fractured, no one is talking to the other person. Yeah. And, I mean, in the large districts that are supposed to have all of these things in place. All the speech therapists are totally overworked. They’ve got hundreds of kids on their caseload and they see somebody once a month for 15 minutes, I mean, so in one sense he is getting excellent services and in the other sense you’re wasting money because not everybody is on the same page and how easy would that be—“Yeah, okay you could use it if it applied to all the other kids, not just him. You’ve got this other kid who is struggling with writing. How easy would that be if you had 15 minutes with the OT? Ridiculous. So, that’s a big struggle now that he is, I mean, that is our single largest time because we know for a fact that there are other children with IEPs who are not given needed services. Yeah. And I worry, if I push the issue are they going to retaliate against CW? We visited several schools and just found they were sadly lacking and we, you know we considered also private school options, but we didn’t know that any of those were, were good and so I think we found out a place you know where CW is getting, I think he is probably in a better situation than a lot of kids and so you know and that was some work on our part, but I think part of it is luck and we found out about it by chance and so that, that has probably been the basic challenge.” … “And he was, you know it’s, I mean we had our challenges there too, I mean we had to be very strong advocates and you know that’s one part of the education process, it’s only our meetings and so forth you know again we are fortunate to know to be to be able to do that to have that. So CW got the rest of (elementary) grade and (__) more years and then, you know then we—his mom and I really have to start kind of trying to figure out what the next step is because that’s going to be a challenge finding the right place for him.”
Family members work together to care for CW: “Sometimes he, sometimes he doesn’t cooperate and sometimes he gets really mad and we have to teach him—we have to give him a timeout., and that usually works.” … “When he didn’t want to go to dinner—He doesn’t like to sit at the table.”… “Sometimes, like when I want to go somewhere and he is like “no.” … ” I will tell them to like try to be nice and not, like, put pressure on them and encourage them to do like good things, because if you pressure him he will get upset.” (The sibling is talking about advice he would give to other siblings.)

Sleep problems were a significant stressor that has now been solved: “Well, so literally for years he would wake up in the middle of the night and he would be awake for the rest of the night and one of us would have to stay up with him and the other would, so what we started doing is one take him into our bed, the one would stay up and the other one would sleep in his bed, but so that was an interruption almost every night for literally probably two years where we were like walking dead. : And a lot of times he would get out of the bed and come here, he would walk around the house and talks at the top of his voice and so it was a very, it was very stressful and so the reason we couldn’t put him on medication initially we had to get a sleep study done to make sure he didn’t have sleep apnea which might cause problems and there is no way he is going to wear a breathing mask. And so finally on the third try I think we were able to do the sleep study because he was so resistant to anything that that sticks or binds with, you know he didn’t like to wear hats and things like that, he doesn’t even like to wear shoes. So they had to, his mother is the one who took him, and finally I don’t, I forget where it was, in a medical clinic or something where they kind of bound him like a mummy with his, to his side where he couldn’t struggle and they have the electrodes on and he finally fell asleep. He was so upset, he fell asleep for like a five-hour period where they were able to get readings, and they determined that he did not have sleep apnea which has then enabled
us to get a neurologist who prescribed medication to help him sleep which took a while to
get the right balance in front of that medication and someone had side effects again
without pretty bad headaches and things like that, so that was another diagnosis?”

Sleep problem now solved: “That was a very stressful period, so overall by the
time we got his medication adjusted and everything it might have been three years, you
know.”

**Significant statements that reflect protective factors.** Persistent and committed
that her child would get the care he needed: “Horrible and more determined, I think that
my child’s life would be different...It was very painful. It was very upsetting. I wanted to
leave as quickly as possible. I felt guilty because I could and in a way felt guilty for my
child who was and is so well taken care of, but it just made this such an impression that I
determined that I don’t care what I have to do in my life until I am gone that that just
cannot be, that cannot be.” ... “I think CW is very lucky in this way is that I do have, like,
this incredible sense of perseverance that I’ve always had, that I’m one of three girls and
the other two do not have that and my other sister has a child with a disability and it was
a disaster and I can’t be judgmental about it, but she is just not that -- she does not have
that inner resilience, she is a very introverted, so I notice it much more in myself in
contrast with others like that and I feel really bad, and again there is the guilt.”

Spouse is partner/friends are supportive: “Probably number one is a good
relationship with my husband because we do work as a team very well and number two is
networking with people, whether that’s a really good friend...” ... “It has been the single
most import thing is networking and having these circles that I can rely on and go to for
things that I never had before, because there was not a need before, that social group
before CW, and even MS, my older son, has medial issues on his own, his own disability,
so I needed things at different times and so I think the networking because of where CW
went to school, he went to a private school, but it was an integrated school with kids with disabilities and without, so that experience expanded my network by ten-fold and even those people, even though I don’t see them every day anymore, because he has graduated from that program, it’s amazing how I can go to them as resources when I need them. We are in fact very blessed because we have developed this great network of friends and kind of like situated families and therapists. I mean we are, it's just an incredible number of people that have just been great, you know for CW and for us as a family and then now WI’s work has her on the cutting edge…” … “Her work has her on the cutting edge so if something comes down the pike she is going to hear about it, so that I mean that’s you know and, and you know I can’t help the point that there is involvement to be you know in that way, so I think it's, I think we are much more fortunate than most families who have similar situation with the child in the fact that we have learned you know we are fortunate that we have been educated and we have learned, you really have to challenge his system where necessary, you have to investigate, you have to ask questions and you have to just never let up and so, so you know I would say all things considered where we are pretty well off and that was set.”

