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RETROSPECTIVE FRAMES OF DISABILITY: THEMES DERIVED FROM PARENTS OF CHILDREN WHO GREW UP WITH CONGENITAL DISABILITY

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RETROSPECTIVE FRAMES OF DISABILITY: THEMES DERIVED FROM PARENTS OF CHILDREN WHO GREW UP WITH CONGENITAL DISABILITIES

A PHENOMENOLOGICAL STUDY

DISsertATION

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Rehabilitation Sciences in the College of Health Sciences at the University of Kentucky

By

Sheryl L. Holt
Lexington, Kentucky

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Lexington, Kentucky 2016

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ABSTRACT OF DISSERTATION

RETROSPECTIVE FRAMES OF DISABILITY: THEMES DERIVED FROM PARENTS OF CHILDREN WHO GREW UP WITH CONGENITAL DISABILITY

Introduction: For children born with physical disabilities, the perspectives and actions of their parents prove significant to their childhood developmental outcomes clinically, educationally, socially, and with regard to community participation. The lived world and perceptions of parents who have children with disabilities however is not well investigated. This study sought to understand parents’ framing of theirs and their children’s disability experiences. Family systems together with family systems intervention models, and disability theory were used to provide structure to interview instrumentation and subsequent analysis. Child-centered and ecologic influences were also used to track the transformative processes over time that infuses parental themes.

Methods: Methods for this study followed traditions of heuristic phenomenology. Open-ended parental interviews, written and spoken, together with field notes were used to explore the meanings given to disability. Analysis focused on collective descriptions and critical themes.

Results: The nine parents in this study revealed four dominant themes around which their children’s lived lives were both understood and framed. Navigating normal for us; Our pride and joy; Anything but disability; Lived lives, looking back. Each is expressed in the words of parents who reared a child with disabilities into adulthood.

Discussion and Recommendations: Parental disability frameworks differ from medical model frameworks and those of disability studies but share similarities with each. The parent themes provided holistic views of what these families have lived and learned. Their perspectives provide potentially vital markers and points of inquiry for interventionists and team members who work with children and families. Themes may also offer categorical means to explore well-being and child outcomes. Additionally, the themes were transformative and empowering for parents, both in the discussion of individual matters and in their narratives. All participants iterated that they welcomed having their voices invited and heard.

Keywords: Framing, family systems, disability experience, parent(s) of children with disability, family, child with disability, qualitative research, phenomenology.

Sheryl L. Holt
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Date

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DEDICATION

I dedicate this dissertation to all parents who have sought and will seek to enable their children to enter in and to have, hold, and cherish life as worth living. With special thanks to those who likewise enabled me: my parents complete with the legacy that was theirs, Mildred and James Holt; my sister complete with the infinite joy of counting her as best friend and a life mentor, Suzanne Holt; my three beloved friends who did not live long enough to see this outcome, yet who believed in me and from the beginning, saw my potential when it mattered most in my life, Martha, Diane, and Nanette; and finally, to my own prides and joys, Mia and Sammy, with all my love and thanks. Mia and Sammy, you both gave up many of your earliest longings to allow me to pursue, while longing right back, a path that I needed to take. I dedicate this dissertation to all the countless families of children with special needs and to their able and gifted children. I especially am indebted to the parents who willingly participated in this study, contributing pieces of their hearts and stores of their wisdom to this research, who told me their stories as they explored their memories and lived experiences. In so doing, they helped me understand why it matters that people share their narratives and inherent views about life. How deeply I respect them both in their living and in their frames of having lived, learned, and celebrated life. Your collective voices have shared a disability perspective that I had not understood before. I hope my efforts and the outcomes of this study can make a small difference in the world.
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CHAPTER ONE

INTRODUCTION

In the United States of America, physical therapists and other healthcare providers are mandated by law to assess the needs of infants and toddlers who have been identified as having a disability (IDEA, part C). For families of children with disability who are eligible for services under IDEA, part C, health and human services becomes a viable option for meeting their children’s needs, often entering into aspects of that family’s life. Some of their service providers may include the special educators, occupational and physical therapists, speech and language pathologists, counselors, and medical specialists, each of whom are able to provide assist to families and help the children achieve skills of developmental importance (Thorne, Radford, & McCormick, 1997). The focus of these interventions modify over the course of the child’s lifespan to ensure inclusion of the child into family, community, educational, recreational, and vocational settings, leading to his or her full participation in life (Simeonsson, Sauer-Lee, Granlund, & Björck-Åkesson, 2010).

At the beginning of this process, a specialized team of providers is set into action by someone, often a physician, who observes the infant’s differences. A team then addresses what is perceived of as the young child’s risks or delays to development (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; IDEA, part C). Once an infant is identified, a system of early intervention service providers is generally positioned to enter into that infant’s life in order to assist physical, social and emotional, and adaptive behavioral development (IDEA, part C).
Early Interventions

Differing experientially from a majority of brand new parents, the parents who have a baby with a disability will most likely leave the hospital with more than simple home going instructions. For many, this may even include the contact information for early intervention services (Humphrey & Case-Smith, 2005). While this intervention can seem intrusive or traumatic to a young mother or father (Piggot, Paterson, & Hocking, 2002), parents who look back may acknowledge, “babies can’t wait.” Early intervention programming in the United States assesses the multi-dimensional developmental needs of a child and his or her family. They also seek to assist the family in understanding their child’s condition, impairments, functional limitations, rights, and life (Bailey, Buysse, Edmondson, & Smith, 1992). The approach within contemporary early intervention is strongly child and family centered, thus seeking to enable parents to frame their experiences around child abilities, regardless of diagnostic labels (Almasri et al., 2011).

In spite of the family orientation and child centered approach of early intervention, the services are implemented at a time when parents are already experiencing high adjustment, uncertain future, and dashed expectations. Families who may have anticipated an uncomplicated home going face exactly the opposite. They are likely to be stretched beyond their boundaries in their new reality.

Early understandings. Early intervention programs in the United States are known to assist the family broadly as they adjust to the child’s need. They may help them learn more about their child’s condition, his or her needs, rights, and potential. They can educate on how to care and advocate for as well as how to communicate regarding the child’s needs. (Bailey et al., 1992). The framing of disability within these services is
strongly child and family centered (Almasri et al., 2011). As this enlarged family team experience unfolds, it can bring new perspectives for parents, which they have not anticipated, and new challenges, which they have not met. It also may bring opportunities to experience empowerment and the capacity to succeed.

**Family Centering Processes**

Families and their infants who begin life with special services for their children may find that they are able to factor therapies and medical services into their normal family routines. Success in this often allows for family routines and a sense of parental control (Bailey et al., 1992). Beginning at a very early age and continuing through school age into adulthood, therapies adapt, changing approach or focus over time. In the earliest stages, the interventions may focus on help-giving and capacity building through the child’s family (Trivette, Dunst, & Hamby, 2010). Later the approach may relate more to transitions to school or adulthood (Couser, 2006).

**Growing family complexities.** Over time, as outside interventions become part of a family routine, the developing family system dynamics may become increasingly complex (Trivette et al., 2010). Parents are positioned to receive education or help for their child; parental interactions with therapists and caregivers become separate journeys for parent and child. They may also be dissimilar comparing those experienced/lived by parent and the child (Jansen, Ketelaar, & Vermeer, 2003). The child may have a simple, even enjoyable therapy session. The parents, however, may have dreams about the child's outcome in therapy. Failure to achieve physical therapy (PT) goals may put those dreams at stake.
As the family system thus enlarges and the family-team dynamics become central to its function, the family-team synergy may affect both the family function and its overall well-being (Barnett et al., 2003). Depending on the particular family team, the parent may or may not have an integral role. Parent roles modify how different factors contribute to systemic changes of family structures and senses of well-being. In fact, as individual and family identities form (Baker, 2008), individual family culture and disability culture may begin to blend (Barnett et al., 2003). This potentially adds notions of needful adaptations, developmental differences, perception of child-related barriers, and other previously unexperienced social constructions (Barnes, 2004). Additionally, the logistics of service set up and coordination may come to dominate a family’s time and energy. The family is challenged.

Each family must figure out: family member dynamics, scheduling needs, emotional sets, responses to a team of providers, and what it takes to meet the needs of their child (Piggot et al., 2002). Many health care providers recognize that families are in the midst of extreme challenge. Providers who use family centered approaches engage the family in therapies and interventions while seeking to meet the family needs. Often family centered approaches can integrate family rituals into therapies, meeting child needs contextually and in naturalistic manners (Darrah, Law, & Pollock, 2001), thus seeking to strengthen and validate family systems.

**Toward mutual understanding of family and team.** Family centered philosophies have broadly influenced the service delivery approaches of therapists and other pediatric health care professionals. The approach seeks to build parent capacity, to offer help, all while validating parent perspectives, capabilities, and motivations. This
approach understands that family ultimately shapes the infant’s and growing child’s developmental outcomes across multiple domains (Trivette et al., 2010). Infants and young children have family as a primary context, including the family’s natural environments, its preferences, values, and priorities (Novak, Cusick, & Lannin, 2009; Rosenbaum et al., 1998; Schreiber, Effgen, & Palisano, 1995; Woods & Lindeman, 2007). Effective family centered practices keep that centrality in therapy (Novak et al., 2009), seeking to support existing family structures, rituals, and identified needs (Darrah et al., 2001; Rosenbaum et al., 1998).

Subtle aspects of ensuring family centrality include sensitivity to family identity and culture, its levels of education and vocation, socioeconomic resources, and activity preferences. Family life, culture, and preference allow for many possible paths for these family centered interventions and supports to emerge. Some early challenges faced by family and child may include the essential journey of shifting resources, adjustments, interactions and relationships with the service sector, and potential for perceived changes in social status.

**The Family Journey**

As parents of a child whose life includes a disability begin the new journey as a family, not only does their family sense of boundaries change, but so do the dreams they had in mind when expecting the child (Gordon, 2009). The parents of a child with a disability face unique parenting challenges in providing for their child, challenges replete with the nurturing of uncertain potential, inevitable twists and turns associated with diagnostic natural history, and the struggle to establish and maintain outcome oriented hopes (Dion 2008). Over time, parents may be especially vulnerable to the tolls of stress
created by providing care, coordinating services for their child’s daily care, and the financial bottom lines. Their child’s medical expenses may include braces and adaptive equipment, medications or surgeries, and outpatient therapies such as physical therapy, occupational therapy, and speech therapy (DHHS, 2004). The totality of the experience is one with extraordinary dimensionality.

Family stressors appear to increase during times of a child’s diagnosis, related illnesses or surgeries, and at points of key milestones, especially when the child does not accomplish developmental transitions. Over time, the parental stressors may alter effective family functioning (Melnyk, et al., 2001). The unknowns of a child’s future may create anxiety. While rearing their child with special health care needs, parents may experience episodes of what becomes a chronic sadness (Gordon, 2009). This chronic sadness is cyclic and characterized by guilt, sadness, or frustration associated with a living loss. In parents with children with ongoing life-long disability, this is a normal grief response. The characteristics parents experiences differs from a response that sinks into a clinical depression (Melnyk et al., 2001; Roos, 2002).

Parents may discover new possibilities they never imagined before: ways to adapt, cope, and live within optimistic themes that co-exist with disappointments (Griffin & Kearney, 2001). The dimensionality of parents of children with disability derive from personal reactions, family impacts, degree of the child’s disabling condition, and societal attitudes, lending to peaks and valleys of adaptation, reason for optimism, and sense of loss (Barnhill & Barnhill, 2010). Coping becomes a critical strength that allows dreams to
Society impact on a family. Families do not live in a vacuum and disability in society is a far from a settled status. In fact, people living with disability remains one of the most oppressed groups in the world with considerable ignorance, disinterest, and bias persisting in language, laws, and attitudes (Charlton, 2000; Home, 2002). Due to increased international and national awareness, including the International Day of Persons with Disabilities, the United Nations Treaty on Disability (2015), updated U.S. federal regulations such as ADA and IDEA (ADA, 2010; IDEA), there have been some broad societal changes in the United State in recent decades. Though progressive in word, the welcome of society to a child with disability remains somewhat ambiguous. Many people living with a disability perceive a continued stigmatization in this reality (Barnes, 2004).

The mixed messages experienced by parents of a child with disability post the child’s birth may modify their perceptions about a once familiar society and its relationship to disability, including the nature of family-child-community interactions and related disability politics (Barnhill & Barnhill, 2010). According to Bronfenbrenner (1979), families and their children live and develop within a layered context, the layers of which intimately relate to family and child developmental processes and outcomes. The family/child experiences and perceptions over time are modifiable by events in community, work, geographic and social situations, or even political environments during the child’s growth and development. Therefore, development in children and families must be understood within processes between system contexts, together with the passage
of time. Such levels of understanding encourage dimensional examination of many factors, including policies and politics influencing a given family and their child. An example of this is the stance taken toward disability by the United Nations.

**International mandates.** According to the U.N., children with disability are invited to integrate into educational, recreational and community processes across the globe, at least at a legislative level. In fact, it is the belief of the U.N. that children with physical disabilities “…should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate active participation in the community” (1989, 2015). While the U.N. promotion of such standards is encouraging, it cannot ensure that the process to be simplistic. Indeed, not all parents and their children with disability have such an experience (Barg, Armstrong, Hetz, & Latimer, 2010). Family by family, each parent who finds herself or himself in the role of rearing a child with a disability, has to face forward into the social contexts of real life to experience full participation. In real life, the U.N. envisions full participation to include the child’s “…effective access” to early childhood services, play groups, education, training, health care services, rehabilitation services, and eventually to “preparation for employment in a manner conducive to achievement of the fullest possible social integration and individual development” (1989). Society is a major participant in the receiving line of the child with disability.

**Parent’s lived knowledge of disability.** As parents experience their child’s disability experiences, their lived experiences would appear to run parallel to the child’s life, with processes related and relational. The journey is one that begins with the unexpected, a loss of dreams. The journey may or may not reconstruct the world they
knew before the child’s birth, and may or may not create the one they hoped for thereafter. As parents find ways to build and define their family, they develop concurrent understanding of disability that is unique, a knowledge that is lived, refined, and rich with insights that they have uncovered over time. How parents frame their responses and reactions to the notion of disability appears to be an important potential marker of their emergent family function, their quality of life, emotional states, family identities, and parent-child relationships. Parents who have reared a child with a disability from infancy to adulthood likely have taken a journey they never imagined prior to their child’s diagnosis (Barnhill & Barnhill, 2010). The journey, how it may have shaped the lives and related perceptions of family and disability, is the interest of this inquiry. Parent experiences most likely began from a point of vulnerability and uncertainty, with steps that moved forward through time, challenge-by-challenge. Life redefined itself in terms of parents’ lived realities. Within these realities, parents, families, and children emerge not as weak or damaged, but powerfully transformed (Hazelwood, Shakespeare-Finch, & Strecker, 2014).

Problem Statement

In spite of marked changes in societies worldwide, persons with disability remain among the most highly oppressed demographic in modern times (Charlton, 2000). Parents and families of children with disability are part of this demographic and are also impacted negatively by stress, sadness, and disorientation (Pigott et al., 2002; Roos, 2002). Families face potential isolation or exclusion, inadequate services and stigmatizing attitudes from those who strongly identify and give credence to a dominant able-bodied society (Home, 2002). How parent respond to the challenge impacts their relationships,
family, and child with a disability (Almasri, et al., 2011). Understanding the lived experience and perspectives of parents who have reared children with disability into adulthood is vital to all who would seek to build capacity and offer help to these families throughout the child’s life. Such understandings increase the dimensionality of disability definitions and create opportunity to enlarge working models of intervention and language. Enabling the voices and understanding the shared perspectives of parents may help provide invaluable information. It is hoped that this information may add to our existing body of knowledge, lending guidance, direction, strategies, and agency for change to new parents who face the challenges of rearing a child with disability. Understanding the lived experience of parents is needed because it is vital to the true dimensionality of the child and family disability experience. Such narrative and its understanding is also vital to parent and family well-being

**Purpose of the study**

The over-arching aim of the study was for parents to investigate and discuss how they have framed or re-framed what they have learned about disability into a perspective and worldview. The study aimed to have them investigate this framing over time, to state views in their own words, and to share their family story lines and conversations (Gee, 2005). Sub-aims included self-exploration of family identity/culture versus disability identity/culture and their mutual influences over time. Other aims included examination of the complex intersections of family demographics, community and intervention contexts, and disability perception (Goodley, 2013). The means to these purposes were both their spontaneous thoughts and reflective processes, each of which may lead to perceptions of meaning.
The explicit purpose of this research was to reveal the lived experiences of parents of children with congenital disability from a retrospective vantage. Retrospective parental reflections may expound upon the parent’s and children’s lived worlds, their experiences and perspectives over time. The critical emphasis was the translation of parental experiences, responses, reactions, and perspective development into contextual frames surrounding disability, including the meanings they derived.

The explicit objective of the researcher through the study instruments was to gain a rich understanding of the how parents interact with memories, familiar perspectives, and time to re-gather parts of their experiences and understandings to re-frame disability. The researcher attained this goal via parental retrospective reflections, written questionnaire, mutual dialogue and inquiry, data analysis, and eventual rebuilding of parental responses into a new frame around disability, something that represents their lived experiences.

**Research Question**

As understood through their lived experiences, how do parents who have reared a child with disability from infancy to adulthood, describe their working *frames* of disability?

**Sub-questions.** Do the meanings parents give disability fit with what others mean when they say disability? Do these perspectives also interact with notions of normativity? Will parent perspectives relate to disability studies? Will parents believe that intervention shaped their disability perspectives? Will parents have a disability frame or perspective they wish to share with parents who are going through the same experiences as they did?
Orientation of the researcher

The researcher is an assistant professor of physical therapy and researcher who once grew up as a child with cerebral palsy, thereafter, a physical therapist who worked with children and their families for over 30 years, then, a rehabilitation science doctoral candidate whose interests were found in the merger of family, children with disability, and disability studies. Now, as a physical therapist, professor of physical therapy, and doctoral candidate, the researcher wanted first, to hear and understand the disability experience of parents and secondly, to understanding what it meant to them to have lived it. It was essential to listen without bias or pre-conceived ideas in researcher-parent-dialogues, in order to represent neutrality. That enabled parental willingness and honesty to share their reflections. The researcher practiced epoche, bracketing, and reflexivity in this undertaking and completing this qualitative research (Ahern, 1999; Bednall, 2006). A model of the relationship of epoche to the study data is in APPENDIX A.

Significance of the study

Empowerment of parents of children who are born with disability is as vital to the children as efforts directed solely toward the children (Trivette et al., 2010). Parents need not feel marginalized from society, because of their attitudes toward children with disability. The unexpected birth of a child with a disability should not take a child or his family away from the world in which their dreams exist. Instead they, as a family, need to participate in life (Palisano et al., 2010), and contribute their new knowledge and understanding. Parent perspectives provide needed support for other families facing the same challenges, support perceived as especially meaningful (Prelock & Vargas, 2004). The study’s journey and findings both supported and potentiated the parent participants
to be unique sources of strength and input for other families attempting to meet the
characteristics of rearing a child with a disability.

Glossary

Bronfenbrenner’s family ecological systems: Ecological systems in which a family’s developmental realities occur, including time. Family systems and those outside the home referenced in parent discussions and in the data analysis.

Child with disability: For the purposes of this study, a child with disability is one born with congenital impairment, identified in infancy, creating non-progressive functional limitations and life-long disability. The child must be born to the parents in question and must still be alive, well, and living part or full time outside the parent home, having transitioned into adult hood.

Chronic sorrow: Based on multiple works (Eakes, 1998; Olshansky, 1962; Roos, 2002), this concept of sorrow defines a pervasive, persistent sorrow that may cycle, but does not disappear with time. It is based on the presence of an unrelenting basic situation (in this study, the situation is having a child with a disability) that does not disappear in spite of time. At times of normative developmental milestones for other children of similar ages, the sorrow may be exacerbated. Each unattended school activity of significance or inopportunity due to social or physical barriers is a recurrent loss. This phenomenon is a potential factor in parent perceptions and frameworks.

Disability culture: For the purposes of this study, disability culture is a sub-culture to any dominant existing culture and represents the comprehensive rights movement among those who live with a disability. Part of the vision of this culture is full
inclusion in society (Barnes, 2004), true visibility (Brown, 2002) across societal domains (work, housing, education, arts, recreation, public access, wages, and representation) but not just visibility, also a non-diminished self-value. Disability culture includes self-advocacy and a voice, dynamics of opportunity, access, and participation as a whole person, not stigmatized. It includes the notions of child self-advocacy for civil rights, advocacy, affirmation of disability culture and history, dating and relationships, education, health care, the arts, current events in public policy and the news, prevention and recovery, recreation, leisure and sports, safety, technology, transportation, vocation, and working as a group (Voices, 2012).

**Family culture:** For the purposes of this study, family culture is the composite of a family’s self-defined rituals, values, traditions, and routines that make them who they are as a family. It includes how family members fulfil the structures of family and bring them to life.

**Disability:** The concept of disability is operationalized at its starting point as the framework of WHO (World Health Organization, 2007), in its International Classification of Function (ICF). This suggests that the person is not born with a disability, rather impairment. Due to functional limitations and societal barriers, the child may develop disablement. For this study and regarding the child with a disability, disability includes the physical impairment that has a visible manifestation, influencing physical skills, strengths, and appearance. To enable parent perspective around the time of the infant’s birth, onset of disability was congenital.
Disability studies: Reference to disability theory entails the large body of research related to the personal, social, and political aspects of disability. Its research is based in a practice coined “Nothing about us without us” (Charlton, 2000) which suggests that only those things known to be true by those who have lived it are valid. Therefore, perceptions of disability by those who live aside it are not truly experts about the lived experience of the one with disability. Those who live outside the disablement experience must frame their sense of disability as an outside perspective. This is the perspective taken of the research topic, that the framework described by parents is a unique outside experience of disability.

Parent of child with disability: For the purposes of this study, the parent participant is a primary caregiver of the child throughout his/her growing up. In a two-parent home where a primary caregiver was identified, the second parent was made welcome to contribute to the initial open-ended introductory written questionnaire or interview, as occurred in one family.

Family systems theory. For the sake of this study, the primary tenets of family systems related to the parent and child dynamics of differentiation and projection. The thinking and feeling self is both represented in perceptions, with the thinking self representing objective thoughts, personal reactions, known biases, developed opinions, and current or past tendencies.

The feeling self may also be represented in discernment of common feelings associated with the time periods and lived experiences as they are lived. The degree of emotion may be used to establish the family’s personal and interpersonal sense of significance. Due to family systems theory tenets, the connections of individual behaviors
to family are considered one beyond the scope of this practice, while acknowledging that individual emotional, mental, or physical states are likely to have a degree of differentiation among family members, while preserving objective relatedness, emotional ties, and connection. Projection is a common parental defense that may infuse perceptions with child anger, frustration, competition, distrust, or any other emotional or cognitive state. This potential phenomenon may not represent the child’s feelings. (Carter & McGoldrick, 1989). Family insight was the family’s ability to rise above existing patterns. Reflective discussion can create insight regarding individual and family patterns (Walsh & Harrigan, 2003). Analysis of individual family member differentiation and projection are also beyond the scope of this paper.

**Framing as a concept**: Framing, for the purposes of this study, relates to how the parents systematically and reflectively reconstruct disability from a retrospective place of analysis. It includes ways in which they conceptualize, perceive, and respond to their child’s disability experience as well as their own (Barnett et al. 2003). It allows for systems of belief surrounding their child’s disability, together with a weighing in on realism. Framing allows parents to examine changes over time. Parents are able to frame disability in structures both near to and beyond the child. The frame does not need to reach a place in which its judgments are final.

**Identities associated with family and disability.** Parents explored identity in a way that both involved family and transcended family. As they explored aspects of their own sense of identity and that of the child, the relationship to family traits versus disability characteristics was explored.
**Family milestone:** For the purposes of this study, the word milestone did NOT represent textbook developmental or social milestones associated with chronological ages or normal curve referents, but rather serve as a marker of personal, social, or spiritual significance to the family over time. It allowed the family to identify and choose those hallmark events or memories that, looking back, may have served the purpose or role of a family/child milestone. It was based on a relevant/significant/meaningful event that occurred in the childhood years in the lifespan of the child.

**Retrospective:** The period of time over which the parents are looking back was not limited in years, but controlled in this study by the following: the time was long enough to provide a true retrospect reflection. Thus, the child must have moved from the home and transitioned into adulthood. The primary caregiver, at the time of the interviews feels comfortable with revisiting this experience, and is healthy enough physically, emotionally, and cognitively to look back and effectively provide meaningful information about his or her lived experiences as a parent of a child with a disability. The child with disability who was the subject of the inquiry and reference around which disability is examined must be living at least part time outside the home, in a place of relative safety and good health, so that the living situation of the present does not create adverse emotional or mental strain to parent or child. (This attempts to pre-empt the interjection of volatile matters into the parent’s ability to look back). The sense of retrospect does not preclude the option or ability of the parent to look forward.
CHAPTER TWO

REVIEW OF LITERATURE

The family, whose expectant new member is born with a disability, moves toward its own normalcy, finding ways to manage, understand, cope, and dream (Barnett et al., 2003). The family boundaries that expand to accommodate a service sector may also narrow and sense the impact of stigma or status change (Barnhill & Barnhill, 2010). Throughout the years of the child’s development into adulthood, parent perceptions of disability may integrate into family routines and the needed actions that ensue. This literature review discusses the process of the family shifting gears, developing and coping amid medical model inputs, imposed societal norms, disability dynamics, and their own family influences. It explores the temporal aspects of child development juxtaposed with disability and introduces the notion and impact of parental framing of disability.

The literature review then explores the roles of research, relevant theoretical structures that were used to inform and provide orientation to the inquiry. These include those regarding family systems, disability studies, and intervention models. Finally, phenomenology and its use with retrospective analysis is explored.

Finding Normalcy as a Family

Families await the word of a healthy birth with great anticipation. The addition of a child moves a couple toward a new identity as a family (Baker, 2008). Upon news of a given diagnosis, parents may react with ambivalence, denial, and confusion. It is also possible that they may feel anger, guilt, and sorrow (Barnhill & Barnhill, 2010). When disability is juxtaposed with the arrival of newborn, family cognitive-emotional responses
cannot be predicted or defined in black and white. The family system is mutable and contextualized (Couser, 2006) and its responses are borne from its unique characteristics, culture, and identity. The anticipation of parenthood, considered universal, is an expectation that rarely considers anything except a normal, healthy, and happy experience (Baker, 2008). When all is welcome news, a child’s birth is most often met with simplistic celebration (Dion, 2008). For a family whose newborn receives a diagnosis connoting all is not well, a sudden unexpectedness prevails.

Life is put on hold; uncertain, the family is disoriented, and shaken (Piggot et al., 2002). Depending on the severity of the infant’s condition, the anticipated paths and dreams parents shared may quickly disintegrate. In most cases, parents meet the sense of sudden detours, unmarked and unforged. When a baby has entered life outside society’s norms, even gradual divergence from the expected journey finds parents and families poorly prepared for what happens next (Barnett et al. 2003).

The advent of extraordinary responsibilities associated with addition of the newborn with disabling condition challenges family and extended family, resetting the stage of their expectations and plans, especially if their child is unable to pass for normal (Brune, 2013). Bio-normativity defines parenthood in terms of predictive developmental outcomes, achieved milestones, first steps, jumping, running, playing, speaking, learning, and participating in the societal structures through which families meet and share (Baker, 2008). Having a child with a disability presents a different model of development from that offered by bio-normativity, lending unpredictability to the child’s emergent potential and development over time.
Parents may find that they elect not to use or validate defective notions of their child’s diagnosis. They may choose not to use words such as disability around their child or family members (Holt, Sepp & Staffieri, 2013). These families may elect simply to emphasize their child’s positive traits and strengths, integrating their child just as he or she is into their own unique family, community cultures, structures, and identities (Brune, 2013). Parental emphasis may shift away from their child being different from other children toward relative his or her normalcy, meaning “what is normal for their child.” In extremes of this tendency, parents may largely shy away from the medical model, rejecting its tenets as they acclimate to their child’s impairments among other unique expressions, interests, and strengths. They may even become militant over time, representing their child’s rights, acting as spokespersons, perhaps for particular disability advocacy groups, sometimes with legal teams in tow (Houston, 2004). Parents who acclimate in this fashion are partially orienting toward disability studies, seeing the child’s beauty not the deviance, standing for the rights of the child to have a full life. However, in minimizing differences, they may be orienting more toward family culture, electing for the child to fit in regardless of his impairments, passing as normal enough (Darling, 2003).

Identification with either family or disability may give them an empowered sense of their choices. Parents may become experts in their child’s care, advocates in their child’s education, part of their child’s interests, and thus pavers of a way for their child to participate in educational and civic activities (Trivette et al., 2010). Parents of children with disability may gravitate equally toward normal family culture and disability culture, based on the acceptance and successes of their interactions among family and community.
groups (Fong, 2001). These two worlds may provide a family functional footing or one of lonely apposition, where they feel caught in the abeyance between (Goudie, Havercamp, Ranbom, & Jamieson, 2010).

**Threats to Family Status.** Parenthood in most developed countries lends a distinguishable and often exclusive status that includes certain privileges, responsibilities, rights, and societal recognition (Baker 2008). Becoming a parent is widely celebrated. Having a child with a disability does not lend that same status (Neumann, 2007). The family whose membership includes a child with disability, especially if the child has appreciable visible disability, may find that a different status is palpable among social contacts (Barnett et al. 2003); the “difference” in their child may threaten parents and family with a marginalized, not elevated, position or status (Charmaz, 2011). This status may be destabilizing at first. The parents may not feel part of community playgroups and sports functions, recitals and social outings in which other same age children are participants. They may not have access or invitation. The status difference and its ramification may persist even as the family adjusts and finds its own adaptive skills and strategies (Piggot et al., 2002).

**Time sensitive life-long processes in family adaptation.** Disability perceptions in parents and family are phenomena that are expected to change over time with acute phases of disorientation giving way to adaptive processes (Piggot et al. 2002). Parents develop worldviews through time and experience. It has been said that “…it is not the child’s disability that handicaps and disintegrates families; it is the way they react to it and to each other” (Dickman & Gordon, 1985). Thus, understanding a diagnosis, its implications, natural history, and prognosis is but a part of the issue associated with the
birth of a child with disability into a family. How they face the situation is critical. How they face the situation is an adaptive process that starts with the family and its resources (Almasri et al., 2011).

In addition to facing unfamiliar diagnostic impairments, parents of children with disabilities face their own adjusting and adapting to a very different future than that for which they had hoped, prepared, and dreamed. Reactions of siblings, extended family, community, medical team, and even casual acquaintances or strangers may have significant impact. These impacts can be simply in the moment or can reaction formations of more significance (Taanila, Syrjala, Kokkonen & Jarvelin, 2002).

As with all developmental processes, whatever has preceded a child and family’s present tense experiences has the potential to completely modify the family and child perceptions of what the experience is all about. Thus, parental perceptions can develop in many different patterns depending on unique aspects of their child’s health and well-being, his therapeutic team, his or her progress in intellectual and educational pursuits, his developmental or therapeutic gains, and his or her overall psychological adjustment. A family’s ability to keep strides with perceived demands, stressors, and changes are keys to family quality of life and perceptions of the possible (Barnhill & Barnhill, 2010).

Perceived Deviations from the Normal Curve

Developmental milestones are a common reference in childhood and depict expected achievements, often achievements of considerable significance to parents. Even though many health care and educational professionals are concerned that achievement of milestones occur over a relative period, parents may worry about the exact times these accomplishments are logged (Kutner, 2007). When a child lags behind his or her peers,
the impact on parents can vary. Such response may depend on how it affects the child’s inclusion in bio-normative developmentally appropriate tasks, which may be the hope of parents as they participate in therapies and home programs (Thompson, 1998). Timing of achievement can become socially significant as parents compare notes; lack of achievement may make a parent of a child with disability feel isolated and sad (Eakes, Burke, & Hainsworth, 1998; Gordon, 2009).

The child diagnosed with a disability may represent a subtle or overt sense of loss to a parent, an ongoing disparity from all that they had imagined with the birth of their child; it creates a practical and personal dilemma that cannot be resolved. The prospects of the child’s uncertain future may add to a progressive sense of sorrow (Eakes, et al., 1998). From a framework of built capacities and coping skills, emerge other emotional responses to the child. These balance the family system with potential for overwhelming pride and joy, celebration, and sense of victory (Holt, Sepp, & Staffieri, 2013). From each step comes another until the facing of this challenge becomes a process that is part of family life.

**New understandings.** Parental frameworks and means of understanding disability enable family participation in the child’s life activities over time. As each activity and commitment becomes salient to the parents, their likelihood for engagement increase, positively influencing both family and child outcomes (Dion, 2008). Paths of understanding relative to disability inevitably diverge between parent and child.

The bodily experience (embodiment) of disability is personal and lived for the child and for him, the experience is entirely normal (Watson, 2002). The outsider view of disability is extra-personal and understood at a distance. This is the view of the parent. A
parent’s perspective parallels the frameworks of their child, but its conclusions cannot always mirror the experiences of the child (Shields, 2006). Children live through what they experience in their eyes and ears, their limbs and senses, life events and happenings that are normal and integral to them (Smith & Samuelson, 2003; Watson, 2002). Parents live outside that intimate bodily reality. They see at a distance and imbibe their views with parental bias, feelings, interpretations, and often include the perspectives and roles needed by parents as helpers, guides, coaches, and cheerleaders. Parents who have not experienced disablement may note differences and deviation from what they themselves knew. This may create conflicts, expectation differences, and tensions between them and their children with a disability (Dunn, Shields, Taylor, & Dodd, 2007).

Though parents suggest that the experience of rearing children with a disabilities can both prove enlightening and bring families together, the experience can also be associated with overwhelming stress (Goudie et al., 2010). Very little is known about the ripple effects of child disability on the family. Only step by step can their worlds take shape, lend perceptions, develop views, and frame disability in terms that are meaningful and personal (Reichman, Corman & Noonan, 2008).

**Inevitable Shifts within Family Contexts**

Whatever the family configuration or re-configuration over time, whatever definition or redefinition of family structure or re-structure, the family typically remains a constant in the child’s life (Prelock & Vargas, 2004). The family’s ability to shift with changing terrain, emergent family dynamics, and their developing child’s needs is the hallmark of its strength. Whether or not they have had any background with the task that faces them does not change the challenge. Parents respond to their child’s diagnosis and
its natural history both as individuals and within a dynamic of couple and family. Parents, siblings, extended family, community resources, finances, and the intervention team create diverse response configurations relative to the child with disability (Arango, 1999).

**Shifts of financial resources.** To meet the needs of the child with disability, parents and family may begin by altering aspects of their inherent structure, e.g., allocations of time, energy, and financial resources (Guralnick, 2004). To successfully meet the needs and demands of rearing child with a disability, even established family routines, preferred activities, and key areas of interest may require shifts (Darrah et al., 2001). In kind, these alterations may duly impact parental work, children’s school schedules, extra-curricular activities, and means of transportation (Woods & Lindeman, 2007). Budgets, finances, secondary payments sources, and available community resources needed explored. Due to trends of higher use of health services, families caring for children with disabilities are more likely to report less annual family income and employment security, together with greater personal financial struggle and related emotional stress (Anderson, Dumont, Jacobs, & Azzaria, 2007).

To cope with financial demands, families may seek disability benefits. These benefits are often idiosyncratic and subject to change, requiring proactive enterprise (Arango, 1999). Many families report resource related stressors include finding appropriate and affordable childcare, therapies, and durable medical equipment needs (Anderson et al., 2007). These affect decisions about work, education/training, having additional children, and reliance or not on public support and programming (Reichman et al, 2008). Families make choices based on their values, beliefs, coping styles, and needs (Prelock & Vargas, 2004).
**Shifts of reference: biomedical perspectives.** With the discovery of the babies’ diagnosis or developmental delays, the opinions and attitudes of the medical team may begin to infiltrate into family thought processes and emotional responses. The medical field may be the first source that suggests to family the notion of something wrong with the child (Barg et al., 2010). Once parents anticipated simple updates on their baby’s development, but now, the frame of outcomes is a diagnosis. The same trusted individuals introduce a shift from normal. Parents may hear references about their child that orient them away from normal and toward disability.

The biomedical model is naturally bound to screen for normal and healthy upon the birth of a child- they must determine if all is well. If so, the medical team discharges the child with relative ease and a new variation of family life is begun. When the screening and subsequent assessment reveals health and developmental issues, the child often becomes the recipient of a diagnosis, a perceived delay of bio-normative development. Subsequently, medical team discussion may turn to how the child presents as a deviant from the normative expectations, (complete with defects, disorder, deficits, and damage), giving primary significance to the child’s impairment (Brandt & Pope, 1997; Smart & Smart, 2006). Together with other adjustments associated with the infant’s condition, parents may feel even more disillusioned, angered, conflicted, fearful, anxious, saddened, and guilty, overwhelmed, or empty (Barnhill & Barnhill, 2010). Whether the child’s status is failure to thrive, at risk, or a known diagnosis, news of this sort almost certainly incurs a broad-base reaction across the status quo. The reaction is likely to affect a family and its social networks, medical team, extended family, and close community. The birth of a child with disability may create the stage for an awkward
welcoming reception, congratulations that are, at best, cautionary, reserved, uncertain, and concerned.

The initial conditions and/contexts, definitions, instructions, shared information, and verbal and non-verbal implications of a child’s birth are often remembered indelibly by parents. Many recall these times with shell shock, sharing in disbelief their recollection of professional coldness, indifference, and impersonal commentary (Barnhill & Barnhill, 2010). These parental reactions are often primary in parent perspective development. They represent an acute phase of flux (Reichman et al, 2008). If parents sense that the child’s bodily impairments equate with a damaged state, needing repair, they are traumatized (Barnes, 1999).

**Shifts among societal norms and institutions.** At the lofty level of the United Nations, children with disabilities are deemed significant members of society (1989, 2015). In individual parent’s reality, the membership is hard-won. They often must forge the life-long and wide range adaptations needed for their child with disability to achieve his or her “full and decent life” within his or her lived-community (Neumann, 2007). The adaptations needed to accomplish such aims are often all consuming. The lives and livelihoods of family, its rituals, relationships, interactions, and identities, are all entailed in the processes of providing the child an opportunity to thrive (Almasri et al., 2011). Many aspects of family life, including the sense of integrity, may be stretched and shaken in the process (Spagnola & Friese 2007).