Persistence: “I think CW is very lucky in this way is that I do have, like, this incredible sense of perseverance that I’ve always had, that I’m one of three girls and the other two do not have that and my other sister has a child with a disability and it was a disaster and I can’t be judgmental about it, but she is just not that, she does not have that inner resilience, she is a very introverted, so I notice it much more in myself in contrast with others like that and I feel really bad, and again there is the guilt.” (There are also quotes under the mixed factors section that highlight parental persistence in obtaining a good education for the children.)
Family members agree on priorities: "We have always prioritized education over everything or vacations and getting what both of our kids need and as I mentioned my other son has, when he was born had juvenile rheumatoid arthritis, which is very unusual in boys and is part of the reason why we’re still in Houston because when he was born most states only had one pediatric rheumatologist and Houston itself has four rheumatologists so we realized we can’t really move, so prioritizing medical needs, where to get the resources to help our family get the best that they need to get and education has and the fact that my husband and I didn’t have to fight about that priority or we just agreed on that, so we both, you know, we’ve given up a lot of things I think financially and where we live and everything to put those two things on the top."

Parents take care of themselves, take care of their relationship, and spend individual time with both children: "Well, part of that I would say, again, is prioritizing and realizing that we can’t be 24/7 about the kids and it can’t be 24/7 about CW even though he demands a huge amount of time just because he is adaptively so low…he is just not independent." … "but we have a three times a month weekly date with just my husband and me on Sunday night. We pay a babysitter who we totally trust, like, she is one of two people we could ever leave our kids with to be able to actually relax, but we didn’t have that until this year." … "We are very involved in our kid’s schools. We, we have our meals together, we try to do a lot of things together, we rely on friends, there are a lot of close friends, we have some people who babysit for us who are more than babysitters…they love our children and our children love them and they are close friends. We try to, WI and I try to spend time together, you know keep our marriage strong, so we have a fairly regular date night, so we can have some time alone and talk and so I think keeping our relationship strong helps keep the family unit strong, which supports everybody.” … “What else, we try to, we—one thing we do is partly by the nature of CW
and also by MS’s nature. We know a lot of families that are go, go, go all the time every minute of every day find out some kind of activities, sports something like that. We believe in downtime, we believe in you know MS get on a computer or games or whatever or reading and we are going in his room and having some more, you know downtime fun with CW, you know and WI and I need our downtime, we like to read, we like this initiative to enjoy being around each other without having to do something and I think that’s all that’s lost today, you know.” … “WI and I take turns putting CW to bed because he requires one of us to lie down until he falls asleep, so I like to – well WI will lie down with CW, well sometimes MS and I will read in his bed, we will sit there next to each other reading our own books, but again we are spending time together. It’s downtime it’s cool…” … “So that that helps us stay, you know support, I mean all that’s kind of I think, supporting our mental health and our emotion health is really important to dealing with every day’s stresses including additional stresses that are brought about by, for children’s for instance disability.”

Attempts are made to meet each person’s needs: “I don’t know if he told you about that…. He wants to be a Texas State Trooper at least initially and then maybe go into the FBI or something like that, so he is interested in police law enforcement.”

CW has some adaptive skills: “Because he is hyperlexic, like, he can read the New York Times and that’s also kind of a disability where if we go somewhere in the community he has to read everything…(Interviewer: “But he is not, I mean, he is cognitively processing yet at a 5- to 7-year-old level.”) WI: I would say, yeah, and he has got a lot of language, he is not always functional, so we have that, I mean, that’s really helpful.”

The siblings play together: “He likes to have, like sometimes he wants to play and we have a lot of fun with that….We like to do a lot of things, I like to like, we like to
throw these green balls at each other. We wrestle sometimes…"… Dad’s comment on how the sibling helps: "Right, right and that’s tough because a lot of times he does and I will say that MS impresses us every day with his, with his kind of reservoir of considered behavior for his brother and you know he is really, he is really very close with CWD and often enough it’s (the sibling) who can bring CWD out of a bad mood, out of a funk, you know or give him comfort when he is upset."

Appreciating progress wherever it occurs: "I do think it's important to point out that it's, it's just incredibly rewarding to see one, you know a child with disability when they make advances that you know it's just like you know, it's just, we can’t explain to someone who doesn’t, hasn’t been through it and just even little things like you know CW is starting to use complete sentences as people take that for granted it's like he is a – you know there is a lot of things like he is a complete sense, so that’s, that’s cool just I don’t know, he started walking with green hat and it was so funny because I don’t know if we had seen him, now we haven’t seen him walk on his own without holding on to something, so he is three and a half, so WI and I were asleep in our bed one morning and I heard this noise and I looked and I see this little figure he is walking alone like this to our room and he came to the bedside and he had the biggest grin on his face like, like he you know he realized what he did and we were just, you know that was like so incredible and it's the most incredible thing because, you know I don’t remember how old those kids are… he walked like in was 14 months, same way instead of walking on his own he started running on his own, so he knew how to do it, he just didn’t want to do. So (the sibling) yeah that was just amazing stuff like that you know that’s just like parent feel so cool. I just, you know remember this little walking out with this Frankenstein walk and he, when he was younger he was, I don’t know if you have seen those I mean he was kind of really round, he looked like a little I don’t know…. Yeah, so he was just a little
round guy, he was walking you know, I just see this I am kind of sleeping and ever since
the kids were born it's like I don't sleep soundly because every single sound, I mean I
wake up in the middle of the night all the time. So you know I just heard a little creek at
the board since he is walking on the floor, the floor boards creak and this little real short
guy just kind of and that was just so cool, just so stuff like that, it's just yeah, just you
can't. Yeah, yeah it's just that's, that's just you know indescribable. I mean everybody
who has got kids can understand, you know every milestones or accomplishments, it's
just that much more…” …

Interchange between researcher and Child Who Has Disability demonstrating
responsive communication during play interaction: “Interviewer: Yeah? What does your
family do that is good -- that helps you? Is that what you like to do when you are not
studying? CW: Yes. Interviewer: Play with your toys? What other toys do you like to
play with? Can you show me your toys? You have toys in your room? CW: Yeah.
Interviewer: Let's go see the toys in your room-- CW: No. Interviewer: No? Can you
bring me one of the toys from your room that you like? CW: Yeah.”