**Shifts caused by a culture of ableism.** The culture of the United States is one that portrays disablement with less than positive regard. The current popular culture
gravitates to images based on eternal youth, ableism, and beauty (Wendell, 1996). These popularized images are normative. Fictions about those who are not so-endowed are used, at times, to explain the presence of others (Lange, 2005). While state, county, and local policies may support a child with disability by making the child eligible for programs and assistance, parents may feel disempowered by such gestures. They may continue to experience imperceptible social barriers in the form of attitudes as if their child is inferior to other children. They may find lack of support in their applications for help, or lack of access in the physical world. These are among the social and environmental constructs that parents fear will challenge them most as they try to rear their child successfully into adulthood (Couer, 2006).

**Socially constructed barriers shift family paths.** Many aspects of society can become barrier-like to children and their families, limiting full participation in community institutions. The barriers faced by the child with a disability are not the barriers faced by the parents. This suggests a dichotomy between the parent’s world and that of their child (Shakespeare, 1996). Parents may feel as if they are stuck in abeyance between the disabilities of the child and its associated needs and the needs of the rest of the family as a whole. Their community participation patterns may also be torn between those structures open to the disability community and those closed off, associated with mainstream able-bodied society (Gilson, Tusler & Gill,. 1997). From early intervention to early childhood education, to school age transitions to eventual adulthood and vocational or habituation choices, there are often new possibilities (WHO, 2007). At many of those junctures, there are new barriers as well.
The service sector and shifts of parental roles. As noted in the introduction to this study, the inclusion of therapists, doctors, teachers, aides, counselors, and social workers in the child and family routines is normative for families with children with disability. These teams attempt to foster the empowerment of the family through various stages of acceptance, learning, and building new capacities (Trivette et al. 2010). With the inclusion of the service sector in their family systems may also come scheduling concerns, conflicts in goal direction, changes in personnel, and matters of team dynamics with which to contend (Barnhill & Barnhill, 2010).

The parent perceptions and parental well-being associated with these team processes are vitally important to the child outcomes, particularly those envisioned by family and team (Trivette et al., 2010). Often parents struggle with how to represent themselves as parents. They wish to emphasize their parental commitments, their emotional attachments to their child, and their nurturance. Parenting can feel lost in home programming aspect of therapies, nutritional expectations, educational prescriptions, and goal directions (Barnhill & Barnhill, 2010; Trivette et al., 2010). Their stability of their home can feel shaken by schooling needs, their community therapies, their medical visits, and efforts to participate in church programs, sports teams, recreational facilities, arts programs, and venues for youth employment. Each opportunity may come with child related opinions, perceptions, policies, and attitudes that wear them down (Barnhill & Barnhill, 2010; Johnstone, 2005).

Parents must learn how to balance who they are as a family (Barnhill & Barnhill, 2010). Within an onslaught of child-related information and opinions, they must determine how to identify themselves. Throughout their child’s developmental course,
families inevitably face countless opinions and directives suggested by the agencies who serve their family and child (Applequist, 2009). They must find the balance between these overarching agency intentions and their own aims. In so doing, they define the team and themselves (Trivette et al., 2010). Interventions alone cannot predict a higher quality of family-child participation in life (Palisano et al., 2010).

**Family culture and adaptation to disability over time**

Family decision making over time regarding family and child almost certainly led to layers of adjustments and adaptations. The form these take may depend on a family’s world view(s), history, culture, religious beliefs and/or personal values. It may reflect its education level, vocational choices, and particular learning styles (Barnett et al., 2003; Woods & Lindeman, 2007). Parent reactions, perceptions, and perspectives may parallel or reject trends common to their given cultures, societies, and families. Parents may be bound by traditions or be comfortable creating new ones. Society or community standards have different expectations and consequences. Just how parents respond to these factors can affect their child in many practical and interpersonal ways (Lerner, Rothbaum, Boulos, & Castellino, 2002).

As agencies and individual professionals introduce themselves to the family, explain their intentions and directives relative to the child with disability, parents may find that they feel differently about the conversations and the professionals, often based on differences in parents’ baseline knowledge. Sometimes, it is personality differences or parents’ conflicting belief about what is best for their child. Parents share with family what they think they heard, information that may be received, understood, or accepted poorly. Regardless, whatever information the families have gathered, whatever their
interpretations and perceptions of their lived experiences, these time dependent processes become the building blocks to their perceptions. Perceptions of the child’s disability and family function around it can include diagnostic understanding, identification of child related services, and knowledge of available support systems. The higher the level of understanding and control, the better the chance that physical and emotional needs of family and child are met (Zaidman-Zait & Jamieson, 2007). Family learning and knowledge is always growing and changing. With time, their early reactive acute perceptions become adaptive and integrative (Piggot et al., 2002). Many families of children with disability, once they begin to settle into manageable routines, begin to step out into community, into institutions associated with growing children such as YMCA’s, church or civic youth groups, adaptive sports or sports, band, theater, natatoriums, and zoological programming (Barnhill & Barnhill, 2010). Once they do, the contextual aspects of disability become relevant to their experiences, as they find themselves either enabled or disenabled to participate.

Disability models

Disability occurs within a framework of multilayered patterns of social inequity (Sherry, 2008). In such a social environment, many who live with disability of their own or of those significant to them must construct facets of their identities based on their daily experiences. These identities can be compliant, defiant, innocuous, militant, spiritual, heroic, or rebellious (Darling, 2003). Often these experiences lead to formulation of conceived differences, perhaps based on labels that parents or child have heard. Such communications may suggest difference, a status of non-ordinary, abnormal, or deviant.
Societal politics of prescript normalcy lead to disablement beyond one’s physical difference or inherent constitution (Um & Won, 2013).

Disability studies identify models of disability that lead to understanding it in dimensional fashion (Charlton, 2000). Models and theories of disability include understandings of the disability experience at the level of embodiment, of the personal response; at the level of the lived experience in the social and physical world, and the politic of integrating into society (Smart & Smart, 2006). On a personal level, disability can create a sense of personal difference from others surrounding the person with disability: in the person living with disability, normal functions are frequently impaired, and their impairments are frequently normative. These inner truths are often hidden or secret (Jones, 2013). Society perceives that having impairments is anything but normal, certainly not how it should be (Corker & Shakespeare, 2002). In disability models, difference models juxtapose with models of universality (Garland-Thomas, 2005). This suggests that at some point, it is usual to experience bodily discomfort or functional changes. As one encounters age related changes across the life span, they enter the normative universality of disability. Another model of personal response is resistance in which the person identifies with his disability in defiant or militant fashion (Brown, 2002; Gabel & Peters, 2004).

These models suggest a reactive response that strives for essential equality (Barton, 2005). Personal responses vary and intersect with physical, social, and political environments. The ecology of a growing child is complex (Couzer, 2006). Meeting a child’s disability within his family’s critical life contexts is full of challenges. The social
model of disability has many variants based on community characteristics. In it, the child’s impairments do not prevent participation in community and social life: it is society and its barriers. These barriers may be attitudinal, environmental, or political (Thomas, 2004). The response of society can enable a child and his family to grow and thrive or it can disable or handicap them (Pfeiffer, 2000). Societal reactions can vary in intensity, but in large or small increments, these can marginalize, ignore, stereotype, misidentify, and discomfort both family and the child with disability (Jaeger & Bownam, 2005).

The social model of disability, through which they may have met some of their child’s programming/interventions/education, likely met complications. It is feasible that societal, architectural, and legal barriers introduced detrimental issues of social, political, and economic significance to their child’s welfare (Rothman, 2003). Unlike the medical model, the social model of disability invites a sense of pride and community amongst those who are impacted by policies, attitudes, and physical barriers (Brown, 2002). The disability identity has been seen by some as synonymous to validation of a family’s lived experience: creating empathy and advocacy for others facing the same issues (Barnes, 2004). In any case, significant adaptation regarding diagnosis and disability must occur to reach a resolution. This may include processes unique to the family systems, their care methods, rearing approaches, or their identity formation as a family. Meeting the needs of the child with a chronic condition moves a family toward these adaptive and needful ends (Thorne et al., 1997). It is clear that the family who develops adaptive strategies adjusts better as individuals and as a family unit (Murphy, 1982).
In 2011, the United Nations presented the first comprehensive World Report on Disability (WRD); it also suggested that rehabilitation was an optimal strategy for implementing both the conceptualizations of the report and the WHO integrative model of functioning. Among the values represented in this concept of rehabilitation are the centrality of the person, the role of society, and a focus on participation. The WRD emphasis is three-fold: empowerment of people to have control, eventual autonomy, over their lives; education with the goal of inclusive, non-discriminatory participation and ultimately, welfare and well-being of the person with disability; improved human resource capacity to work and earn a living (Rubinelli, Fletzer, Guistini, Saraceni, & Stucki, 2012).

**Families trying to find a life fit.** Over time, based on experiences of family and child, parents may begin to modify their expectations, their sense of identity and the shapes of their dreams. How they fit into their communities, families, and society-at-large has been challenged by the child’s disability. They may begin to make room for different possibilities than they originally envisioned. The promise of any easy fix generally grows smaller and the need to cope bigger (Barnhill & Barnhill, 2010). With the adoption of modifications, however, they may also find a need to forge a new fit in order to function and succeed as family and individuals within their home and community contexts (Barnett et al., 2003).

For some families, the fit follows the course set up by professionals. Their advice is a primary reference for the family. When this is successful, trust builds, capacity develops, and hope is strong (Trivette et al., 2010). Parents envision their child’s
improvement and offer that belief to their child. They are part of a team who works toward bodily improvements and adaptations (Barnett et al., 2003).

As another possibility, families gravitate toward disability rights for inclusion. Often parents identify with others who are going through the same thing, and they find purpose in disability awareness (Charlton, 2000). This tendency may inadvertently create a separation between their lived experiences with disability and those of parents whose children do not have disabling conditions (Barnhill & Barnhill, 2010).

Other families of a child with a disability may resist the need to find significant meanings in those impairments experienced by their child as he or she moves through childhood processes. It may seem more natural to them to de-emphasize the child’s impairments, “passing” for a more normative fit into community, education, and vocation roles. With this approach, parents may or may not explore the child’s perception of disability impact (Brune, 2013; Olney & Kim, 2001).

As the child gets older, this negating of the impact of living with bodily impairment can create distance with the child, who may not believe the parent understands what his or her life was like (Watson, 2002). The fit of family is challenging in the outside world and at home. Siblings may believe that the privileges and experiences of the child with disability are not only different from their own, but take away substantial parent attention from them (Jones, 2013).

**Family impacts.** While the impact of disability is personal and salient to parents, perhaps even the child’s siblings, the bodily impairments of the child are only the child’s. Experiences that siblings and parents face are often external considerations such as their own unique interactions with others outside the family (Barnett et al., 2003). Siblings also
express needs for attention, direction, and voice as regards their coping, learning, and living with their brother or sister with disability. Often they believe their views are invisible (Dodd, 2004). Sibling reactions to the child with disability may be unique to the siblings but they factored into parental experience, stress, and perspective. Though each family member has differences in their lived disability experience, the whole of member roles, attitudes, perspectives, and perceptions contributes to the family landscape and the parent frame of disability (Prescott & Naylor, 2004).

Families raising children with disabilities face a long-term commitment to remain functional as a family, to develop the kinds of relationships that help the family and its members to remain resilient and vital (Turnbull, 1988). If invasive procedures have corrected impaired joints or muscles, the parents may feel conflicted because of the potential for suffering to achieve a desirable outcome. Though the child’s angst is separate from the parents, both may experience stress as they face the same circumstance. Parents may question if they made the right choices as they struggle with the child’s pain or resistance to therapies or refusal to wear braces (Piggot et al., 2002). They must learn to make peace with their choices.

Parents may find, even reluctantly, that advocacy is a necessary choice. To have their children included in normative activities, they may have to fight for their child’s rights to participate (Barnhill & Barnhill, 2010). In the processes they face, they seem to create their own style of/responses to disability (Jones, 2013).

As parents become more child-centered, knowledgeable and confident, they may feel protective when they hear representations of their child as someone who needs fixed. Other times, they may desire a fix (Barnhill & Barnhill, 2010). Families’ inclination to
approach their child as a complete person can motivate their wishes to see him or her included in all aspects of family and community life, but this is often betrayed (Sauer, 2007). That inclusion, even when it ours, may subject family to frequent societal inspection, interrogation, and interpretation that violates their sense of privacy (Couser, 2006).

In spite of social dysfunction and stigmatization, some families refuse to let such transgressions and barriers impede their child’s participation in life, thereby preventing the child’s gradual isolation (Charlton, 2000). Research reports that tragedy is not the presence of a diagnosis or impairment but rather in society’s forbidden access to life’s joys, loves, and opportunities, privileges associated with the able majority (Goodrich, 2013) Families experience *disablism* when put in a position in which the only access to their children’s services, supports, and recognition is by fighting for them. They also experience disablism when they experience disparate socioeconomic challenge and disadvantage related to excess of disability expenses. A family advances the goals of the disability rights movement when they refuse to accept these situations or other inequities, including the lack of educational and leisure inclusion, or any persistent devaluation of their child by the dominant society (Goodrich, 2013; Lance, 2005).

**The Concept of Framing**

The efficacy of parental adaptability to life with a child with a disability may depend on how effectively they conceptualize, perceive, and respond to their child’s disability (Barnett et al., 2003). Defined by their personal experiences and family culture, each family tends to develop its own beliefs and game plan regarding their child’s disability. These experience-based beliefs and actions become salient building blocks.
Once they are lived experiences, they become reference points around which parents can organize, modify, or share their views. Such framings are variable, flexible, and inevitable (Applequist, 2009). Research suggests that when parental framing is done with a realistic sense of a child’s disability, it positively and protectively affects the integrity of the child and the family as well as its collective health and well-being (Barnett et. al., 2003; Guralnick, 2004; Johnston, 2009; Taanila, Jarvelin, & Kokkonen, 1998).

Because parental and family dynamics and word views are expected to change over time, they can also present themselves to others in ways that are not yet coherent or cohesive, as if in a state of flux (Piggot et al. 2002). Their perspectives may be emerging, evolving, silent or voiced, real or abstract, welcomed or unsought, unifying or ambiguous (Jackson, 2005). They may also revisit existing memories to reconstruct or rethink past realities. Often such retrospective practices enable people to find new or reinforced meanings relative to their past experiences. These reconstructions are not a simple return to the past (Weiss, Fine, Wessen, & Wong, 2000). They are a processed extension of the person’s worldview.

Some parents, in reflecting on lived experiences, seem able to discern new understandings (Jackson, 2005). For example, they may recognize that adequate environments increased their child and family feelings of independence, dignity, protection, safety and security. They may be able to distance themselves from uncomfortable experiences and analyze their life options. This is vital since stressors associated with disability are many. Coping and adaptation are essential. Parents have reported comfort in faith, family, friendships, and positive framing (Goodrich, 2013). Some may find essential coping strategies in their educational and leisure opportunities.
(Barnhill & Barnhill, 2010). Whether a person has had such assets to support their journey and its challenges may change their sense of value (Goodrich, 2013). Retrospective frames of what an experience has meant to parents may capture such realities.

Acceptance of a child’s impairments does not preclude a sense of grieving. In the case of a child with motor impairments, parent may experience such grief when they see the child unable to keep up with walking or running peers (Griffin & Kearney, 2001). During different developmental phases, the parent is likely to experience new emotions related to the child’s condition and how it impacts life participation (Barnett et al. 2003). The views parents take of their child’s disability are as developmental as the child’s emergent life. These become integral to their working disability framework, their often hidden persuasions (Lillrank, 2002). Parental frames and world views contribute to their perceived quality of life (Taanila et al., 2002). Positive adjustment and adaptation of parents enable the child’s participation in family, and family participation in the community. This adjustment includes their dynamic efforts to meet ongoing needs of the child over time, their responses to disability and disability processes, medical needs, therapies, education, and vocational options (Taanila et al., 1998).

**Correlations of parent perceptions.** Researchers have tracked perceptions of need in families of children with a disability. They found that parents perceived intrinsic health needs of their children of greater concern than needs outside the children, e.g., finances or areas related to the community access (Almasri et al., 2011). Intrinsic health needs may correlate with severity of disability. The family impact created by a child with disability derives from many factors. Examples of impact include those derived from a
child’s gross motor function, fine motor skills, and intellectual and social behaviors. Impacts also depend on the family’s level of adaptive behavior within the family roles and relationship quality among parents and siblings (Hames, McCaffrey, & McCaffrey, 2005). Impacts relate to resources and resourcefulness, to family income and the effort it takes for parents to secure waivers, coordinate and access needed services, and access their services (Almasri et al., 2011). Perceived supports may also have an emotional and motivational impact. Parents of children with disability may perceive disrespect of their family needs, schedules, and boundaries by interventionists and specialists (Applequist, 2009; Darrah et al., 2001). Parents may perceive that child interventionists are insensitive. Many professionals that serve the child’s needs are unaware of how their language or behaviors affect child and family well-being (Darrah et al., 2001; Novak et al, 2009).

How parents label, define, and measure their child disability is expected to influence the long and short-term strategies they develop to rear their child over time. Perceptions and assessments of the health care team not only influence program eligibility, care choices, and service delivery but also family optimism and hope. The synergy of perceptions of family, team, and society helps shape the potential of a child beyond the disabling experiences he or she faces. Perceptions of parents accompany and infuse their lived experiences. They intertwine with their health, economic, and extended family outcomes (Reichman et al., 2008).

Qualitative insight into the disability perceptions of parents may prove vital understanding in a number of domains. How they frame disability may define the relationships between parental responses, reactions, conceptions, interpretations, and
summative meanings of their child’s disability. These in turn may influence some of their capabilities to provide for their child over time. They may predict whether parent couples can find a way to maintain a healthy relationship while taking on the parenting challenge associated with a child with a disability. Respecting a parent’s framework potentially enables good starting points for parent relationships, both interpersonal and professional. For example, a physical therapist’s understandings of a parent’s worldview may competently direct professional family centered practices. This is possible in terms of not only intervention selection and style, but relative to sensitive and relevant communication of assessment results, goals setting, family education, and a therapist’s expectations (Darrah et al., 2001; Novak et al., 2009; Piggot et al., 2002; Rosenbaum et al., 1998; Trivette et al., 2010). Therapists and other service providers of the child may also be contributors to the way parents frame disability. The dynamic parent frame of the disability experience may reflect the health, depth, and mutual respect inherent in relationships with their team. This frame may include what they need and have needed from therapists and teachers; as such, it may affect how they make their choices relative to rehabilitation participation and its outcomes (Barnett et al., 2003).

**Understanding potential impacts of parental framework.** A parent’s conceptualization of disability may direct future choices, current quality of life, and family health (Putnam, 2005). Over time, it may affect the child’s self-perceptions and opportunities, even if they are minimally disabled (Banks, et. al., 2001; Dunn, et al., 2007). Parent framing of disability over time may afford insights about the complexity that disability is to them, lending structure and meaningfulness to the world in which they live and function (Smith, Harre & VanLangenhove, 1995). Those able to understand
parents of a child with a disability (how they frame their disability experiences) will further validate and empower parents in their experiences.

Parental frameworks may mirror the distress or the well-being of parents, child, or the whole family. As family dynamics and identities infuse parental perceptions, it may serve to limit or enhance information they are able to receive. Their framework may sometimes serve to block inputs such as parental instruction and teaching by the professional team or it may welcome such input and provide critical starting points that open dialogue and foster capacity building, trust and working relationships between parents and their support systems. For providers, awareness of parent perceptions may facilitate understanding of their motivation and value systems. How they frame their child’s disability may correlate with their resilience, and thus, a given family’s participation in the community, their sense of resources and support, their planning for their growing child, and even their ability to have goals and hope for the future (Greeff, 2011; Greef, 2013).

Theories Proposed to Serve the Study of Parental Framing of Disability

Most people who chose to become health care professionals such as physical therapists do so to “make a qualitative difference to people’s lives” (Neumann, 2007). Whether therapists know how to go about that challenge is not always clear. Theoretical models can help a researcher orient to study participants, to sensitively ask the right questions and hear what is being said (Almasri et al., 2011). Applicable theories to the study of parental framing of disability have several needs. Among these needs are to engender their contextual dynamics and identity constructs that relate to families with disability experience. The merger of these two areas is currently not well studied. People
with disabilities themselves have multiple identities, but most do not identify with impairments, though impairments are acknowledged. Disability may have many facets of meaning and formation. It is a source of positives and negatives of vulnerability and empowerment. It is the individual sense of self-reflexivity understood within one’s own story (Shakespeare, 1996; Charmaz & Mitchell, 1997). Parents have an intimate relationship to their child with a disability and tend to have their own constructed stories and narratives regarding these matters.

Family Systems Theory (FST) adds a basis for understanding family interactions. Two other frameworks, Family Systems Intervention Model (FSIM) and Disability Identity Theory (DIT) also appear to lend potential patterns, relationships, and layers of understanding. Each of these three provide basis for parent framing of disability and the merger of family and disability understandings. The given structures of each help identify whether a family gravitates toward identities common to disability or whether that family resists this and seeks to absorb their child’s disability into non-disabled norms. The role of outside help/intervention may also shape disability perceptions since interventionists often play critical roles in family life from early infancy into adulthood. The impact therapists have on how parents view the disability of their child is not well known.

**Family systems theory.** Family systems theory’s central tenets regard patterns of an individual family system and its inter-related functioning. In it, the family strengths and weaknesses are seen as contributors to the health and societal participation potential of each individual family member (Ayvazoglu, Hyun-Kyoung & Kozub, 2006). Tenets include the following: a family unit is considered an organized whole, one whose members are interdependent (Ludlow, 1990). The patterns of their interactions are not
linear, but circular, not static, but inherently adaptive, frequently changing, evolving as needed. (Humphrey & Case-Smith, 2005; Ludlow, 1990). Though families develop subsystems, each with their own boundaries, the interactions of families have collectively understood rules. Family behaviors develop in response to the rules, which develop in response to the behaviors (Ludlow, 1990). Understanding the patterns of behaviors, actions, and decision making among family members is useful for members and outsiders, especially when the system faces challenge.

As with systems theories generally (Rosenbaum et al., 1998; Trivette et al., 2010), family systems are expected to be diverse and complex, accommodating all types of families (Kozub, 2001). Family contexts include a family’s unique values, beliefs, morals, and customs (Ludlow, 1990; Rosenbaum et al., 1998; Trivette et al., 2010). These contribute to the development of member roles. Negotiations and re-negotiations are dynamic, constant, and evolving (McGinty, Worthington, & Dennison, 2008). Critical constructs include the overlap of family attitudes and their differentiation as are outlined in APPENDIX B.

**Family systems intervention model.** From an interventionist standpoint, FSIM proposes that each family be assessed for its unique capacities and strengths, its needs for help and support, and it resources to meet the needs of family and child over time. Interventionists affirm family priorities and through these priorities, seek to integrate family strengths along with intervention toward meeting the unique challenges they face (Trivette et al., 2010). Certain elements are predictor variables to child outcomes in this model. These include a family’s beliefs about their own efficacy, unique characteristics of family and child, senses of family well-being, character of family and child interaction,
and aspects of child disability. Improvements made in parent efficacy and competencies are as important as the interventionist’s help giving toward their child and the child’s developmental gains. As with FSM, FSIM also proposes that impact experienced by a family member is an impact experienced by a family. This suggest that an intervention that affects the child potentially affects the entire family (Turnbull & Turnbull 2001). The FSIM model also proposes that reaching the child through the family is useful and desirable (See APPENDIX C).

Disability identity theory (DIT): constructed identity. Disability studies and disability theory include all sorts of models and persuasions, including feminist, socio-political, sociological, environmental, identity related, and dynamic combinations, conceptual hybrids or integrated versions. The field as a whole has examined normative and disability culture, social politics, norms, labels and the purposes they serve, identity development, and influences of dominant society (Corker & Shakespeare, 2002).

For the sake of this paper, the researcher views disability partly through the lens of disability, in particular, DIT. One of its key tenets is difference, a construct derived from the societal assumption of able-body norms, particularly with the birth of a baby (Watson, 2002). In DIT, disability assumes its difference. For the person living with a disability, bodily and cognitive variations are legitimized. Difference is not seen as something that is embarrassing or minimizing. It just is. It is not hidden or disguised (Charlton, 2000). The difference may be value neutral or affirming.

DIT also recognizes constructed differences. These are differences imposed by social perceptions, barriers, and unattended environmental impacts. They both contribute to and reinforce the notion of difference, and based on their influence, a person with
disabilities experiences an overall disabling impact (Darling, 2003; Lange, 2005; Williams & Mavin, 2012). Parents confront this constructed difference as their child approaches school age, when comparisons with other children enter the conversation (Ho & Keiley, 2003; Lynch & Morley, 1995). Norm referenced “differences” often serve to qualify young children for related services, including physical therapy (Applequist 2009). Parents also experience constructed difference interactively and pragmatically. These experiences occur within experiential /realms of the personal, the social, and the political (Corker & Shakespeare, 2002). In reality, the whole of disabilities studies contributes to this study as the various aspects of disability influenced parental perspectives, depending on the setting in which they referenced. Details of disability studies considered in this research may be found in the APPENDIX E.

**Juxtaposed theoretical orientations.** Together family systems theories (FST), family intervention model (FSIM), and disability identity theories (DIT) serve the research query by providing dimensional, holistic, and sensitive markers. FSIM adds a lens with which to consider therapies (Trivette et al., 2010). With DIT, the study includes critical disability constructs in its analysis (Williams & Mavin, 2012). With FST, contributions of family dynamics factor into data gathering and analysis (Ho & Keiley, 2003; Humphrey & Case-Smith, 2005). Parents do not choose disability as a factor for their family dynamic. Both family and disability processes go forward together as parents rear and care for a child with disability, and as the family forms its identities (Dion, 2008). Each of these theoretical orientations presumes normative ecological and environmental settings.
The merger of disability with environmental factors appears in rehabilitation models such as ICF (World Health Organization, 2001). The person with bodily impairment experiences disability across contextual domains and environmental factors, each of which have enabling or disabling attributes. Researcher cite need for further research on ICF model applications to children (Goldstein, Cohn, & Coster, 2004; Simeonsson, et al., 2010), recognizing dynamics and contexts unique to child disability. Visibility of the child’s impairments adds a different factor for consideration. Those who do not have visible impairments have issues of invisibility, and may feel compelled to fit in. Those with visible disability may be self-conscious because their appearance alone sets them apart as different (Um & Won, 2013). More specific awareness of family systems may contribute to ICF applications to childhood disability, child well-being, and also, the whole family impact.

Theory awareness helped elucidate the complexities of parental frameworks of disability. Used together, the three proposed theoretical paradigms contributed to a structure for the research topic. They guided initial set up for parent discussions but did not limit explorations of parent thoughts. Parents much like their children with disability, appear to “exist in the space between” disability and typical life experience,” traveling in and out of two juxtaposed identity categories” (Valeras, 2010).

Heuristic Phenomenological Analysis

One of the aims of all qualitative inquiry is pragmatic discovery, which, via dialogues and emergent dimensional understandings, helps to elicit, find, describe, and define (Charmaz, 2000). Phenomenology is described as an interpretive method that views constructs of time and space as fluid parts of a whole. Its design and pathway are
able to thread parent-child experiences in and out of their history toward an ever-emergent perspective (Conner-Kerr, Wittman, & Muzzarelli, 1998). Phenomenology acknowledges the modifications of perceptions over time. Changes add essential dimensionality to collective impressions of retrospective perceptions. The recollected and re-analyzed experiences of parents and their associated perceptions serve to validate what they have learned over time. Heuristic phenomenology considers the structures surrounding a phenomenon as essential (Kleining & Witt, 2000). In this case, it examined how various community characteristics, socio-economic and personal factors, and disability features contributed to the framing of disability by parents of children with a disability (Patton, 1990).

**Retrospective analysis** Understanding a person’s position within given times and places is important as perspectives change over time and with new lived experiences. Looking back helps reframe the modalities and fluctuations in people’s expressions of thought (Conner-Kerr et al., 1998) The nuances of retrospection are applicable to the building of a frame that described lived experiences, especially the essence of one’s collective experiences. In parents of children with disability, recalled experiences and perceptions related to the child, the disability, and family formation. Parent and family impressions linked together, through reflection and perception to create new patterns of understanding. Phenomenology combined with retrospective input is a method that proceeds with clear regard to process/evolutions over time, inviting an interpretive component (Conroy, 2003).

Retrospective perceptions of lived experience were captured in written questionnaires, active live interviews, field notes, informal group discussions, or mapping
interactive phenomenon of family life in the real world (Creswell, 2009). The multiple layers of data as previewed and described above, called triangulation, benefits a study, adding dimensionality and verification. It provides multiple checkpoints for the research to assess findings. It is used across data analysis processes and conclusions, when doing post analysis literature review, while peer debriefing, and even in setting up methodological procedures and design. History and change challenge findings and validity, but may be seen as meaningful and true when concurrent to research; subjects (inter-subjective validity) and readers find that the results fit. All data should fit somewhere in the reconstructed findings. Introspective processes and triangulation ensure richness.

Because in-depth interview is the primary source of data for this research, quotations from the interviewees were the primary source and the primary focus of data presentation. These illuminated and supported the final thematic narrative analyses. The data analyses strove to be true to both science and art: systemic, analytical, rigorous, disciplined, and critical in keeping with a scientific perspective; explorative, playful, metaphorical, insightful, and creative in lending an artistic perspective (Patton, 1990).

Multiple data sources and multiple structures were useful to allow for retrospective processes, allowing both subject and researcher to reflect and process current, past, and future conceptualizations. The written format used in the preliminary questionnaire elicited a different mental process and memory task than did the oral interview. In the former written process, parents finding key moments encouraged a reliving of the past, a revisiting. Each parent, by revisiting a memory had potential for a new formulation of perceptions than those that the parent had formulated at the time of an
event. The element of time between inquiries further allowed for depth of process for which a single process would not have allowed. Heuristic qualitative research is open to new concepts and follows the data. The topic itself may evolve or change directions. The gathering of data, likewise, is flexible. The paradigm of maximum structural variation prevents bias in the findings. The findings derive through layers of analysis of all data toward common themes, representing the similar, the accordance, and the connection. Such a process is dialectical and proceeds via dialogue. The conversation provides a means to adjust the epistemic structure of the researcher to the structure of the phenomenon, bringing it in line with itself (Daly et al., 2007).

The process of phenomenologic inquiry is systematic and layered. Using written, spoken, and visual format, individuals explore matters according to their own strengths and proclivities. The layered processes facilitated participant recall. The face-to-face interview enabled resonance and reconsideration of personal experiences that can increase the reliability of final introspective outcomes, how individuals aligned their final framing (Kleining & Witt, 2000).

As parents of children with disability shared their perspectives, the researcher’s objective was to derive a structure and essence of the experience they described into collective themes that both encapsulated their experiences (Patton, 1990), and led to understanding. Perspectives and experiences become constructed meanings (Buckley & Waring, 2009). Such research is a venue to those whose voices are typically underrepresented, ignored, even silenced. It is also a way to meet them in their own words on their own terms, without standards of right, wrong, normal, or abnormal (Janesick, 1994).
In summary, the study has sought to learn what parents of children with a disability have come to understand about disability through their relationship to their child. By inviting them to frame their lived experiences of disability, parents explored something they may not have discussed before with anyone. Their unique experiences and lived knowledge increase disability awareness and understanding. Whatever framework they developed was acceptable. It was also a fit that they found, revamped as needed, as they looked back. The researcher intentionally did not preconceive of disability as a diagnosis or an outside assessment. Rather, Disability was simply parents’ recall, their say, and their meaning. As such, disability was their lived experiences and developmental perspectives, building blocks in their words, retained ideas, what had stayed over time. This study was both about changes in ideas and enduring perspectives. It took a word that others applied to their children without much thought and handed it back to them to reconsider for themselves. This research asked them to share those reconsiderations with the researcher, redefined and honestly explored.
CHAPTER THREE

METHODS

This study used qualitative heuristic phenomenology to investigate parental framing of disability. Heuristic phenomenology, as a method, derives its findings by examining the attributes and mechanisms of introspection, exploration, and discovery (Moustakas, 1990). These methods accommodate both the passage of time and the process of looking back through time. The development of research instruments was done with sensitivity to temporal processes, to lend reflective, but objective, data to the collection process, tying reflections to particular lived experiences and events.

Study Participants

The study participants were parents of children, grown into adulthood, who fit the following criteria: the child had an inherent, congenital childhood disability that created a need for the child to receive services from physical, occupational, and/or speech therapy during the child’s development. The services for the children in the study sample began with early intervention and continued through early childhood and school age with regularity. The informants for the study were either mother or father, based on parent choice. All informants considered themselves primary caregivers for their children. The children in question were their natural children, not adoptive, fostered or acquired via surrogate. Both parents were welcome to contribute to any phase of the interview, but one parent needed to provide all phases of the interview.

Sampling Procedures

The participants for this study were selected using a purposive intensity sampling technique (Creswell, 2009). The sample was developed from leads from three different
parent organizations which researcher contacted by phone. This included a support group, a respite care facility, and a family child-learning center. This study’s sampling technique is consistent with the purpose of developing information rich case studies to manifest the studied phenomena of parental framing of disability. Such sampling derives its power from choosing those parents who are able to provide the greatest amount of useful information about the central issue (Patton, 1990). This research targeted parents who have children with disability who had already transitioned to adulthood. Additionally, each selected family had just one child with disabling condition. The final sample size was nine parents, after two parents declined participation based on time constraints of the interview.

Demographics of the sample included one fathers and eight mothers. One additional father sat in on the interview, contributing on three different occasions. Two of the mothers were African American, and six were Caucasian. One father, the part-time informant was Caucasian and the other, a primary informant was Hispanic. Five of the families were from northeast and central Ohio and four were from north central Georgia. The families described their socio-economic status variably from low income to upper middle class. The average income was modest. All of those parents interviewed, except one, were working at least part time at the time of the interview. Five of the mothers reported that they did not work when their child was in school, because the child’s needs were too many. The parent who was not working at the time of the interview stated that she was going back to school to get a degree related to research. In depth demographics of parents and children can be seen in Tables 3.1-3.3.
**Inclusion criteria:** Participants: were the natural parents of a child who had a congenital, non-acquired, slowly or non-progressive disability; identified as the primary caregivers of their child from infancy through adulthood; reported that their child was a participant in regular physical, occupational, or speech therapy from infancy through childhood, through home-based services, clinic, or school. Parents demonstrated the cognitive and emotional capacity, capability, and willingness to complete a written questionnaire and a face-to-face interview effectively. Parents reported that their child has successfully transitioned into adulthood: this transition may have included living outside home or if still at home, be actively involved in adult programming, respite care, or work. The children’s conditions physically manifested as motor deficits that were slowly progressive or non-progressive. Additionally, their disabilities required attention in the form of therapies, orthotics, assistive devices, surgical interventions, medications, and/or durable medical equipment.

**Exclusion criteria:** The following excluded parents from this study: routine life-threatening conditions in immediate family; any significant period of a custody loss due to parental lack of fitness, specifically as consequence of not being able to care for the child’s disability; uncontrolled mental disorders, anxiety disorders, or conditions that limited interview accuracy, tolerance, or full participation.

**Informed consent:** The University of Kentucky Institutional Review Board (IRB). approved the informed consent for this study. All participants read and completed the consent form prior to initiating participation in the study. The consent form is in Appendix F. The consent form explained the research study and clarified that participation was voluntary and without incentives.
Table 3.1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Parent age</th>
<th>Age at the birth of child</th>
<th>Highest level of education</th>
<th>Occupation</th>
<th>Child's age</th>
<th>Child's diagnosis</th>
<th>Severity &amp; age of diagnosis</th>
<th>Income</th>
<th>Marital status</th>
<th>Marital status</th>
<th>Early Childhood involvement</th>
<th>Community involvement</th>
<th>Community involvement</th>
<th>Supporting in early childhood</th>
<th>Parental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>40-49</td>
<td>23-24</td>
<td>BS, dad</td>
<td>Dad, Software sales</td>
<td>Mom, stay at home</td>
<td>24</td>
<td>Cerebral Palsy/ moderate 1 year</td>
<td>&gt;100,000</td>
<td>M</td>
<td>M</td>
<td>PTA, church</td>
<td>Advocacy, Church, youth groups</td>
<td>Church, mother's parents</td>
<td>Fair, father Good, mother</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>60-69</td>
<td>32-33</td>
<td>BS, MS, mom</td>
<td>Dad, farming, industrial</td>
<td>Mom, Insurance</td>
<td>31</td>
<td>Cerebral Palsy/ severe 9 months</td>
<td>25,000-50,000</td>
<td>M</td>
<td>M</td>
<td>Work, church, dance, kids sports</td>
<td>Grandkids YMCA, Hospital</td>
<td>Immediate family, Mother's family</td>
<td>Good, father and mother</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>50-59</td>
<td>20-28</td>
<td>MA, dad</td>
<td>Dad, Minister, educator</td>
<td>Mom, stay at home</td>
<td>23</td>
<td>Sensory Integration Disorder, Developmental coordination disorder, DCD moderate, 14 months</td>
<td>25,000-50,000</td>
<td>M</td>
<td>M</td>
<td>Ministerial association, YMCA, school board</td>
<td>YMCA, school board</td>
<td>Missing, our own nuclear family</td>
<td>Good</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>50-70</td>
<td>31-39</td>
<td>HS, dad</td>
<td>Dad, Sales and service, Mom, part time title search, entrepreneur</td>
<td></td>
<td>25</td>
<td>Cerebral Palsy/ Mild. 1 year Hemiplegia,</td>
<td>25,000-50,000</td>
<td>M</td>
<td>M</td>
<td>Mom – PTA, youth leader at church, sports’ team mom, (basketball &amp; baseball), Dad – School bd, Rotary, host/exchange student</td>
<td>Ladies Auxiliary,</td>
<td>Mother’s parents and siblings, aunts and uncles</td>
<td>Good</td>
<td></td>
</tr>
</tbody>
</table>
Research Tools

**Instrument design.** The instrumentation used to address this study’s questions required new or adapted research tools, based on the limited research on the subject. Tools used to gather data were reviewed by a selected panel of experts, whose collective backgrounds included family studies, pediatric physical therapy, and disability studies. Their review of the instruments deemed each as valid and reliable for their intentions. This includes the written questionnaire, face-to-face interview outline, and adaptations to the MAPs form which was originally designed to support inclusion of children with disabilities into general education but used more broadly to provide an ecological look at the child amid the structures of his lived life (O’Brien & Pearpoint, 2003). The tools are...
available in Appendix G. Assessors who reviewed this adaptation along with the other study instruments found that the composite of research instrumentation invited meaningful data related to the phenomena described as parental framing of disability.