Another interchange: “Interviewer: Oh. Good -- that's why I am putting your
animals up here for you -- you can show them to Sibling if you want to? Which one do
you like the best? CW: …let's go Janis. Interviewer: Let's go -- go where -- where do
you want to go? CW learning: “Interviewer: These are tigers right? CW: These are
tigers. Interviewer: These two are tigers? CW: Yes. Interviewer: How are they
different? Do these have stripes or spots? CW: Spots-- Interviewer: These two -- are
those stripes or spots? CW: Stripes. Interviewer: That's right, they are stripes. CW:
Stripes-- Interviewer: Those are stripes -- how about this one, stripes or spots? CW:
Stripes. Interviewer: Very good -- does a lion have stripes or spots? CW: No.
Interviewer: Good -- good job -- good job, so that's the difference -- no stripes, no stops.

CW: No stripes.”

Sensitive expressions. “Finding services and supports is a constant struggle; on top of the struggle we already have with a child who needs so many supports. It's a neverending search for the right services. And even when we find services, they're cookie cutter services that are so ineffective because they're not looking at our little boy; they're looking at one of his labels. And then...sometimes...there's a service or treatment he would benefit from but he can't get it because he doesn't have THAT label.”

“Trying to care for a child without adequate resources is unnecessarily destructive to everyone in the family. There's recognition that almost no typical family can afford medical care for someone with a chronic condition but it's as if we're invisible. When he has a condition that's beyond our ability, that requires us to function on little to no sleep, how is anyone supposed to survive that? Now we have Medicaid for people who have chronic conditions, and the sleep problem has been solved, but why did we have to go through that, hanging on by the skin of our teeth? The school system seems to be operating to intentionally withhold what children who have disabilities need. The teachers want to teach all of their students but the administration is more concerned with the short term reduction of expenditures without considering the cost of having children reach adulthood unprepared to function as adults. Students are put into a box, again based on someone's label, and the child is not allowed out of a box unless the family hires an expert to tell the school system, ‘You’re wrong!’ And that’s for families who are persistent. The information and service systems are ‘fractured;’ there’s no coherent way to find out about or get services. Who knows what happens to children whose parents either don't know contesting the school’s decisions is an option, or who are simply too overwhelmed to stand up for their children.”
“Another issue that creates a feeling of being ‘caught between the fire and the frying pan’ is how to include the sibling, who does not have a disability, as a fully participating member of the family; while worrying if we are asking too much of him, or if he will grow up and feel he was neglected. We feel ambivalence about the sacrifices a sibling makes in having a sibling who requires so much attentions and so many resources.”

“We are fortunate to have a circle of support that we have been able to build through persistence in solving problems, and providing care and nurturance for each member of the family. We communicate to insure we have the same priorities and one of those priorities is that each member of the family gets time and attention. We treat our marriage as a necessary support and component of the family and set aside time to spend as a couple. We realize that our CWD will not achieve the same milestones and accomplishments as children who do not face his challenges; but we take joy in whatever accomplishments our family achieves, whenever they occur. I will not sit down; I will not shut up; I will keep fighting for what my family needs.”

3.5.6.2: The researcher’s notes on data collection and analysis of data contributed by Family Six.

As I sought to discover the second essential structure of FCD, it seemed to me that the metaphor of the glass half-empty or half-full fits the families’ seeking of services to support continued development of their children. I then realized that I had already come across this structure in the work 2002 article by Timothy Hartshorne titled, “Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities.” That helped to clarify this structure that is presented in the next section.
One of the challenges in qualitative analysis is to examine processes, entities, and feelings that are important but cannot be measured. If we had units to describe love, we would have more of an opportunity to learn how much of it is necessary for commitment to be present. I would like to be able to tell you many watts of love is needed in the presence of a number of kilometers per minute of stress for persistence to emerge and survive. It appears the, often, unrelenting stress families of children with disabilities face draws forth this perseverance, if the love and commitment can withstand the searing effects of deprivation. And, yet, deprivation is not what the families in this study felt. They may have felt rage or frustration at injustice but the perseverance points to a goal that one will not give up on and will not back down on, in this case on behalf of family members one loves.

The first essential structure to appear was “persistence.” Persistence is composed of the constituents of “love” and “commitment.” Both of these constituents are more than elements because they are essential to the structure of persistence (Giorgi, 2009).

In trying to identify the constituents of “persistence,” it appears that love is a necessary constituent. However, one can see examples, in daily life, of people who love someone but do not continue to attempt to provide care when barriers to resources cannot be overcome or at least have not been overcome in previous efforts. Similarly, commitment to care for a person is evident in persistence but someone who is committed is not necessarily perseverant. These families persist in attempts to access resources when faced with barrier after barrier after barrier. In addition, as evidenced in Family Four, a family can have overcome a barrier or have acquired a resource only to have that resource withdrawn or another barrier emerge. Watching these families fight to take care
of their family members raises the metaphor of the myth of Hercules battling the Lernean Hydra. The animal with six snake-like heads was nearly invincible because each time one head was cut off, two more emerged (Leadbetter, 1999). Likewise, these families seem to surmount one obstacle only to be confronted by another.

Beyond love (essential but not sufficient) and commitment (also necessary but not sufficient) is perseverance. The kind of perseverance that soars some days, crawls other days, and sometimes barely survives, but goes on because there is love, and there is commitment, and the alternative to perseverance is unthinkable.