Table 3.2

<table>
<thead>
<tr>
<th>Child Trait</th>
<th>Child's occupation/living situation</th>
<th>Highest level of education</th>
<th>Special ed?</th>
<th>Therapies in school</th>
<th>Medical/surgical procedures</th>
<th>Perceived Impact of Impairments</th>
<th>Outcome participation</th>
<th>Health</th>
<th>Sibling Number</th>
<th>Birth Order of Child With Disability</th>
<th>Transition And Current occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Assisted living</td>
<td>High school, Community classes</td>
<td>Yes</td>
<td>OT, PT, Speech, APE</td>
<td>Increased PVP, shunt</td>
<td>Severe</td>
<td>High</td>
<td>Good</td>
<td>2</td>
<td>3</td>
<td>19 Grocery burger</td>
</tr>
<tr>
<td>2</td>
<td>Group home</td>
<td>High school</td>
<td>Yes</td>
<td>PT, OT, Speech</td>
<td>Respiratory care, PEG at 15”</td>
<td>Mild</td>
<td>Fair</td>
<td>Fair</td>
<td>2</td>
<td>1</td>
<td>22 habilitation</td>
</tr>
<tr>
<td>3</td>
<td>Group home</td>
<td>High school</td>
<td>Yes</td>
<td>PT, OT, Speech</td>
<td>No</td>
<td>Moderate</td>
<td>Fair</td>
<td>Good</td>
<td>1</td>
<td>2</td>
<td>22 sheltered workshop</td>
</tr>
</tbody>
</table>
| 4           | Independent                         | Master’s Degree           | No         | PT, OT, Speech     | Yes, tendon lengthening, osteotomy | Mild                         | Surgeries with medi
ation effects | High               | Fair   | 2              | 2                                   | 18 athletic training |
| 5           | Semi-independent/assisted living    | High school, technical college | No        | PT, OT, Speech     | None                         | Moderate                     | High                 | Good   | 1              |                                    | 22 vet tech                    |
| 6           | Group home                          | High school               | Yes        | PT, OT, Speech     | Remitting releases           | Moderate                     | Fair                 | Good   | 1              | 1                                   | 22 habilitation                 |
| 7           | Group home                          | High school               | Yes        | PT, OT, Speech     | None                         | Severe                       | Fair                 | Good   | 2              | 2                                   | 28 habilitation                 |
| 8           | Group home                          | High school               | Yes        | PT, OT, Speech     | Open heart, pacemaker       | Visible due to syndrome feature | Several surgeries required, Fragile Low | Poor to fair | 1              | 1                                   | 22 habilitation                 |
| 9           | Assisted living, employed in community | High school            | Yes        | PT                 | None                         | Moderate                     | High                 | Fair   | 3              | 1                                   | 21 works in Movie Theater       |

Table 3.2: Child Demographics. The information in this table was provided by parents during the first phase of research by completion of a demographic form provided by the researcher. All information provided was self-reported and could not be otherwise verified.
Retrospective parental framing of disability entailed each parent looking back over time from their child’s current status as an adult to earliest memories of their child, both when the child was growing up and when he/she was born. This unexplored area in research required instrument design that could invite accurate recollection and freedom to explore and express ideas. For the parent of an adult child, the instrument design included a format that facilitated multiple layers of thought, tracking environments, family processes, and events over time. Assumptions or interpretations about the subject matter may impose biases that threaten the research design.

Critical aspects of the data collection process are outlined in Table 3.4. For all participants in this study, the data collection began with gathering of demographic

<table>
<thead>
<tr>
<th>Study participants</th>
<th>Married Y or N</th>
<th>Child</th>
<th>Parent Age category</th>
<th>Parent Age at child’s birth</th>
<th>Child current age</th>
<th>Child’s diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rebecca (Tyson)</td>
<td>Y</td>
<td>Josh</td>
<td>40-49</td>
<td>22,24</td>
<td>24</td>
<td>Hemiplegia Cerebral Palsy</td>
</tr>
<tr>
<td>Ken (Susie)</td>
<td>Y</td>
<td>Steffie</td>
<td>60-69</td>
<td>32,35</td>
<td>31</td>
<td>Quadriplegia Cerebral Palsy</td>
</tr>
<tr>
<td>Tori (Carlos)</td>
<td>Y</td>
<td>Stephen</td>
<td>50-59</td>
<td>29,29</td>
<td>23</td>
<td>Developmental Coordination Disorder</td>
</tr>
<tr>
<td>Molly and Jamie</td>
<td>Y</td>
<td>Sari</td>
<td>60-79</td>
<td>33,39</td>
<td>25</td>
<td>Hemiplegia Cerebral Palsy</td>
</tr>
<tr>
<td>Patsy</td>
<td>N</td>
<td>Mara</td>
<td>50-59</td>
<td>27,29</td>
<td>25</td>
<td>Developmental Coordination Disorder</td>
</tr>
<tr>
<td>Carli</td>
<td>N</td>
<td>Layla</td>
<td>50-59</td>
<td>20</td>
<td>20</td>
<td>Rett syndrome</td>
</tr>
<tr>
<td>Nina (Bradley)</td>
<td>Y</td>
<td>Jocelyn</td>
<td>50-59</td>
<td>19,22</td>
<td>29</td>
<td>Rett syndrome</td>
</tr>
<tr>
<td>Christina</td>
<td>N</td>
<td>Anna</td>
<td>40-49</td>
<td>22,22</td>
<td>22</td>
<td>Quadriplegia Cerebral Palsy</td>
</tr>
<tr>
<td>Dee Dee (Ed)</td>
<td>Y</td>
<td>Roger</td>
<td>60-69</td>
<td>29,33</td>
<td>31</td>
<td>Down syndrome</td>
</tr>
</tbody>
</table>

Table 3.3- Profile summaries of study participants, including parent and the child. The information was provided by parent participant in the first phase of the study in a demographic form provided. All information provided was self-reported and could not be otherwise verified.
information and an open-ended questionnaire. The written questionnaire asked parents to think of special memories of their child, highlights, hallmarks, and personally relevant events. It did not focus on typical milestones, but rather, on the family and its own realities, what typical for them. This written questionnaire is in Appendix G.

Table 3.4

<table>
<thead>
<tr>
<th>Table 3.4 Data sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of data</td>
</tr>
<tr>
<td>Demographics</td>
</tr>
<tr>
<td>Preliminary Questionnaire</td>
</tr>
<tr>
<td>Interview</td>
</tr>
<tr>
<td>MAPS</td>
</tr>
<tr>
<td>Field notes*</td>
</tr>
</tbody>
</table>

Table 3.4 summarizes the type of data gathered through all phases of the research study, when the data were gathered, and the source of the data.

Once the questionnaire was completed, a face-to-face interview was set up. Each participant’s responses to interviewer questions were recorded on site with a hand held audio recorder, with audio files retained for transcription. Throughout the interview, the researcher kept field notes of overt observations regarding both participants and environment, as they contributed to the interview. Notes included such things as postural changes, amount of eye contact, and behaviors demonstrating felt emotions. These observations made during the interview were used to describe and contribute detail regarding the interview and related interviewer-interviewee interactions (Denzin & Lincoln, 2001). Field notes were collected from every interview. The purpose of such practices is to align what happened during interviews to interview processes (Groenewald, 2004).

All interviews were completed in familiar settings of parent choice, either at a parent home or a nearby center at which parents had attended support groups and/or taken
their child for respite care. Such flexibility in interview format and environment added increased potential for parent comfort, spontaneity, and invitation to share. Each parent played a vital role in the interview, adding discussion points about personal experiences with their child’s disability. Each parent was allowed, throughout the interview, to guide the interview process, together with its directions or re-directions. All parents completed the full interview in 45-60 minutes.

After parents completed the face-to-face interview, each filled out a MAPS diagram with the help of the researcher. This final instrument, MAPS, was included to create an ecological sense of where each parent’s story took place, with what activities, supports, and structures. It included a diagram that equated with an ecological map that answered questions such as *Who did I spend my time with*, identifying close relationships and friendships. It also asked about the community participation with the question, *Where did I spend my time?* The question, *What did I spend my time doing*, addressed school, work, recreation, and transitions of the child and family as the child grew. Once the MAP was completed, parents responded to several dynamic questions relating to content on the MAP diagram, including actions I have taken or wanted to take, having to do with what I wrote; what worked; what did not work?

The MAPS was set up as a child centered instrument. MAPS was adapted for this study under the direction of a content expert. Each MAPS graph was done by hand or dictated directly to the researcher. MAPS was strategically placed at the end of the interview to allow for full processing of parent experience as well as researcher regarding essential ecological influences.
Data Collection Procedures

All data collection followed the phases described in Table 3.4 between May and December 2014, at which time, data achieved saturation. The introductory phase generally lasted 20-30 minutes during which arrangements were made for face-to-face interview. Information regarding researcher credentials, email, and phone number were provided in either phase one or in the process of recruiting. Questions or concerns were welcomed during, in between sessions, and/or any time after completion of research. Contact with the researcher was invited by whatever means was most convenient for parents, email or phone.

At the beginning of the study, each participant was allocated a study name that protected his or her identity. All their data sources were protected. Materials completed in phase one, informed consent, the demographic data, and written questionnaire, were turned into the researcher prior to the face to face interview.

Phase two was the face-to-face interview. All audio files from this interview were derived from recordings from a hand held tape recorder, and preserved as both electronic mp3 files and written transcripts. All gathered data, including transcriptions, were now stored in safe, locked files in the primary researcher’s home office. These materials are to be destroyed upon successful defense of the study, per IRB specifications.

The third and final phase of the study was member checking, which occurred after completion of data analysis. Three of the nine participants were randomly selected to participate in this process and all three agreed. Each of the three participants was emailed an individual copy of the themes derived in this study, with brief descriptions of their core content. All participants completed the member check within a week of having
received the themes. All three participants affirmed that the themes represented what they shared in the written questionnaire, interview, and MAPs diagrams. The member check email, in addition to asking parents if the themes were representative asked if they believed that additional information should be added to the existing themes. Two of the three participants added one to two sentences related to specific theme dimensions. These inputs were added to the content of the themes.

Data Analysis

Upon the completion of data collection, a file for each participant was created. The file housed raw data, including their demographics, individual written interview, individual interview transcripts, related field notes, and individual data from MAPS. These data sources were retained for each participant for developing descriptive profiles of each, separate from the analysis of their questionnaires, interviews, MAPS data, and field note information. The profiles were envisioned as a way to create a rich description of each participant that could provide the reader of this research an in depth personal background of each participant. Use of raw data allowed elaboration beyond what their demographics could provide, but were not designed to be used in data analysis.

Data for analysis was derived from three sources which were pooled. These were the written questionnaires, interview transcripts with field notes, and data derived from the MAPs form. Interview content was transcribed verbatim with field notes added by the researcher. Written questionnaire data and data from MAPs were combined into two pooled data sets. All three were analyzed together. Data analysis was done in a manner consistent with constant comparative analysis or concurrent collection-analysis, utilizing observation, careful data reviewing, sensitive assessment of interview materials and field
notes, and meticulous logging of all sources (Field & Morse, 1985). In this way, every possible comparison of all data sources was attempted. In-depth familiarization and subsequent analysis occurred with data sources that included all sources described.

Table 3.5

<table>
<thead>
<tr>
<th>Table 3.5 The Order of Coding Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Researcher select what pops out of a sentence or sentences in pooled transcripts creating → Labels (1243)</td>
</tr>
<tr>
<td>2. Researcher combines common labels creating → Collective Codes that group similar ideas (85)</td>
</tr>
<tr>
<td>3. Researcher reviews collective codes in order to develop Categories that will invite all data to rebuild data (7)</td>
</tr>
<tr>
<td>4. Rebuild data by organizing codes into categories → Chunking of ideas (pre-theme) (18)</td>
</tr>
<tr>
<td>5. Review big ideas that occur across categories to develop Preliminary themes (6)</td>
</tr>
<tr>
<td>6. Retain and refine preliminary themes, using transcripts, to derive Final themes (6 → 4)</td>
</tr>
</tbody>
</table>

Table 3.5 outlines the temporal order of process from early coding efforts through themes. The actual process is multi-layered with constant comparisons and looping back through stages to ensure fit, adding qualitative observations based on data and literature, theory and researcher discovery.

Pooled data transcripts were then coded individually according to their source and retained in files that reflected the layered processes, similar to those described by Pope and Mays (2000). The sequences of the analysis are included in Table 3.5, above, with samples of labels, collective codes, categories, chunking of ideas, preliminary themes, and the eventuation of final emergent themes.

For further description of the data and data analyses that was instrumental in theme discovery and final formation, including a composite summary of process as well as samples of completed instruments, information is provided in Appendix H and Appendix I. The summary of the analysis seeks to depict the logic of process and outcome. The researcher assured that data from all sources were both coded and categorized. All data was used in deriving preliminary themes. Final theme synthesis maintained all content embraced by preliminary themes.
Trustworthiness of Results

Multiple data types and sources over a protracted time were designed as a form of data checking. Participant voices were represented through use of different modalities, descriptive demographics, written answers, oral interviews, and use of a graph to obtain data. In addition to data, current literature served to ensure that themes represented the participants. Triangulation invited consistency and was considered essential in heuristic research, seeking to ensure that data gathered were more than just word association or quick unprocessed response information. For example, a greater likelihood for deeper and more reflective thought and feeling is associated with writing (Van Horn, 2008). In this study, the preliminary use of the questionnaire in phase one appeared to facilitate ease of participation leading into the face-to-face interview and MAPS discussion that followed.

Because of the researcher’s own background as a therapist and a person with a disability, it was essential not to add innate tendency and bias to the research in data collection or analysis. For example, based on knowledge of disability literature that the researcher has used both as a practicing therapist and an instructor, the tendency to want to educate parent participants was often overwhelming. The researcher made a conscious effort to educate only as necessary. Throughout the data collection and analysis, the researcher maintained a reflexive journal considered part of the study to provide a means to make adjustments during the research process and limit behaviors that would introduce bias. Bias from the researcher is a known source of research error. Enabling open process ensures that the reader is aware of researcher roles, perspectives, and influences. While the researcher attempted to limit bias actively during the data collection and analysis phases, reflexivity was a secondary line of defense.
Audit trails ensure that all data has been included in analysis. Each data source used in the study was retained, including all transcripts, open ended questions, emails or phone calls from respondents (including the parent who was not considered primary caregiver) and notes of the researcher. One parent provided an additional artifact in the form of poetry she had written about her daughter, including a picture of her when she was small. The audit trail included researcher bracketing and epoche as well as all original data from interview.

To add to trustworthiness of the study, the study themes were member checked by three randomly selected members of the parent group who agreed to review the themes that were developed. Member checking is a reliable way to employ rigor, adding a final analysis of themes, offering opportunity to make modifications based on input received (Krefting, 1991). It ensured that the results of this study represent the research subjects and their views.

Peer review of the research process was done on a regular basis, provided by colleagues from my dissertation committee. Their thoughts and ideas were included at every stage of the research process, from the proposal through analysis. In conclusion, standard methods used in qualitative researcher were used in this study based on the works of well know qualitative research and authors (Creswell, 2009; Denzin & Lincoln, 2001; Field & Morse, 1985; Groenewald, 2004; Moustakas, 1990; Patton, 1990). These methods included purposeful sampling, collection of data from multiple sources, including literature, and a rigorous analysis process using inductive reasoning toward results. They also included intuition and a willingness to be guided by the participants.
that pushed boundaries, something not uncommon in qualitative researcher (Feyerabend, 2010).

Below are samples of early coding and how these codes lead to rebuilt data pools through the use of representative categories. Chunks of emergent ideas are represented in the right hand column.

Table 3.6

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>Doing/being</th>
<th>Family</th>
<th>Child</th>
<th>Status/Disability</th>
<th>Time</th>
<th>Others/near or far</th>
<th>Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal staff families experience</td>
<td>Loves getting out for walks and rides, being part of everything the other kids do</td>
<td>Family routines were different than our neighbors, doctors, and therapists, but they also did daily things</td>
<td>Loves getting out</td>
<td>Family routines were different than our neighbors, doctors, and therapists, but they also did daily things</td>
<td>We only go places we all can go. If Joe can’t go, we can’t go. Always tried to take him with us (work, shopping, vacations, games, fishing, to the Y).</td>
<td>When we were out, our time was met with comments that we were hurtful. If children asked, that was ok—far.</td>
<td>Therapist was like family. Hannah and I just talk away.</td>
</tr>
<tr>
<td>Perceptions parents develop, world view</td>
<td>Eating was her thing. Wherever we were, she was the last to eat, so we stopped when food came out.</td>
<td>Wheelchair became like part of the family. We didn’t see it any more</td>
<td>She got bigger and the disability got smaller. We learned her and she learned us.</td>
<td>I hated it when people stared at her in her chair. I just wanted them to know how sweet she was. (All they could see was her disability, but she had to let it go.)</td>
<td>Over time, her laughter got less and less. Her favorite word, Grandma, got sloppy, but she still tried to say it.</td>
<td>She was like an angel to my co-workers. They loved her coming to work, as much as I did. ~NEAR</td>
<td>I don’t know what we would have done without the support group. They taught us so much.</td>
</tr>
<tr>
<td>Child centered ideas based on child interactions and behaviors</td>
<td>In the band, he felt he was another kid, and we were so proud.</td>
<td>The kids just treated him like any other brother/sister and were always hugging and kissing on each other</td>
<td>One day, she discovered that she could hit a baseball and made us all so happy and so excited.</td>
<td>She was so limited, but she could still manipulate and smile when she did. And it drew us in.</td>
<td>Little by little she figured out a way to play her sport, plenty of bruises.</td>
<td>Steven learned to ask for hugs. If you got one, you were special. ~NEAR</td>
<td>The PT had all his favorite stickers and knew what fun things to do.</td>
</tr>
<tr>
<td>Parents adamant re: No to the notion of disability</td>
<td>I only use the term disability to make other people understand. My daughter has not been taught to see herself as disabled.</td>
<td>I can’t believe how many things I did in a day to keep this family happy.</td>
<td>She may have special needs, but her thoughts in poems and songs were so Wholesome. She worked hard to get that bottle to her mouth.</td>
<td>We sometimes used respite so we can survive as a couple.</td>
<td>Mara knew who liked her and who didn’t. Her behavior was like any kids toward both types.</td>
<td>Her teacher helped her confidence in herself by pointing out her strengths in everything.</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER FOUR

RESULTS

Themes

Each data source provided by parents offered unique descriptive aspects of nine families’ lived experiences and their related perceptions of disability. Profiles of each of these families are in Appendix J. Analysis lent four dominant themes: (1) Navigating Normal for Us; (2) Pride and Joys; (3) Anything but Disability; and (4) Lived Lives, Looking Back and Looking Forward. The themes, in short, represent collective thoughts and ideas regarding lived lives of parents with their children and the frames they found most relevant to their child’s disability.