Part of the essential structure came from significant statements, and also through the bio-psycho-social sensitive lens. Two mothers had spent some time in a long-term care facility for children, probably an Intermediate Care Facility for the Intellectually Disabled, an ICFID. The mother in Family Six had to spend the weekend in an ICFID with her son in order to be eligible for Medicaid Waiver Services. This is what she had to say about what she felt there: “Horrible and more determined, I think that my child’s life would be different…It was very painful. It was very upsetting. I wanted to leave as quickly as possible. I felt guilty because I could and in a way felt guilty for my child who was and is so well taken care of, but it just made this such an impression that I became more determined that…I don’t care what I have to do in my life; until I am gone that just cannot be, that cannot be.”

A sibling from one of the families had accompanied a parent to visit an ICFID when the parent was doing some volunteer work. This is what the sibling had to say about children living in institutions, “Yeah, I remember one thing when my mom was very involved with the kids in the institution and the nursing home, those were bad memories of my—my mom used to take me to their nursing home to read and play with the kids. And I hated it. I hated the nursing home, I hated how they smelled, I hated the scary
elevators, I hated how old it was. I didn’t like what these poor kids were having to go through because my empathy was so strong. I wanted to block it. I really did, I didn’t want to go. I didn’t want to know that that was real. Right? Because not everybody gets to know in time and that was hard, having to accept that. Or just shutting yourself off from it just like that.”

The second structure to appear was the frame of reference that is ordinarily referred to as “optimism.” This structure is explained by the metaphor of the view of “the glass half empty, as compared to the glass half full.” Optimism seems an insufficient term for what Hartshorne (2006) has identified as courage. What he found, in families of children who had disabilities, was boundless hope. Here, again, we run into the difficulty of conceptualizing something that cannot be put into units. However, this hope was not the denial of the child’s disability. He identified this trait of courage when he observed the unlikely confluence of families being fully in touch with the reality of the chronic nature of their child’s disability, and yet the families continued to hope for an improved quality of life, and worked to gain access to resources to make that happen. Courage is also seen in the family that rejoices in the first steps of a ten-year-old, and the ability of a child to answer dichotomous questions with a shift of the eyes.

Framing emerges as a constituent of the structure of courage. Froma Walsh and Aaron Antonovsky identified the place of a spiritual perspective and developing a sense of coherence in function and coping (Antonovsky, 1987; Walsh, 2006). Conversations with families in this project have revealed that they celebrate and value progress that, in typical families, might be mourned because it is viewed in the frame of, “What would a typical child be doing?” This structure, at first glance, appears to be related to the perspective of “seeing the glass half full versus seeing the glass half empty.” However, I suspect the term “optimism” is inadequate to describe what goes on in families of children
who have disabilities. “Optimism” seems to be related to “hope” in situations where the potential for improvement or cure exists. That situation does not exist for families of children who have disabilities (Lloyd & Hastings, 2009). Usually developmental disabilities are not “fixed” or “cured.” How, then, do we consider what called “courage” and identified as hope in the face of reality? How do we respond to a family rejoicing in a child’s first steps...when the child is ten years old and will never walk typically? It does seem related to seeing the best in a situation; but what does one call this “perspective” and, if it is a structure, what are its essential constituents?

The families in this study faced the double adversity of having a child who had a disability, and the need to search for services and supports. Often when they would find supports, they would be told their child did not qualify because of guidelines associated with various factors, because the program was limited, or simply because the provider would commit to providing a service but in practice would not provide the service. Nonetheless, families persist in searching for services and often in attempting to hold providers accountable for what was supposed to be provided.

The family persistence in mediating consequences of its child’s disability reveals a protective and adaptive response, integrated closely in time and systems with the barrier. Often the only avenue parents have to the services the family needs is through the system that is not responsive or is overloaded. They persist in finding a path over, under, around, or through the system that is gatekeeping, in an exclusionary manner, the needed resources. Through advocacy when the preceding responses fail, families will often create a new path by altering regulations or advocating for new programs.

Family courage emerges as families strive to maximize quality of life for the family in the face of developmental disability diagnoses that are seldom mediated and “cured.” Realizing that their child, and hence their family, will never be typical, they
pursue resources so that the family can achieve a higher quality of life in the future than they are experiencing in the present. They do not evidence the expectation of a cure, or the belief that their family will be like families who have members who do not have disabilities. They seek and pursue resources and processes to attain the highest practicable well-being for their unique family.
Chapter 4
Discussion and Implications

4.1: Discussion and Interpretation

The results of this study show some issues that need to be pursued to expand the knowledge base about what families of children with disabilities need to support adaptation. Families of children who have disabilities are faced with the overwhelming stresses of trying to ensure that every family member has their needs met while the family maintains function as a unit. Conversations with parents, children who have disabilities, and their siblings have revealed both issues that warrant further investigation, and changes that could be implemented in the near future.

The differences among families who experience injury, trauma, or overwhelming stress have implications in how support systems should be designed to assist with adaptation. Related to salient differences among families are the differences within the same kind of negative event, or the parameters of the negative event. Some families face regular destabilization, but due to complex factors, these destabilizing events appear randomly. The history of research into injury, trauma, overwhelming stress, and the resilient response shows many of the studies were conducted by collecting data from one family member (Ylven, et al., 2006). Additionally, resilience theory posits that protective factors can sometimes act as risk factors, or that a factor can have simultaneous protective and risk impacts (Rutter, 1999; Smith-Osborne, 2007). The following paragraphs give more detail on findings of this research in relationship to the issues given above.