Navigating normal for us

The first theme describes the inroads parents found to, from, and within the world that was theirs, particularly their navigations on those roads to their own sense of normalcy. Key constituent areas within this first theme included their observations of what was typical for them, routines that were not especially normative for many others they knew. Another was parents’ on-going learning in daily experiences that included developing a common language and the learning of needed skills. Change and revision was another key area, revolving around the child and other family members as well as the systems that affected them. Finally, the first theme included dynamics of commitment. They defined normal for them not in terms of outside norms, but rather based on their own senses of identity, senses that emerged from managing their own lived reality. They were unique individuals in their own unique family system. Their response to having a
child with a disability was a multi-layered emergent process of reflective actions and the related understandings they gleaned. Normal for them was what and who they were.

Families navigated their daily normal as both necessity and as part of a structure or rhythm. The rhythms of familiar routines and rituals helped provide individual families functionality and some sense of predictability. Finding access through a day’s challenges, in their home and the outside world, was a process that required patience, hard work, and needful adjustments. Any success they had in finding their ways today made tomorrow potentially more predictable. Parents came to understand that changes were inevitable, often unpredictable.

The family team. Teams most often met families as they emerged from their acute responses to diagnosis and stayed with them over time. Often families had therapies, respite care, and medical interventions as normative routines. Integrating outside help was a necessity for most. Carli shared: “It’s always something, I mean, (some days) you’d be totally overwhelmed. And that is part of why I really needed help. That’s why you break down and get it. You give yourself permission to get help.” For families who welcomed help in their homes, they found certain helpers became part of family structures. Rather than disrupt the family, these chosen few, the family team helped achieve a better sense of normalcy. Pat elaborated, “The school OT and PT were here a lot...(laughs) … (they) pointed out that (Mara) not only had developmental delays but sensory issues. So, that explained why she only wore certain clothes in her closet, only liked certain foods. I understood better why she preferred low light.” Rebecca talked about outside help as part of a group of people to whom “she entrusted her son.”
Families often opened their doors to the services of physical therapists, many of whom, by visiting at home, got incorporated into the family team, especially in the child’s early childhood. Christina shared this recollection: “Because I felt like I had to keep Anna at home for school, I got her into PT and OT and all that…we fell in love with our (home) PT. When she came, it brightened my day. I always told her I felt like she was my therapist also because I had somebody to talk to that cared. …it was just like she was part of our family.” Rebecca shared how their team not only honored what was normal for their family but they joined in it: “Teachers (through early intervention) bent over backwards helping Josh … and they were there for some of his first words, first steps. My friends felt like that was something we’d have rather experienced just our own family. But, no. they were being family to us- it was perfect having them there (at home) to celebrate with us.”

Susie’s two daughters, who did not have disabilities, believed that the outside help that their mom had attempted to bring in for respite disrupted their family more than they could take. Susie explains her experience: “I was excited to have some time to myself. Stephanie adjusted pretty well to the few times we used it. But, my other two girls came to me and told me they really did not like this. It didn’t fit for them. So, I put them before me and we stopped. The girls needed our home to feel like home.”

Family systems and their normative functions were central, but were often a work in progress. Carlos, as a father, had already had his family routines in place with their first born son. When Stephen came along, the routines they had did not work anymore. The family felt disoriented and in a state of flux. He discussed how, through the help of an occupational therapist he developed understanding that led to his enlargement of
normal. With some outside insights, he was able to “manage Stephen’s sensory integration needs.” The family system was able to recalibrate around that new knowledge and become functional again.

When disagreements occurred with team members in the home, parents suggested that this created a real cross road for decision making that sometimes required the development of a new strategy that either allowed them to move on with the same providers or to change providers. Nina explains parent sentiments well: “You can’t waste a lot of energy venting about things you don’t like or don’t agree with (in your home). Most team members try to do the right things. If you can’t work it out with them, you say thanks, and find someone you can work with”. Keeping family routines working was essential for family function. Parents expected those who helped the child to contribute to the family’s priorities.

The absence of outside help when needed also affected family senses of normal. Molly expounds on her challenges after her daughter’s surgery to explain, “Sari’s needs were so great and she was so isolated. The other two (children) got so independent, sometimes resentful. Sari, I didn’t know how to deal with her pain and sadness. I didn’t know what to do.” Molly described changes in relationships her children, routine changes, fear, confusion, new medical challenges. Her family did not have the resources to cope well with everything that the surgery brought and thus, family, for a time, lost its sense of normal and its viable routines.

**Becoming “us.”** As contributors to the sense of “normal family,” most families discussed the dance between what they envisioned for their own nuclear family and the desire to maintain identification with the husband and wife’s families of origin. In some
cases, based on their personal array of factors, the resultant sense of that larger “normal” shaped the way they did holidays and celebrations, chose certain religious or spiritual persuasions, selected rural or city lifestyles, and even made their eventual vocational choices. There were grandmas and grandpas, aunts, uncles, nieces, nephews, and cousins to factor in. Through these relationships, all participants had established realities of working family routines and rituals that blended new and old patterns.

Some families discussed how they found normal for themselves in baby steps. Some talked about how their unique past experiences helped them. Susie built on foundations she and her husband had before they had children, their life as farmers. “We were farmers before we were parents. That work ethic and culture prepared us for Steffie. I was disciplined. I was a farmer…Every day, I was just trying to meet the needs of the whole family. Steffie was there in the middle of everything- I had a marriage to think of, the two other girls, church, work, all that business. But no matter what, it was Steffie in the middle that pulled me back to the necessary things.” Nina added her observation regarding typical daily decision-making, saying, “here it is- I’ve got this barometer in my life that sets my priorities. Jocelyn.”

Among all the contributing factors that made families cohesive and functional, the child appeared to be a central member. Although it was sometimes easy to get lost with all the challenges their children brought to the table, parents found satisfaction including their children in their family outings. Nina said they always took Jocelyn with the family on vacation “just because it wouldn’t be the same without her. I include her in everything we do as a family. That’s something we insisted on.” Carli agreed that Layla was going
to join her when she was able: “Taking Layla to work or family picnics made a lot of work for me, but if I didn’t take her, people were on me. ‘Hey, we need her here.’”

**Normal toll.** Amid the normal all families experienced was their usual wear and tear. This included mental wear, like constant planning, research, and advocacy; emotional wear and tear, the roller coaster of emotions in their child’s vicissitudes; and the physical wear and tear with the home therapies, lifting, braces, and wheelchairs. Even with adaptations, parents were emotionally weary, mentally fatigued, and dealing with their own sore backs from the care associated with their children with physical impairment. Whether from specialists, therapists, teachers, or caseworkers, the overload of emotional, mental, and physical was palpable.

Most agreed that some of the hardest things parents went through mentally related to accumulation of explanations of medical procedures, tests, therapy programs, and outcomes of assessments. Carli, with reference to her physician, said: “You can break things to us that need to be said. Just don’t send us home completely confused and without hope.” She wanted professionals to realize, too, that parents might look lost or remote at times, but they were “weighing every word.” She explained, “You don’t have to talk so much without asking how we are doing with what you are saying. We respect your knowledge, but we are only human.” Mental overload was common.

One of the most dreaded emotional experiences was watching their children in pain. Molly shared: “Sari was always getting hurt. I ran out of Band-Aids on a regular basis, but I never ran out of sympathy for her.” All parents resonated with Christina’s assessment, “seeing your child suffer was the worst kind of normal.” There were also the emotional hurts that they saw their children endure on a typical day, the bullying or being
left out. Their children regularly experienced physical pain as well. They had had heel cords lengthened, G-tubes inserted, breathing treatments that were scary, blood drawn, and fractures set. Parents hated seeing their children in pain. Carli remembers a day that Layla came home from school hurt: “She came home wailing in pain. I took her off that bus and my heart was breaking. At the same time, I knew I had to get her to ER, to figure what was going on. So no matter what I was doing, it was instinct to stop, drop, and roll.”

And there was the physical wear and tear that parents endured on themselves. Day after day, they lifted and helped get dressed, and put on braces, helped with baths. Nina pointed out: “I was used to this little ache at night, but I didn’t think much about it. As I get older, it just stays.” Most parents felt a variation of this: my low back pain, this catch between my shoulder blades or in my hip, a little hitch in my gait, creaking in my joints, my headaches, my carpal tunnel. Their normal day’s wear and tear was real wear and tear. Carli tried to find humor in her observations: “There came a point when I realized that I really had to take care of myself. I hoped it wasn’t too late, but who knows? I think I over did it for a long time before I realized this. Aside from emotions – I have bones – and my hip sure is jacked up [Laughter].”

On different paths. Though they found a “normal for them” that they navigated well, not one of the parents believed that rearing a child with a physical disability came naturally to them. The birth of their children had been a shock, a “trauma that was not normal fare for any expectant parent. Finding out my son’s diagnosis felt like my … world crumbled,” said Rebecca. Parents had to pick up, learn as they moved on, digging for new information and/or pragmatically trying new things. Normal for them built on adaptability from where they had landed. Parents were constantly both meeting their
child and their child’s needs. The child’s needs were researched both intuitively and by seeking help from the expertise of other parents who’d been there. As Molly said, …

“meeting Sari’s needs is a given but it’s also a given for the other two and for Joe. We all do that for each other.”

Problem solving mattered because navigating normal often led them to new problems that would need to be solved. For most families, that increased their determination and their adaptive skills. Dee Dee observed: “What we knew at the beginning would never have been enough to survive with Roger and his needs…but with what we learned we functioned as well as anyone.” Carli described the daily navigation as pragmatic, imperfect but personal: “You know, you wake up and see your daughter looking at you like she knows you got it covered. That’s a lot to take in. But it was also what I needed to go out in the world and figure it out for her. I don’t know everything, baby, but I got you…”

Parents described the time related path of transitions as challenging, including: starting or changing schools, beginning a new therapy, getting new equipment, or losing skills the child once had. Rebecca shared this analogy: “I’d say it’s like …you get forced to take an unexpected exit. Without warning we are lost- we’re like ‘where are we?’” Part of the adjustment of parents’ early acute phase of life changes was reorientation. As parents grew, they developed stabilized identities that were adjusted and more secure, but it was work. Each family had to figure out developmental change as it came.

Transitioning toward adulthood also brought many changes. Parents took part, in most cases, of recalibrating their support systems and factoring in new people, transportation, respite, and housing. Patsy said she welcomed adulthood as middle school
and high school had been very difficult for Mara: “School was never easy for her. Work experiences were different because it interested her… Still, it took every bit of advice of three professionals, me and my parent advocate, two years, and 7 sites before Mara, got her work situation situated, (her) bus and a bus route to work and school. For now, we have landed.”

Susie discussed the change to adulthood in the opposite way: We hadn’t imagined life without our school team, but suddenly, Steffie was 22, and then they were gone. I thought it would be easier as an adult, but it wasn’t. Not for us, anyway.” Commitment to necessary care and commitment to keeping order was something every parent described throughout their child’s development. Christina noted: “Being a mom was a joy to me but it was surely the hardest thing I ever did, ever will do…to keep order for Anna and me, …that’s what I did.” Some of parent commitment was ownership as Susie describes with Stephanie: … “whatever it took, I needed to be a parent to the child that was ours, to the children that were ours.” The vital role of love in family norming could not be overestimated. Love of family became a guiding force behind the scenes, strength when facing difficult decisions or the tolls of care and transitions.

Our pride and joy

As one parent pointed out during member check, pride and joy in their child was complete with the fears and tears we keep inside. Pride and joy was an extension of their love, but it was really all about the child. The theme included the way parents saw their child: whole and blessed with inherent gifts and beauty. It was testimony to how the child fit into the family. That fit was not remotely peripheral. Their child was a valued member. Parents talked about the depths of the relationship they had with their child.
While parents each identified as a sometime caregiver for their child, they did not see their son or daughter as a passive recipient of care. Sisters and brothers, cousins, nieces, and nephews adored them. They were beloved.

These children, as students, patients, or athletes, were respected. They were welcomed, honored, and valued by family, friends, teachers, therapists, school parents, band directors, coaches, co-workers, their peers, and eventually job or habilitation supervisors. As parents looked back on rearing their child, one of the first observations for every participant was that their child was loved—not just by them, but by many. All talked about following their child’s lead. Doing that helped them, as parents and as people, to learn a different perspective than they might otherwise have known. They talked about the growth of their pride and joy over time, as their child grew toward adulthood. This theme was tremendously meaningful to families.

In this sample of parents, parents never described their child by their diagnosis, rather by their own intrinsic and extrinsic attributes. The pride and joy parents described emerged as they got past the often challenging start of the child’s life, their diagnosis and prognosis. Dee Dee explains it simply: “The Down syndrome became less and less of what we saw, less Down syndrome and more and more Roger.”

**The child we lost and the child we gained.** Parents described looking out a window and wondering about the child “supposed to be there”, the child they hoped was off-limits to tragedy. Parents had given children nicknames based on the hand and leg they used preferentially. Some of the nicknames were based on a child’s small size, or the sounds they made, or even related to their accident proneness. They were named for their attitudes, wild hairstyles, and resilience. They were “Lefty,” “Peanut,” “Tong, tong”,...
“Pipi”, “Booboo,” and “Zip.” Joe explains: “I called Sari ‘Lefty’ because that was her strong arm and leg. When I called her that, she took pride in her strength. She’d show me her muscle and even pumped it. I liked seeing her succeed and give me that big smile, my little ‘Lefty.’”” Stephen’s dad acknowledges that his son is not speedy, but he “ran like he was.” They called him “Zip” or “Zippy” and it stuck.

Christina said she realized that Anna, with all her weaknesses, would always be somewhat dependent on her, but that did not change how much she adored her daughter. She pondered how others could not seem to see past Anna’s disability to the little girl in whom she was so proud. She perceived a certain cruelty when some strangers reacted to her Anna, saying: “Well, it always really aggravated me when people stared at her, or looked away, because, to me, she was always just a beautiful little girl, sitting there as sweet as could be… people were ignorant. Come on- why can’t (some people) see she’s just a sweet girl?”

Two parents in the study reported that their girls experienced a steady regression of skills related to their diagnosis of Rett syndrome. For them, it was sometimes hard to find their child through these transitions: Carli shares about her daughter’s once infectious smile and her favorite words for a favorite person in her life as they faded away: “She was always going on about “Granddaddy. Granddaddy.” And then, after a while, it was “Gra… dahh” then, no sound, you know. She couldn’t finish his name. And then, it was just garble—Granddaddy was the last word she had. She hung on to it but it went away… trying till she just couldn’t. I miss the way she was, but I know she’s still in there somewhere.”
When parents described their children, they used these words: beautiful, affectionate, ordered, cautious, loving, profound, competent, warm, and bright. They were adult-like as children (Stephen, Sari, and Mara) and child-like as adults (Jocelyn, Layla, and Josh). They were innocent, ornery, manipulative, conniving, selfish, and sometimes compromising when they wanted to fit in. Carlos assured the researcher that his son never missed a detail. Many parents expressed pleasant surprise at the characteristics they observed in their children in the real world, particularly when the children were under duress.

Molly shares her pride in Sari, as an 11 year old, and how she handled her orthopedic surgery: (After the surgery)”I’d walk in to the nurse’s station, and the nurse would say, ‘She had a rough night.’ So I’d tip toe in her room to not wake her and she’d open one eye and then reach for me. I always feared she’d be sad and depressed. Instead, she often would be excited about having made friends with a doctor or nurse and telling me, she’d be happy. As bad as it was, that stupid surgery introduced us to a strong little girl.” Susie remembered the day that Stephanie was born: “I loved Steffie immediately. The whole birthing process- it was very traumatic- I would have thought it would have ruined (my) looking back. But there, in that place, I still just see her. (Smiling) Her beautiful little face …I was connected. I never lost her like some people describe. … (she was) so heart bending. I love being with her. I love her.” Pat talked about her daughter in the same proud way, sharing: “I have two favorite pictures of Mara on my desk at work. I was talking about her to my boyfriend the other day and he said, did you know you beam when you talk about her?”
**Membership and belonging.** The family relationships the child shared with others impacted both family function and individual family members. Rebecca reported that her husband had become increasingly withdrawn and depressed after Josh’s diagnosis. She shared how the relationship that Josh had with his dad pulled him back: “Josh was 10 or 11, becoming a young man, and you could see him inviting his dad to join him doing stuff— not the other way around— it was Josh taking the initiative, and they’d go for walks, go fishing, or you know, watch a show. The boy had to find the man in his dad.”

In families, the children were always treated as valued family members, who could initiate as easily as anyone else. “I love it when Roger sits across the table from me and talks with us over a meal,” shared Dee Dee. As in all families, the relational piece was endearing to her and an important part of her routines. Parents who had additional children in their family describe their child’s sibling relationships as very close. Susie talked about Stephanie and her younger sisters: “They grew up with her and were very comfortable with her. After school, it was normal for them to just go and kiss her… say I love you. They played with her as if she were just another sibling… I loved the give and take too. Steffie was definitely in the mix.”

Carlos talked about Stephen and his older brother and some of their challenges: “I often feel that his brother Devin got left out of things as much as Stephen did, you know, just because he hung with Stephen. They were true brothers in so many ways and that’s what they valued. I was proud of all three of our kids.” Dee Dee described her three by concluding: “I can’t imagine kids being any more proud of each other.” Carli, and Patsy had only children, but talked a great deal about closeness with cousins. Anna was also
Christina’s only child. She was wheelchair bound, but that only changed how they did things, not if: “…it was just me and Anna, we did everything together.”

For most participants with the exception of Christina, who was not close to her family, these parents watched their child grow up in the midst of extended family, their own parents and sometimes, their own siblings. As the child grew up, siblings often got married, and the child experienced being an uncle or aunt. Those extended family relationships were described as primary and pride-filled. Dee Dee talked about her impressions: All our family love him and include him in everything.

Patsy talked about her large extended German family and how Mara grew up with them: “I have 4 brothers and two sisters- that means Mara has a busload of cousins and aunts and uncles. In our bunch, there was nothing but love and acceptance of Mara. Her cousins are among her biggest fans” Carli describes her daughter’s life long relationship with her own mother and father, Layla’s Big Momma and Granddaddy: “Big Momma, she watched out for that little girl. Like a momma bear…but to my dad, it was different. She was his girl. And, you know Layla loves her granddaddy. His name is the only one she would ever shout out. Granddaddy! So excited – no mistake there. He didn’t worry about what she had or anything like that. At least not to me. Before I had her, I was always daddy’s girl, when Layla came along, it was like ‘move over.’”

Therapists, teachers and friends were among those who added to the child’s accolades. Christina talked about the relationship Anna had with her physical therapist: “Anna… couldn’t hold her head up by herself or anything…but she’d smile and just tolerate everything the therapist would do, and the therapist told me she just fell in love with her.” Many also reported that their child found fellowship and membership in
school organizations and church youth groups, which were a huge strength to them and their children. Carli spoke about a friend with whom Layla would have burping contests. This was how they related: “It was crazy.” Others recalled their children loving and being loved by special teachers, sharing a bond. Carli recalls a teacher that she said all the students in her daughter’s classroom adored: “It was not just a job to her. She took the time to know her kids and Layla responded by always competing for her attention.”