Differences. To consider the possibility that the same supports will be efficacious for families who have experienced an undifferentiated negative event (i.e., any kind of injury, trauma or stress) is alluring but not logical. Research shows that people respond
differently to different types of trauma. The type of negative event makes a difference in
the adaptations needed to regain stability and function. When considering this concept
extended to providing supports to a family, the question is, “Does a family of a child who
has a disability need the same resilience supports as a family living in poverty? Does the
FCD need the same supports as a family that has had its home damaged by a hurricane
or flood?” This study is a step in the direction of discovering what is effective for families
facing this specific stress: having a member of the family who is a child who has a
disability. This study suggests the following specific conclusions: families with children
with disabilities, more than other families under stress, need to be viewed holistically and
with the understanding that available services/supports are not effective when they are
dispensed according to labels. This finding supports the previous research findings of
Price, Higa-McMillan, & Frueh, about the response to trauma based on differences
between traumatic events (2013).

The family acts as the interpreter communicating the family’s abilities, needs, and
the resources required to a system that is seldom capable of the holistic analysis that is
required. This, by necessity, activates persistent responses from families that do take into
account the gestalt created by place in the structure of each family member.

Parameters. A way to understand the different stresses that families face is by
considering the parameters, or characteristics, of the event. Families of children who
have disabilities usually do not experience the trauma as a one-time, discrete event.
Being in a family of a child who has a disability is not like having been a victim of crime.
The crime victim responds to a one-time event. The crime is committed, it is over, the
family starts adaptation and recovery. This supports previous findings of Briere and
Spinazzola (2005) in their research on posttraumatic stress disorder. They have
determined that how trauma has been experienced needs to be understood during the
beginning stages of planning service delivery and supports. A finding in this study on FCD is the manner in which stressful events happen in this population is variable.

The parameters of the disability identify the different and individual response that is needed to guide the adaptive process. A consideration of parameters informs the selection of problem solving priorities to maximize support for family well-being. However, parameters and priorities change as resources change and the family’s needs change, requiring periodic rearranging of resources to meet the need of the family.

**Chaos and destabilization.** The family of the child who has a disability faces continuing “attacks”: stressful events to which the family has to mobilize resources again and again. Additionally, one seldom knows when or where these events will occur. A child’s health may be stable for months; the next day the child is in the hospital. A family’s income may be stable for years; then one day the primary wage earner is unemployed and without health care insurance. As one of the families in this study experienced, a child who has a disability may have been getting 45 hours per week of attendant care until the day that person turns 21 years old and the family is suddenly told, “The child no longer needs that much attendant care.” Even a family with decades of caregiving experience, such as this family, may not have the advance information necessary to prepare for shifts in policies based on age or developmental stages. This finding also suggests a societal assumption, reflected in policy and regulation, that all children with disabilities “grow out” of their disability(ies) and thus their need for related services or alternatively that their needs change substantially once they are transferred to service systems for adults with disabilities. Another example from the literature of such a policy assumption is the procedure typically enforced by college offices of disabilities requiring students to obtain costly re-diagnosis of their childhood-onset chronic disability in order to
obtain classroom accommodations. This supports the findings of McDonald and Raymaker (2014) on the importance of supports for FCDs.

These destabilizing events cannot be planned for. There is little warning to the family that the system that’s been effective for “years” is about to be disrupted. Support systems, such as government programs and school systems, make the situation worse because the supports that are offered can be changed or withdrawn in a preemptory manner. This compounds the stress. The family has no firm system of supports it can depend on. What has been revealed is FCDs face repeated destabilizing events, and some of those destabilizing events are the result of systems that are supposed to be providing supports. This echoes findings from the research of McConnell, Savage, and Breitkreuz (2014) on additional stress from systems induced instability.

Families are not static entities but change and develop over the family lifespan. This constant change in abilities and needs call upon persistence to adjust processes as the family changes. When the family is dealing with uncertain information about the disabling conditions and uncertain access to resources, stability becomes harder to maintain and the family is more vulnerable than the average family to finding themselves with insufficient resources. Family courage is displayed as resources are sought to provide for family members’ needs.

*Direct assessment.* This study has also assessed resilience in families by assessing the adaptation of each member of the family as compared to many studies of resilience that gather data about the family’s resilience from one person in the family. Usually information to assess family resilience is gathered from the mother. One of the goals of this research was to provide the field of family resilience with more work based on an assessment of each member of the family (Hoogsteen & Woodgate, 2013; Ylvén et al., 2006). Although only three of the six families in this study had siblings, interviewing
them provided a great deal of insight on significant risk and protective factors. The adaptive responses of siblings are liable to being incompletely understood by parents. A parent cannot report the resilient responses of one of their children that is offering secondhand information. Even a parent who wants to understand what works for his or her child cannot understand the lived experience for that child. A parent is limited in reporting the resilient responses of one of their children, that is, offering secondhand information and has been found to have certain patterns of bias, depending on the problem under analysis. For example, studies of youth depression have documented a pattern of underreporting of symptoms by parents. The findings from this research on the importance of direct assessment supports what has been found by Hoogsteen and Woodgate in 2013, and Ylvén and others in 2006 on the importance of assessing each family member when researching and reporting on families.

Even a parent who wants to understand what works for his or her child cannot understand the lived experience for that child. In a 2011 study by Ünal and Baran, families of children who have disabilities had neglected to investigate siblings’ experiences (in Thompson, 2013). Researchers Moyson and Roeyers found siblings of children who had disabilities thought they should not bother their parents with their concerns because the family was overburdened with the problems of the child who had the disability (2012, in Thompson, 2013). The findings from this research support those from Ünal and Baran in 2011, and Moyson and Roeyers in 2012, as found in Thompson (2013) that parents have not always reliable reporters of the thoughts and feelings of non-disabled siblings when one of the family members was a child who had a disability.

Therefore, although there may be difficulties in talking about resilience with young children, the child’s intact communication abilities should be accommodated to get information directly from the person. This need to get information directly from the
individual also pertains to getting the experiences of fathers directly from them. This supports outcomes of previous research by De Los Reyes and Kazdin (2005) on the importance of data gained from fathers.