**Gifted.** At least four moms suggested that, according to their closest friends and peers, their girls had an angelic status, a presence, impacting their group with calm and mindfulness. Susie confirms that sort of reaction: “My co-workers loved Steffie. To them, she was nothing at all like the fast-paced world spinning around her. I think that’s why (they) were drawn to her. They said she opened their eyes to a different reality.” Dee Dee shared her son’s influence on his classmates, teachers, and coaches at school: “Roger’s take on life is that he belongs. Everyone knows him and speaks to him. He gives everyone a chance to be his friend.”

Placement in jobsites was hard for some of the grown-children, because often times as adults, they had their own ideas. Parents reported that they eventually found success. Parents said they were especially proud of their maturing young adults and their roles in the workforce or their habilitation programs. Nina shared how Jocelyn always went with the flow. “I know she doesn’t say a lot, but I know she is engaged. Her supervisors like that about her. They think it contributes to everyone’s morale.” Rebecca also shared: “Once Josh found that he could manage bagging groceries without messing something up for someone, he really started to both relax and give it his best. His boss
told me that people commended him all the time for being so polite, caring, and professional.”

**Following their lead.** Although parents had managed doctor visits, therapies, wheelchair repairs, social services, and whatever else it took, at times, they all reported that what they really needed was a cue from their child. That assured them that they were on the right track. That was part of what they were most proud of – their child in his or her own expressions of life. They also learned from their child all the time. Dee Dee gives this example: “When people asked about Roger’s Down syndrome in front of him,” Dee Dee said “…it used to upset me.” If Roger saw her upset, she shared that he always would try to catch her eye to signal that it was okay. Roger taught her not to sweat this at all. She elaborated further: “If someone called him a name, like retarded, it didn’t seem to faze him. He knew the name, but his behavior was as if he really had no idea what they were talking about -because in his mind, he really was just another kid, involved in everything...” Seeing that had helped her let it go and move on.

**Anything but disability**

Dee Dee, while interviewing, referenced her son Roger as a “high functioning child with Down syndrome.” She said “.that’s just what I’ve learned to say to therapists and doctors, because that’s how they talk and that’s what they want to know. I figured that would help you know what he was like.” In this study, however, parents described their children not based on what they thought others wanted to hear, but on their child’s able-ness. As each family tackled its unique demands of parenting, they built brand new skill sets, new ways to cope, understand, care for, and interact with their child. Many parents grew into and/or researched the roles of advocacy, practically and legally. For the
children with more severe conditions, their parent’s advocacy persisted into adulthood. Often it took all a parent had to meet the needs of their child.

In their words, this had only to do with real effort and ability. Thus, disability was not their word. It took real effort for their children to be children. It took all the children had to enter the world, participate, be real and keep developing toward becoming their own maturing persons. Parents found strengths in their family resourcefulness and talked about their views about the juxtaposition of strength in weakness. One father, shared: “I think now that our being so broken allowed us to become more whole.” Carlos was describing how his family dealt with getting knocked down as Stephen grew up. They got up again. As a former minister, he made sense of this through his concept of wholeness.

**Defined by abilities.** Parents’ aversion to the term disability was more than semantics. Parent efforts and eventual capacities were comprised of many different levels of on-going development, culminating often in skills they (eventually) could do well. Their lives were not a moment in time, a status. As Carli, noted, “it’s all a process! That’s the word.” Often parents described extraordinary efforts in the processes of providing care to their children using words that included, all consuming, exhausting, crazy, hard, impossible, chaotic, rewarding, and so necessary that it was scary to think of missing it.

Parents looked back at their lives and could not fathom how much they accomplished. In all of that, they could NOT find a place for the notion of disability. They sure didn’t live it. Neither did they didn’t reference it (except to talk to health care professionals, perhaps in the course of filling out forms). Disability as a concept did not apply. As a label, it was off the mark and offensive. No matter how hard it got, (and it got hard), that just did not define them.
Parents did occasionally reference their child’s diagnosis, often not to discuss their children but rather, their children’s condition with others. Sometimes, as in the cases of the parents whose daughters had Rett Syndrome, it also helped them both seek out information they needed, including support groups where they found others who were facing the same issues. Just as Dee Dee had learned to describe Roger as a “high functioning child with Down syndrome,” each of the other parents learned to reference diagnosis.

As a practice, however, parents described neither themselves nor their children by their needs or as their needs. They did not routinely compare themselves or their child to others. Christina, when asked if she ever used the word disability to describe Anna, she replied: “Disability was not a factor for us. I just took care of her, and more importantly, I had a relationship with her. She was just my little girl. I was being her mom.” Words in circulation for children with disability were okay if they had to use them. Some that the parents considered the least inaccurate were: “children with sensory or motor problems or limitations, with special needs, or just a child who was differently abled.” They all wondered “why they can’t just be (insert every child’s name).” Dee Dee shared a story whose ending made her happy: “Roger was a member of the high school band and one night at half time, when he was on the field with the band, the director overheard some of the people (behind him) talking about the boy in the band with ‘special needs.’ Anyway, he (the band director) calmly turned around and asked which band member they were talking about... ‘Because,’ he said, ‘they are all special to me.’

In the community and school settings, parents focused on accessibility and practices such as inclusion and integration, practices they believed ameliorated the impact
of their children’s conditions. They all acknowledged that, in certain settings or circumstances, they and their child had been made to feel disabled or different, unwelcome, and stigmatized. They’d been barricaded from opportunities by real lack of accessibility. That disablement was in the environment, though, not in their children.

**Skills and resourcefulness.** Parents touted their successes as, both focal points of every day and, precedents or hope for tomorrow. These included: meeting therapy goals; completing school homework; finishing a chore; competing (not necessarily winning) in athletics; interacting and socializing; having fun; playing an instrument in band, being artistic/creating art; making us laugh; and learning how to do a new skill at work or school. The child and family claimed success stories across physical, social, and intellectual/emotional domains. They learned to negotiate, adapt, and transition from one setting to another. The succeeded at home and in the community, at school, work, and even in virtual social networks. It was the outcome and the effort that defined them.

Parents all had shared that wear and tear was normal fare, but all admitted that some of their struggles exceeded anything they had ever imagined. It was beyond navigating normal. From those experiences, they had to develop an ability to cope and manage things that would “have buried them before their child was born.” Through the worst of days for their child and their family, they pulled off the some form of caring and care giving. No matter how hard they described their first days or their fears of the unknown (i.e., awful, frightening, surreal, gut-wrenching, heart-breaking, wrong, and terrifying), parents appeared to develop an often unexpected resilience. It was an inner resource. They recalled this especially as they faced their children going through adversity, recovering from accidents, surgeries, or illnesses. They described these
experiences as unbearable, yet the parents bore them: it took all they had to endure. They described experiences as: unfair, heartbreaking, and cruel. Each family described different agonizing moments of waiting and not knowing, of getting bad news, of wanting to run away, and of watching children suffer. They hated seeing their children experience pain, fear, and sadness.

Susie, Carlos, Christina, Carli, Rebecca, and Nina also reported the negative impact of medications. They realized that their children regularly needed medicines, but they grieved that their children’s known personalities were being subdued because of the dosages required for their medical needs. They missed their easy smiles, orneriness, wide-eye interest, fun gestures and engagement. Parents found vitality in knowing everything they could about their child, of being not just competent with their child’s care, but being among the experts in knowledge, having the whole picture, and have a strategy. Carli explains: “One of the ways I get unstuck is to look things up, figure it out. I go to bed thinking about it and I wake up with it on my mind. There are a lot of answers out there, not everything, but for me, I gotta try to find them.” Christina talked about the joy of discovering a strategy that worked for reaching Anna: “I always wore what I thought was the most beautiful perfume. It was to help Anna, because she couldn’t see or hear all that well, so just so she could find me. I’d always be telling people, my Anna, her nose works!”

Being resourceful was an accomplished way of life. It took commitment, determination, and effort. It wasn’t just having resources, it was learning how they worked, finding ways to access them, and that included being resourceful. Managing resources took time. It also required a balance. Whether the team was medical,
educational, or vocational; whether it was competent, caring, frustrating, or distant, families tried to work with them. Parents also sought advice from many other sources, from libraries, websites, foundations, parent groups, and word of mouth. When parents and child found the right professional or source of information, it boosted their understanding and sense of security. At times, when the relationship was not working, parents sometimes battled with what Nina called this us versus them mentality.

Nina explains: “I don’t like myself getting into this us versus them mentality...because without everybody working together, it is difficult. You’ve really got to pick your battles, you have to give people credit where they deserve it. These people are a resource.” She said she and other parents worked on strategies like this “through a Rett syndrome Support Group”. Several other parents attended formal family support groups at some time in their child’s growing up. Christina shared her perspective: “Part of my succeeding with Anna was my support team of other parents who have kids with special needs. They understand and connect with me, they are close to me (They) kind of get it …”

Sometimes parents could not use resources because the parents could not find how to access them or ran out of time. Nina shared her sense of challenge and frustration getting to the resources she needed for Jocelyn: “I have passed up opportunities for Jocelyn simply because I couldn’t figure it out in time to do it. You move down the list.” Carli agreed: “These guys are a full time job…I’ve got a stack of papers I’m going to probably do tonight or tomorrow, you know. They come with so much paper work.”

**Strength in weakness.** Autonomy and self-reliance were parents’ go-to strengths but need for help was also normative. Knowing how to get it and how to use it was both
an aptitude and an effort. Asking for help was not how any of them were wired. Nina shared: “Before Jocelyn, I wasn’t used to reaching out for help. It takes strength to ask for help, it’s easier to try to do everything yourself. You really can’t be afraid to ask for help, though.” Receiving help from others did not change their fundamental competency, but it felt humbling. Carlos agreed that parents are the ones who have to help the help: “you train help as much as they train you.”

One of things that parents found most inspiring in their children was their effort to just be a child... Those who had other children before their child with special needs were conscious of the patience, determination, and physical effort it took get through ordinary things. Patsy describes Mara as an old soul from an early age. Patsy elaborated on Mara’s almost perfect behavior at a parent teacher meeting: “Mara sat perfectly quiet for the first 15 minutes of her first grade teacher conference. The teacher had no sooner said how grown up acting she was than she started talking out of turn, singing, and being silly. Her teacher spoke up and said, ‘Mara, you know you should not talk when adults are talking.’” She did not know, though. Instead, she grinned impishly like any five year old and blurted out: “But I want to say something.” The teacher admitted that her typical grown up behavior made her forget how small she still was.

Even though parents did not resonate with disability, they did identify with certain descriptors, weakness, difference, vulnerable, for example. They were part of their daily reality. Susie reflected: “Were we affected by disability? Yeah. Our choices were modified by Steph’s condition. Because of it, we experienced things differently than with our other kids. I think of the deep questions we asked ourselves.” Molly shared her thoughts on this: “We never knew everything ahead of time, but parents are so committed
to their kids that, they literally jump in over their heads all the time. And we do have to be rescued once in a while. But we learn to be courageous. For our kids.” Nina summed up what parents were saying this way: “There’s a certain vulnerability built into being a parent of a child (with a disability). Oh well!”

**Becoming an advocate.** Their children had each grown into young adults. The parents, each in their own ways, had done what they had to do to ensure that their grown children were as prepared as possible to thrive, even as they had thrived as children. Carlos made significant life changes to ensure this transition. He described his job description changing from pastor to Stephen’s dad this way: “I changed jobs from full time ministry to teaching to teaching part time just for Stephen, trying to be there for him. It was a change in my identity and my priority. I was Stephen’s dad first. It took a lot of financial adjustments and lifestyle adjustments…for our family. But Stephen has to fully transition to adulthood. That matter is not complete in my mind. I have to set him up to succeed in his life.”

**Lived lives, looking back and looking forward**

The final theme expounds on the dynamic of living. It appears to validate the family efforts, for better and for worse, as having gotten them to “where they are”- to have enabled each family member the claim of having really lived life. Some of the aspects of this reflective theme developed in stages parents could see in their family development individually and collectively. This theme also included views that formed by purposeful revisiting of memories and some of parents earliest views. The theme explores some of parents’ shifts in priorities and values and their need for faith. Finally this theme, across all parents, concludes with self-recognition that wonders, looking back
at themselves, how they managed to do everything they did. This theme also includes what parents thought they might wish to share with others who could benefit from hearing about their experiences.

Parents in this study accommodated unfamiliar interview topics that could provide information of value to them. An example of this was in parents’ introduction to the concept of chronic sorrow as one of the interview topics. No parent in this study had heard that term before, so it was defined. After having it defined, many parents began applying the concept to their own lives. It appeared to resonate with all. Each parent went back through time, revisiting places of sorrow, as if exploring the concept for fit. Said Nina: “Oh, wow. I like that. I think I always tried to hide my sadness because I guess I didn’t want people to think I didn’t love Jocie. ‘Chronic sorrow.’ Yeah, that’s right. I feel like all those tears just joined my life again (laughs).”

Transformed perceptions. Each participant seemed adept at talking about their lives and their beliefs, including fresh exploration of ideas they had not considered before such as chronic sorrow. Many parents spoke of rethinking as they reminisced and discussed old actions, perceptions, and ideas. Molly talked about early days she remembered with Sari: “Looking back at those early days with Sari, I really regret the times I spent worrying so much.” Carlos said he now believed that his family, “by standing with Stephen through thick and thin,” probably transformed their own development and their values: “I look back at how we, as a family, shared our son’s disability. We started trying to see the world his way. When he had troubles, we had troubles.” Christina could say similar things about her experiences with her daughter: “Looking back, I just feel like I was lucky to be around Anna. She taught me so many
things that can’t be put in words. She gave me a perspective that looked at the big picture.”

Parents said they recalled just a few close friendships as their children grew up, as they were all so busy. They looked back and realized how important that close friendship was and all it had added to their lives. Nina remembered a special friend in Jocelyn’s life. … “I really think parents need a buddy to get to know your child on their own merits… who can develop true love for your child. We had a friend like that. She brightened our day when she was around. She’d offer to stay and watch Jocelyn or just join us for dinner. It’s something that I think is a real need for families. It helped us keep a sense of wholeness.” Dee Dee, as she looked back, recalled her son’s tireless efforts developing relationships in school: “Sometimes you have to work for the inclusion and wait for the relationships. In the end, we felt fortunate for those who included him.”

Among their recalled memories, parents shared some old misconceptions that had developed around their children’s lived lives. These misconceptions were clearer now as were their fits into a completely different worldview… Susie recalled: “Sadly, I realize we never could completely assure our daughter that there would not be an emergency around the corner for her (when she was growing up). It was just her life. I understood the concern in the E.R that we were somehow to blame. I forgive them. I know it wasn’t personal.” Carli agreed that, looking back, there were places she felt strong and places she felt very weak, even embarrassed. Life with Layla brought out her best and worst. She remembered a major melt down and smiled: “(Doctors) hated it when you lost it. (She laughs). My gosh, but we were so human.”
From where I stand. Times had changed for parents, their children were grown, their memories were full and rich, and they were able to see things somewhat clearly looking back. Many had messages they believed could help others understand what rearing a child with special needs was like. This included other parents, family, friends, and professionals.

Parents had come to some conclusions about the medical field and school system. Too often, looking back, they had perceived that they were, as parents, judged and assessed, along with their children. Nina wished that professionals could have come to realize “how very tired parents got with everything on their plates,” and have “cut them some slack.” She goes on: “Truthfully, I was almost always more emotional in meetings with professionals … because I was out of my routine and almost always way over tired, over, over, over tired. I don’t know how parents pull everything they do off, but looking back, I can see that it wasn’t without a cost.”

Susie said she sometimes felt attacked by the medical doctors. She said, if she could dialogue with them afresh, she’d simply point out to them: “You don’t know this, because you don’t ask, but I have a sick husband and a child with many needs. Being attacked by you – well, it just about finished me off some days.” For many of the parents, they remembered the birth of their child like it was yesterday. It was a memory that was still utterly traumatic. Rebecca recalled what felt like “a chasm of uncertainty.” Looking back, she wondered why so few professionals “…just couldn’t stop their routines” to be next to them during that period: “It was the darkest time. I had so looked forward to having this child, but that was all gone. If anyone said, “What can I do to help you,” I
don’t remember it.” Rebecca went on. “My beautiful boy. My room went pitch black. I wept alone.”

Christina remembers when Anna was little that she believed that giving into stress demonstrated her consummate caring. She remembers spending a lot of time worrying, as if that could change (anything): “Looking back I think of not only Anna, but the other children I met through her. I wish I could tell all their parents to try to not get too stressed out, that this too shall pass. Cuz your kids, they’re going to fight -- they’ll fight to live until they can’t fight anymore. I realize that this is how Anna responded to her own challenges, it was up to her.”

The parents all considered that being a parent for any child is plain hard. Establishing priorities was not textbook. When you added enough extra childcare demands to each day, it became even more intense. It took many hours a day and on many days, was consuming. As parents looked back over their children’s lives, they found it took their recurring efforts to establish balance. Some of the biggest balancing acts parents identified related to providing necessary care and making time to simply care about their child. Joe and Molly shared their experiences with trying to balance therapy and quality time: “I think that we put a lot of pressure on Sari to do her PT, stretch, to work on how she walked. That was what we thought the therapist wanted and honestly, we thought it would help her.” Joe went on: “In the middle of all this… I think you have to treat your kids like they are worth everything to you.” Molly nodded agreement: “Now, I always leave the door open to Sari … for her to come and talk. It’s nice to just be mother and daughter...”
Another issue parents had was finding time for just being a family, constantly answering to the demands of care schedules. Christina addressed this as she shared the dilemma: “In a way, I did always feel bad that I couldn’t just stop taking care sometimes, checking (Anna), bathing her, dressing her, feeding her, and just, you know, take her to a park and hold her … do something that didn’t revolve around all the medical needs.” That was the challenge.

**Being human.** Carlos reflected about Stephen’s needs, especially his needs as he got older. They had to do with advocacy. Carlos believed that, for him as a dad, the “balance between being polite and being effective was almost impossible.” He shared these regrets: “I really wish I had been an advocate sooner and with more determination. Because frankly, there were, really, very few open doors to Stephen in our community. The work of standing up for Stephen in this way has been harder than anything I ever imagined. And, he’s still not in.”

Parents, as they reflected back sometimes seemed genuinely surprised by their own perseverance and stamina. They seemed quite humored by some of their more radical mistakes and the egregious missteps of others. They sometimes saw the desperation behind their own smiles. Nina, after having had filled out all the questionnaires for the study and completing the full interview, responded by exclaiming: “That’s what I did? Oh, my God. How was that humanly possible?” Carli was taken aback, too “…you know what? It was superhuman ability, just even the logistics of getting through the (kid’s) paper work, much less with living with the child and learning to understand with skills that aren’t given to you ahead of time. Yeah. You just trusted (yourself), even though you have no good reason to.”
For other parents, the recognition was a place where faith had become their glue. Susie recalled the challenges of keeping her daughter healthy: “They sort of allowed us to develop our sense of smallness and that led us to be in relationship with something greater than us. Through our faith in God, we came to believe that Steffie had a purpose as important as anyone else.”