The family cannot be understood from the perspective of one or two family members. Attempts must be understand the perspective, skills, and needs of each family member. However, even that is insufficient because family internal dynamics and how the family functions in the community is a dynamic process that is different from what is found when the family is viewed as a collection of individuals.

**Mixed factors.** Protective factors sometimes have risk effects, and risk factors can have protective effects. These factors can exist so closely in time and context that they become one mixed factor. This supports similar finding from 2008 by Spano, Freilich, and Bolland (2008) on the simultaneous protective and risk-invoking factors found in gangs. Additionally, context and time influences on whether behavior was protective or risk-inducing was found by Foster in 2010. Further, the factor that can be protective at one stage of life can be risk-related at another. The research was on the resilience of adults whose parent had serious mental illness during the childhoods of the participants. The assumption of responsibility in childhood was protective but resulted in boundary problems, between the (now adult) children and their parent (Rutter, 1999; Smith-Osborne, 2007).

In this study, the emergence of mixed/risk and protective factors came from a completely different direction. As the researcher was applying the ‘strengths perspective’ to some of the stressful situations in the families’ lives, the realization occurred that resilient responses were occurring in reaction to the stress. This supports the seminal findings of Saleebey in 2009 and previously about the importance of using the Strengths Perspective. There was a confluence of the risk evoking the protective. A metaphorical
image emerged of the ‘stress calling forth the strength.’ Additionally this falls in line with the Inoculation Effect, mentioned by Rutter in 1987. What he found was previous exposure to stress conferred a sort of ‘experience related vaccination’ which assisted families in dealing with later stressful issues. However, in the case of FCDs, the exposure to stress, and the adaptive response, occur much more closely in time; and are not necessarily preceded by an ‘inoculative’ experience. This supports similar findings by Shuttlesworth and Zotter in 2011; and Giallo, Roberts, Emerson, Wood, and Gavidia-Payne in 2014.

The mixed factors also emerged in the situation of siblings. The extent to which siblings experienced this mixed/risk and protective ‘situation’ as children depended on the extent of their exposure to other families. Children tended to ‘not know their families were different’ if they had not been exposed to varying family situations. In isolated families, or where children were isolated from peers, his or her family was more likely to be seen as ‘normal.’ This supports previous findings by Jager, Bornstein, Putnick, and Hendricks in 2012, McCall in 2013, and Thompson in 2013.

The mixed/risk and protective factor presented as a double-bind as parents attempted to minimize risk, and maximize protective nurturance. It could be presented, in an internal conversation with oneself as “I don’t want to dump my parenting responsibilities for C.W. (child who has a disability) on H.S. (his or her sibling). But there is no way to completely protect HS from the effects of CW’s care needs. CW either has behavior problems, which hurt HS, physically or emotionally. Or CW requires more time and money for care; and hence there will be an unequal ‘distribution of resources.’ It will not be fair to HS.” The risk factor, as in the family where a parent has a mental illness, is the undue burden on the sibling. The protective factor is everyone in the family is included and everyone has a chance to contribute to the family’s well-being. There is a
certain sense of security in seeing every attempt will be made to meet your needs, even if your needs become atypical. Similar findings come from previous work by Simsek, Erel, Simsek, Uysal, Yakut, Yakut, and Uygur in 2014.

This study sought to understand how families constructively adapt to the stress of being in a family that has a child who has a disability. These families face these challenges with inadequate resources. None of the families in this study had access to all of the resources needed to provide for their members. What did emerge was their persistence in searching and battling for resources. Additionally, they display the courage to rejoice and gain strength from success however it appears. Timothy Hartshorne first observed this in 2002.

A more accurate understanding of FCDs is achievable when information is obtained from each family member directly. That is the beginning of comprehending the family dynamic that occurs as the family searches for processes and resources to meet the needs of the family. As FCDs have persisted in seeking information and resources that are difficult to find, and often difficult to access even if found, the family protective mechanism of persistence emerges even as the risks and barriers persist. Families exhibit courage as they seek sources of moderating and reducing conditions of adversity and work toward achieving a higher level of well-being.

4.2: Implications for Future Research

Some of the areas in which further inquiry is warranted have the potential to make contributions to the areas of theory, practice, and research, in the field of social work. The updated literature review and this study pointed to areas in which more research is needed. What do siblings and fathers know about resilience in their family that may not be revealed if only some family members are interviewed? Walsh (2006) has shown that resilience factors for families are displayed differently than are those
factors for individuals. Amedeo Giorgi speaks of a discipline related sensitivity in phenomenological data analysis (2009). The phenomenological data analysis reviewed in the updated literature review revealed social work researchers are relying on the psychological lens and not fully using the powerful bio-psycho-social lens that is the more functional tool we have at the disposal of social workers. Attempts were made to contact families that were not part of support groups. As peer support is a protective factor in resilience; and emerged during this study as significant for families as well; it is critical that research be done with families that do not have access to that protective factor.

Families provide nurturance and protection to family members that benefits society. More research should be done to show the functions that are not performed when families under stress disintegrate because supports were not available. All six families in this study mentioned inadequate educational supports as an overwhelming stressor. Yet the ongoing literature review revealed this is not emerging in other studies. More research needs to be done to discover whether educational supports are, indeed protective or risk for this population (Woodman, 2014; Strecker, Hazelwood, & Shakespeare-Finch, 2014). Families provide supports to their communities by socializing and nurturing children and providing support to adults in the family system. Little research was found to render those valuable functions more tangible (Giordano, Merlo, Ohlsson, Rosvall, & Lindstrom, 2013).

Schools are seen as barriers by FCDs in this research, and in the researcher’s experience of 14 years of networking with families. And yet I found little in research on families of children who have disabilities, about this issue, outside of research performed by professional teachers and educational administrators (Sorani-Villanueva, McMahon, Crouch, & Keys, 2014).
Social work theory. The results of this research expand on Family Systems Theory and Resilience Theory as they are applied in social work. Specifically for Resilience Theory, the characteristic of resilience factors to act both as risk and protective is emerging. Preliminarily, the adaptive structures of “persistence” and “courage” have been identified as essential structures in families of children who have disabilities. Further research is needed to replicate this project or discover if different structures exist. Preliminary work done by Briere and Spinazzola (2005) to identify parameters of trauma, should be expanded to ascertain if the same parameters hold for injury and overwhelming stress. This would hold great value in exploring resilient responses and whether they operate differently across different parameters. Walsh has already identified the differences in significant factor in family resilience. Further research to explore family responses to different destructive events will deepen and strengthen Family Systems Theory (Luthar, Sawyer, & Brown, 2006; Rutter, 2000).

Social work practice. This research has identified “persistence” and “courage” as ways that families use their strengths to adapt. Not to negate what McConnell, Savage, and Brietkreuz (2014) have found about the necessity of external supports, in the absence of those practitioners need to know what structures families find most useful in adaptation to the stress of living in a family which includes a child who has a disability. As with theory, continued research needs to be done to discover if these structures hold and if families responding to different types of injury, trauma, and overwhelming stress use different structures more effectively (Martinuzzi, 2003). Additionally, the new information that for some families factors can act as risk and protective can be incorporated into support practices.
Appendix A

IRB Approval Letter
EXPEDITED APPROVAL OF HUMAN SUBJECT RESEARCH

IRB No.: 2012-0429
TITLE: Resilience in Families of Children Who Have Disabilities
Effective Date: October 17, 2012
Expiration Date: October 17, 2013

Approved Number of Participants: 50 (Do not exceed without prior IRB approval.)

The University of Texas Arlington Institutional Review Board (UTA IRB) has made the determination that this research protocol involving human subjects is eligible for expedited review in accordance with Title 45 CFR 46.110(a)-(b)(1), 63 FR 60364 and 63 FR 60353, category(6) (7). The IRB Chairman (or designee) approved this protocol effective October 17, 2012. IRB approval for the research shall continue until October 17, 2013.

APPROVED NUMBER OF PARTICIPANTS:
This protocol has been approved for enrollment of a maximum of 50 participants and is not to exceed this number. If additional data are needed, the researcher must submit a modification request to increase the number of approved participants before the additional data are collected. Exceeding the number of approved participants is considered an issue of non-compliance and will result in the destruction of the data collected beyond the approval number and will be subject to deliberation set forth by the IRB.

INFORMED CONSENT DOCUMENT:
The IRB approved and stamped informed consent document (ICD) showing the approval and expiration date must be used when prospectively enrolling volunteer participants into the study. The use of a copy of any consent form on which the IRB-stamped approval and expiration dates are not visible, or are replaced by typescript or handwriting, is prohibited. The signed consent forms must be securely maintained on the UT Arlington campus for the duration of the study plus a minimum of three years after the completion of all study procedures (including data analysis). The complete study record is subject to inspection and/or audit during this time period by entities including but not limited to the UT Arlington IRB, Regulatory Services staff, OHRP, and by study sponsors (if the study is funded).

MODIFICATION TO AN APPROVED PROTOCOL:
Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, “promptly report to the IRB any proposed changes in the research activity, and to ensure that such changes in approved research, during the period for which IRB approval has already been given, are not initiated without prior IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject.” Modifications include but are not limited to: Changes in protocol personnel, number of approved participants, and/or updates to the protocol procedures or instruments and must be submitted via the electronic submission system. Failure to obtain approval for modifications is considered an issue of non-compliance and will be subject to review and deliberation by the IRB which could result in the suspension/termination of the protocol.

ANNUAL CONTINUING REVIEW:
In order for the research to continue beyond the first year, a Continuing Review must be completed via the online submission system within 30 days preceding the date of expiration indicated above. A reminder notice will be forwarded to the attention of the Principal Investigator (PI) 30 days prior to the expiration date. Continuing review of the protocol serves as a progress report and provides the researcher with an opportunity to make updates to the originally approved protocol. Failure to obtain approval for a continuing review will result in automatic expiration of the protocol all activities involving human subjects must cease immediately. The research will not be allowed to commence by any protocol personnel until a new protocol has been submitted, reviewed, and approved by the IRB. Per federal regulations and UTA’s Federalwide Assurance (FWA), there are no exceptions and no extensions of approval granted by the IRB. The continuation of study procedures after the expiration of a protocol is considered to be an issue of non-compliance and a violation of federal regulations. Such violations could result in termination of external and University funding and/or disciplinary action.

ADVERSE EVENTS:
Please be advised that as the principal investigator, you are required to report local adverse (unanticipated) events to The UT Arlington Office of Research Administration; Regulatory Services within 24 hours of the occurrence or upon acknowledgement of the occurrence.

HUMAN SUBJECTS TRAINING:
All investigators and key personnel identified in the protocol must have documented Human Subjects Protection (HSP) training or CITI Training on file with The UT Arlington Office of Research Administration; Regulatory Services. Completion certificates are valid for 2 years from completion date.

COLLABORATION:
If applicable, approval by the appropriate authority at a collaborating facility is required prior to subject enrollment. If the collaborating facility is engaged in the research, an OHRP approved Federalwide Assurance (FWA) may be required for the facility (prior to their participation in research-related activities). To determine whether the collaborating facility is engaged in research, go to: [http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm](http://www.hhs.gov/ohrp/humansubjects/assurance/engage.htm)

CONTACT FOR QUESTIONS:
The UT Arlington Office of Research Administration; Regulatory Services appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact Robin Dickey at robind@uta.edu or you may contact the office of Regulatory Services at 817-272-3723.
Sincerely,

Judy R. Wilson, Ph.D.
Associate Professor
UT Arlington IRB Vice-Chair.
Appendix B

Inventory for Client and Agency Planning
ICAP domain and scale intercorrelations (ages 3 to 59 months)

<table>
<thead>
<tr>
<th>Domains</th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
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<td>Broad Indepen.</td>
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</tr>
<tr>
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<tr>
<td>Broad Indepen.</td>
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<td></td>
<td></td>
<td>(.99)</td>
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(N=549)a,b

Soc/Com Skills=Social and Communication Skills
Per. Lvg. Skills=Personal Living Skills
Comm. Lvg. S.=Community Living Skills
Broad Indepen.=Broad Independence
a Values in parentheses are square roots of reliability coefficients.
b Correlations corrected for age.

ICAP domain and scale intercorrelations (ages 60 to 127 months)

<table>
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<th>Domains</th>
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<td>.76</td>
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(N=540) a,b

Soc/Com Skills=Social and Communication Skills
Per. Lvg. Skills=Personal Living Skills
Comm. Lvg. S.=Community Living Skills
Broad Indepen.=Broad Independence
a Values in parentheses are square roots of reliability coefficients.
b Correlations corrected for age.

ICAP domain and scale intercorrelations (ages 162 to 138 months)

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<td>Broad Indepen.</td>
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(N=421) a,b

Soc/Com Skills=Social and Communication Skills
Per. Lvg. Skills=Personal Living Skills
Comm. Lvg. S.=Community Living Skills
Broad Indepen.=Broad Independence

a Values in parentheses are square roots of reliability coefficients.
b Correlations corrected for age.

ICAP domain and scale intercorrelations (ages 3 to 348 months)

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<td></td>
<td></td>
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</tr>
<tr>
<td>Motor Skills</td>
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<tr>
<td>Per. Lvg. Skills</td>
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<td>(.87)</td>
<td>.88</td>
<td>.96</td>
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</tr>
<tr>
<td>Comm. Lvg. S.</td>
<td></td>
<td></td>
<td>(.83)</td>
<td></td>
<td>.96</td>
</tr>
<tr>
<td>Broad Indepen.</td>
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<td></td>
<td></td>
<td></td>
<td>(.93)</td>
</tr>
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</table>

(N=1,510) a,b

Soc/Com Skills=Social and Communication Skills
Per. Lvg. Skills=Personal Living Skills
Comm. Lvg. S.=Community Living Skills
Broad Indepen.=Broad Independence

a Values in parentheses are square roots of reliability coefficients.
b Correlations corrected for age.

(Bruininks et al., 1986, pp. 69-70)
Appendix C

Interview Questions
Interview Questions (Questions address factors effecting individuals or family)
1) supports, 2) barriers, 3) needed supports, and 4) other
For Adults/older Adolescents w/o Disabilities

Tell me about things that have helped you adapt to being in a family in which a child/brother/sister/family member has a disability?

Tell me about things that have prevented you (your family?) from adjusting to being in a family in which a child/brother/sister/family member has a disability.

Tell me about things that would help you (your family?) have an easier time living in a family that has a child/brother/sister/family member who has a disability.

Tell me about other aspects of being in a family that has a child who has a disability that are important to you.

For Verbal Children and younger Adolescents

Tell me about the good things that go with being in a family of a child who has a disability.

Tell me what bothers you about being in a family of a child who has a disability.

Tell me what would make living in a family of a child who has a disability the would make life easier for you and your family.

Tell me about other things that are important to you in living in a family with a child who has a disability.

For Non Verbal and Pre Verbal Family Members Who Cannot Use an Augmentive Communication Device - Asked of a significant caregiver, parent, attendant, etc.

Tell me about things that help name of the non-verbal family member to cope with distress/unhappiness? Do any of these ways seem especially helpful in situations that involve care of the family member who has a disability?

Tell me about things that hinder name of the non-verbal family member to in coping with distress/unhappiness? Do any of these ways seem especially helpful in situations that involve care of the family member who has a disability?

Tell me about things you think would help name of the non-verbal family member to cope with distress/unhappiness? Do you think any of these ways would be especially helpful in situations that involve care of the family member who has a disability?

Tell me about other things that you think are important to name of the non-verbal family member in coping with distress/unhappiness? Do any of these ways seem especially helpful in situations that involve care of the family member who has a disability?

For the Family Member Who Has a Disability

Tell me about things that help you and your family adapt to stress.

Tell me about things that prevent you and your family from coping with problems.

Tell me about things that would help you and your family adapt to stress.
Tell me about other things that impact your ability, and you family's ability, to deal with problems.
Appendix D

Cultural/Non Peer Reviewed & Indirect References


References


Foster, K. (2010). ‘You’d think this roller coaster was never going to stop’: Experiences of adult children of parents with serious mental illness. *Journal of Clinical Nursing, 19*(21/22), 3143-3151.


Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement, 1*, 165-178


University of West Georgia, Department of Psychology. (n.d.). Obituary: Clark Moustakas. Retrieved April 8, 2014 from the University of West Georgia web site: http://uwgpsychology.org/2012/obituary-clark-moustakas/


Biographical Information

Janet Appleby works for the Texas Department of Aging and Disability Services. From 1987 to 1999 she was the parent of a child who had severe cerebral palsy. Her Bachelor of Science in Psychology is from Louisiana State University, Baton Rouge, Louisiana. Her Master of Elementary Education is from Southwestern Adventist University in Keene, Texas. Her Master of Social Work and Doctorate of Philosophy in Social Work are from the University of Texas at Arlington.