**What next?** They had plans, questions, and dreams, just as in the beginning of this journey. Disability had woven itself into their story, but not without their worldviews and aptitudes to help balance. Patsy expressed it this way: “As a young adult, (Mara) has her own life, but her central part in my heart stays. The future may change but we are more whole because we are in the same family. I wouldn’t want it any other way!” When it comes to finding adult roles, housing, and means of survival, as Carlos notes: “(They) are not in yet!”

Some parents have already acted on the development of careers, some as nurses, and some as businesspersons. Others are just beginning to act on their hopes, some of which include the development of careers, the reclaiming of friendships, or the work of reviving their own health and fitness. All are seeking a new balance in life with their grown up children. Carli is the mother of one of the youngest of the young adults. She stated that she had just finished her bachelor’s degree: “I don’t really have a career. I hope to work on my master’s soon. I want to work in clinical research. And there would be nothing more delightful to me than to work on the team that works on Rett’s Syndrome.”
Summary

What parents shared throughout these themes about disability are strong and recurring worldviews based on lived life, not ideology. Parents contributed each thematic building block in the form of their personal recollections, understandings, and experiences. Their rich detail across their own unique times, spaces, and circumstances colored their retrospectives, and included emotional sets, persistent beliefs, ethical persuasions, values, learned associations, philosophies, and values. The final themes appear to have variably developed, taken shape, evolved, and endured from their child’s infancy until their children transitioned into adulthood.

Parent frameworks of disability, according to the information they shared, appear to have sustained parents and families through some tough times, affirming and directing their values and efforts, even fostering their courage. Even though parents often encountered contrary views and conflicting assessments of the meaning of disability, their own frames were held firm as their truths. Truths of theirs were not one-dimensional. They included good times and challenging times, triumphs and defeats, times of stability and times of uncertainty. Participants embraced, and still embrace, life within all contexts, family, community, medical, educational systems, and at times, the larger politic. The ideas, feelings, and thoughts they shared in the form of disability frames reflected a stubborn, even defiant, resilience that overcame the challenges they faced.
CHAPTER FIVE
DISCUSSION

The results of this study reflect how parents strove across the lifespan of their child to achieve normalcy in their routines in all environments and how they found in their child an essence far greater than any condition. Participants described how their families lived life fully and as learners, championing change and challenge in life’s every day matters. They found purpose, meaning, resolve and ultimately a unique and satisfying quality of life.

How do the results of this study represent family life affected by childhood disability over time? In considering the theoretical frameworks that underlie the research question of this study, the themes that emerged appear to represent a significant merger of each of their primary tenets. Parents both navigated normal and they lived quite differently from many of their peers. They defined normal for them both in universal terms and with values, priorities, and necessities tightly and specifically correlated with their children’s issues. In so doing, families operated consistent with the model proposed by family systems, but their living and its choices also embraced disability concepts. According to disability studies, people who live with impairments often try to pass for “normal” as a way of coping or accommodating their conditions. For others, accentuation and understanding of their differences in bodily experiences becomes a source of truth-telling and empowerment. Regardless of whether people with disability have sought to pass as normal or have lived openly with their conditions, each must learn to accept themselves as they are. In so doing, they do not have to hide who they are or the
condition with which they live (Corker & Shakespeare, 2002; Shriver, 2014). Parents identified with both approaches, passing for normal and accentuating difference.

Participants described the experience of transformation from who they were before the birth of their child. Post-traumatic growth theory, as proposed by Tedeschi & Calhoun (2004), suggests that a family is often able to adjust and transform as an outgrowth of early trauma. The disorientation and acute pain that accompany such trauma is not dissimilar to what families described upon the birth of their child and the shock and disorientation that accompanied news of the child’s disabling diagnosis. Certainly the change in perspectives, values, and priorities are similar to what parents described.

Study participants used framing as an informal method throughout their lives to create both foundational beliefs and over-arching views of life. As parents revisited their lived experiences in this study, framing allowed for an emergence of fresh descriptors and salient life lessons. Thus, the retrospective method used in this study appeared to help parents add what disability meant to them to their frames of life.

While the study’s intention was to explore how parents framed disability, parents in this study seemed to owe a portion of their over-arching worldviews to more than just the experience of rearing a child with special needs. Their beliefs, evolved from their own pre-child backgrounds, including things like pre-existing temperaments, values, and views, including those of their families of origin. The processes and new steps that began with their child’s birth and subsequent development affected parent and family learning and abilities to cope. The same event added meaning and a quality of life. The parents’ larger worldview and their consequent skill sets do not appear, then, to derive from some
extraordinary repository of strength or skill or otherness but from their lives as ordinary people.

Each family described the foundations that supported them differently and yet they held many significant similarities. These parents learned a great deal about being human from the experiences of rearing a child with special needs. They offered, in their final assessments, testimony to the eventuality of contentment in circumstances that were anything but easy. They talked about the unusual strength they found for each step of the way and often, their true surprise at all they accomplished.

**Implications for professionals**

The findings of this study promoted child and family strength, resilience, and participation. They are themes that affirm both reparative and transformative potentials of families amid the real challenges and potentials of their children growing into adulthood. It should be the moral obligation of professional systems to meet family and child with presence, mindfulness, and forward thinking. Curiously, the derived themes of disability are overwhelmingly consistent with rehabilitation best practices, adding credulity to the use of family centered approaches (Bailey, et al., 1992; Trivette, et al., 2010), moving away from notions of bio-normativity (Baker, 2008), toward emphasis on enabling. Parents’ sense of well-lived lives included significant participation (Brandt & Pope, 1997; Johnston, 2009), and inclusive practices, partnerships (Arango, 1999), and access (Barnes, 2004).

The unique sense of normal for each family and their felt pride and joy in their child may easily be overlooked in the business of meeting child and family needs, assessments, evaluations, interventions, and outcome planning. Parents may be excited by
the prospects ahead, yet they are protective. Their child is a developing individual, one who will transition to adulthood, separating from family. Judicious use of services that allow for respite for the parents are essential throughout the child’s life. Such services should emphasize and appreciate the essential developmental transitions of the maturing child and know its own limitations and roles.

Inviting parents to true two-way conversations is a win-win when it comes to learning about and understanding the family. This is particularly true in child development, rehabilitation, education, and medical practices. Listening to parent stories and perspectives can add vitality and shared wisdom to the body of knowledge that shapes the understanding of disability (Applequist, 2009; Burkhart, et al., 2015)

For professionals, the retrospective parents shared and the frames of disability they projected offer a meaningful glimpse into the inner and outer realities of family life with children with special needs. Their discussions of normal routines and rituals should remind professionals that families’ navigation of normal are unique and socially constructed. Parents need to be acknowledged for their strengths, abilities, and accomplishments. Professionals must find ways to both praise parents for their efforts and successes and forgive them for their moments of collapse. For selected professionals, families afford them an honorary membership in their family that is both an honor and a duty.

Parents emphasized ownership and the inclination to trust themselves in parenting and decision-making. They emphasized that their children were their responsibility and as such their investments. Knowledge about them and strategies for their care were always being refreshed. Parents highly valued knowledge, skill, and healthy coping. They could
usually read between the lines, developing deep parental intuitions. Professionals need to acknowledge these parent tendencies and traits. Professionals can facilitate parental development at the beginning of the family journey. As core strengths, such traits lend to healthy family dynamics and committed parental investment (Roper, Allred, Mandleco, Freeborn, & Dyches, 2014).

This study suggested that having resources together with a functional team were essential to parents. Professionals should be accountable as team members and also serve as repositories of valuable resource information. Professionals are strategically positioned to advise and direct families where and how they might get shoes, orthotics, adaptive equipment, oxygen, nutritional supplements, wheelchairs, crutches, and care supplies they need. In the same way, professionals should familiarize themselves with nearby community resources, adaptive sports, libraries with augmentative technology, travel training programs, and public transportation. When applicable, professionals should refer children to driver education programs equipped to support young adults with special needs.

Professionals should also be aware that parents’ investedness in their children can exhaust their personal resources. Their constant caregiving for the child’s unique needs and desires may occupy them night and day. They may experience deep sorrow and unresolved losses. Parents are often over-extended, sleep deprived, and somewhat unsettled in the processes of unfinished business. These findings are in agreement with the phenomena of both chronic sorrow (Barnett, Clements et al. 2003; Barnhill & Barnhill, 2010; Gordon, 2009; Raji, 2004), and post traumatic growth, in which parents
emerge from uncertainty to create new perspectives and develop new purposes (Tedeschi & Calhoun, 2004).

At the beginning of their journeys, parents are especially vulnerable and fragile (Piggot, et al., 2002). Professionals should be cognizant of these issues. In spite of occasional disorientation or fears of the unknown, all parents expressed being “at home” with their children and expressed the success they felt they had in rearing them. Use of such knowledge may inspire a family in uncertain time, offering them the extra boost and vision they need. All parents addressed the need to have hope at the beginning, in the middle, and especially at tough intersections in their lives.

Parents hated the pain and suffering of their children more than any other thing. They longed to see, in those times of suffering, an acknowledgment or sense of pause from their professionals, even a glance or touch. Those small gestures were always appreciated when they happened and missed when they did not.

Results indicate that parents adapt to the way professionals speak. Professionals should consider whether those adaptations also veil opinions, feelings, or concerns parents may have. To be relevant to parents’ worldview, professionals should consider the language they use to communicate with families of children with special needs. Would language in which children are not labeled as disabled or abnormal contribute to and invite greater mutual trust and respect?

Finally, one of the questions this study raised was whether non-family members, including practitioners, can truly understand the whole of a dynamic family system, such as those of a family who rear a child with special needs from infancy to adulthood. The dynamics of such a system are difficult to assess or interpret in cross sections of time and
space. Cross-sectional assessments are, however, the most common evaluative practice. Long term exposure to such families may provide a far more informative picture of family characteristics and functions, providing a picture that healthcare practitioners may disseminate with fair confidence that they have shared a reality, not an anomaly.

Based on the longitudinal outcomes represented by this study, professionals who disseminate information about parents must be conscious of time sensitive processes common to families and develop understandings that derive from comprehensive and representative family domains. These understandings may be significant. Interpretations about families of children who have special needs should be based on sources that identify personal, social, and ecological influences over time. It is important for professional in higher education to disseminate their knowledge and interpretation of topics (such as parental framing of disability) in ways that neither inflate nor deflate the experiences.

It is also important that professionals routinely frame disablement as a normative part of life, not as an exception. Whether early in life due to a challenging start, or midway through tragedy or illness, or late due to aging, change or loss of ability is part of normative human experience (Hillyer, 1993). Allowing for this truth takes away an exclusionary way of seeing children with special needs and invites them fully into a human experience, a vital distinction that this study supports. Immersion in family systems, as is common in some service learning programs, may be an effective tool for helping students learn these concepts through firsthand experience (Coker, 2010).
Implications to parents of a child living with “a disability”

For parents, the findings of this study may afford practical help and meaningful encouragement for both short-term needs and long-term hopes. The participants in this study, by sharing their lived experiences as human, real, imperfect, and sometimes weary and worn, invite a sense of real belonging and of universality. Themes that rejected the nomenclature of an exclusionary “normal” and “disabled” encourage parents to assert their wholeness. To parents, results of this study also suggest that rearing their children to adulthood can end well, lending to a satisfaction, contentment, and purpose. Life with a child with special needs equates with perseverance, commitment, and even disbelief.

Furthermore, the results of this study reflect an important reality that parents of very young children may not envision: the child they see today, overwhelmed by diagnostic realities, can become their pride and joy. Parents in this study discovered a valuable and viable role for following the lead of their children. Parents constantly referenced how their children rolled with ups and downs with little or no complaint. It is important that new parents know that learning from their children will be rewarding and valuable. Parents who developed knowledge and skill based on their children’s leads found that it was not only practical, but often allowed them to rise above their own mental, emotional, or philosophical blocks. Theirs was a mutual trust and love that made the effort seem worth it and in many ways, led them into adulthood.

Another implication for parents is the vital role of re-framing. Parents in this study emphasized how important it was to manage the perceptions and misperceptions of others. They strategized with what they had learned to constantly redefine who they and their children were. Their worldviews directed their actions and the essential natures of
their identities in the process. According to research, strategies that allow parents to self-
define lessen the sense of stigmatization and help families cope (Nario-Redmond, 2013).
Such strategies also enhanced the child and family’s well-being, keeping family values
strong. Parents in this study encouraged other parents to get help if they needed it, not to
be afraid to ask. They knew asking was not easy but judicious use of help was a valuable
part of parent and child visibility and success. Teams were built, and retained as they
helped the family and child; they were changed as needed. The role of teams and parents
was a discussion not a given. Parents may benefit from understanding these distinctions.

Advocacy was considered by participants to be difficult to do, but vitally
important. Parents believed that when their child was handicapped by something, it
affected the whole family. Most parents in this study regretted not advocating sooner and
more. Advocacy for the child included advocating for those things that enhanced the
child’s participation in life and contributed to the family’s quality of life and its
functional outcomes (Brandt & Pope, 1997; Nagi, 1965; Verbrugge & Jette, 1994).

Finally, faith was described by many parents as vital on a personal level, but they
had often found conflicts among people of faith. In the end, the importance of personal
faith in making sense of life, coping with ups and downs, and finding purpose was a
sustaining force. New parents could be cautioned about the difference between nurturing
faith and the behavior of church goers. The literature confirms that people of faith are
often confused on the roles of healing and inclusion particularly as it pertains to children
with special needs and with illness. Many faith communities acknowledge that they have
room to grow on such matters (Goldstein & Jones Ault, 2015).
Implications to policy makers

Parents shared their lived lives and sometime embattled life as it related to forging their children’s access to both quality of life and meaningful participation. As their children transitioned into adulthood, many who had not achieved full independence were met with new challenges such as finding work, housing, transportation, and adult recreational pursuits. Children deserved and parents expected a world that would demonstrate not just equal opportunity as a right, but equal opportunity as a reality. It is essential for policy makers to do all they can to foster a society whose institutions and communities offer readiness and willingness to incorporate children with special needs into the real world, not only as young children, but also as adults. While such a reality may seem far off at present, steps taken in the desired direction are far better than apathy.

Strengths and limitations of the study

In a qualitative study, there is no true generalizability to a larger population. However, application of information may be feasible based on readers who find the information salient. This study took many steps to ensure face validity including subjecting data prior to analysis and analyzing data using input from the researcher’s professional peers and committee members. Final themes were subjected to member checks. Research claims made by the author were acknowledged as interpretive processes based on data. Using multiple checkpoints, these interpretations were considered throughout the research to be subject to change. Final interpretations were based on phenomenologic methods by which the researcher resolved “ambiguities, tensions, contradictions, and synergies” (Moravcsik, 2014).
The theoretical basis of the research inquiry, while setting up a valid research question, may have limited the data in its depth, width, or breadth. To minimize this impact, open-ended questions were asked, allowing parents to explore concepts without restrictions. The retrospective style of the inquiry may have made data collection vulnerable to certain factors such as individual participant’s ability to recall information across the critical domains of parent and child contexts and systems. Because the study required parent reminiscence, common issues such as maturation were eliminated. By adding a two phase data collection process, the first of which was used to jumpstart family memories of early childhood, some of the threat to validity related to recall may have been lessened.

Data were gathered from multiple sources (e.g., written questionnaire, face-to-face interview, and visual MAPS tool), from diverse families (variable in parent number, ethnicity, gender, and age), from multiple locations, and across an extended period of 5 months. While these elements can introduce threats to data collection reliability as well as validity of data, it was hoped that these same features added validity to the findings: both time extension and triangulation are known to increase sensitivity and consistency of data collection (Creswell, 2009).

To ensure that the researcher was not imposing her own ideas upon the data during its analysis, the researcher’s impressions and interpretations of data were tested not only against those of the parents but also against the impressions of other experts, by conducting a literature review on discovered ideas. Reflexivity of the researcher was employed via journaling and epoche, limiting threats of researcher bias. Such steps are
thought to help judge the study’s meaningfulness as well as its potential for applications to other constituents and situations (Polit & Beck, 2006).

Open lines of communication through phone and email were offered to all participants to check into progress of the study or to modify their inputs. These practices contributed to analytic transparency. Analytic transparency assures readers “access to information about data analysis” (Moravcsik, 2014). Relative to participants, three of the four participants knew each other through a common parent group. This allowed for the possibility that they may have discussed the interview questions prior to their actual interview. If so, this could have influenced what they shared.

Because the primary investigator of this research was a novice researcher, both procedural aspects of the research and consequent analysis may have lacked full insight or completeness. The contributions of others in the process of the dissertation are also necessarily limited.

Each of nine participants had a story to tell. Each represented somewhat successful outcomes in their efforts to rear their children into adulthood, a fact that should be considered in their disability frames. It was evident that the stories they told and ideas they shared were full of lived experiences and insights that had not only merit, but deep truth and value to them. The value and contribution of the individual narratives were powerful and moving. Because, however, the purpose of phenomenology is to seek the whole of the experience, some of the poignancy of an individual parent’s stories may have been lost. A different methodological approach such as narrative inquiry would have prevented this. Further studies of the family narratives, as shared, or with further elaboration may reveal truths that this study has only begun to consider. Parent themes, in
their final state, should be viewed as neither right nor wrong, exact or inexact. The opinions are neither binary nor permanent for all time.

**Future studies**

The study results lend support to the importance of language in both establishing rapport and building mutual respect and trust. Future studies in any profession should evaluate language use and the valuation versus devaluation that patient families assign to words. Parents redefined the notions of disability and normal. They did not use either term indiscriminately. Their usage did not appear a matter of mere semantics to parents. A survey of impact of particular words on parents and their children may be helpful; additional surveys of professional usage may help raise awareness about when and how such words are applied.

Additionally, investigation of parent perceptions of the impact of various kinds of disability may provide helpful insights regarding matters they face in rearing their child, including those financial, social, educationally, medically or in diagnosis related matters such as adaptive equipment, rehabilitation, wheelchairs, and surgical intervention. Insights may also be explored that relate to community programming and accessibility.

Research regarding adaptations in individual family system norms may help identify markers of current or future family stability, functionality, and quality of life. Further studies on both parent and professional perceptions of family needs across the life span may help develop essential understanding of vital family resources.

Research of the critical cross sections of parent/family experience may help identify adaptive versus maladaptive behaviors of parents and families in the process of raising a child with special needs. Whether rehabilitation and medical specialists are able
to recognize the difference between family markers associated with such behaviors is important. Studies about this matter could focus on single markers such as sleep deprivation or categorical markers such as those described in this study. Qualitative research may contribute to family empowerment and understanding through immersion experiences using ethnographic or pure immersion methods. Sibling perceptions of the impact of disability could also be explored.

Finally, parent-to-parent communication may also represent an interesting future inquiry. How and what do parents share regarding support, knowledge, and life direction? Comparisons of parent’s reception of information from professionals may be useful. Comparisons may be based on vital factors and perceptions, e.g., having children with shared diagnoses, shared educational levels, and other similar demographics. Conversely, it may be interesting to compare receptiveness and mutuality of discussions among parents with diverse and disparate background.

**Parting thoughts**

How parents framed disability mattered to them. Their thoughts, feelings, and reflections were supported by existing theory and by the literature. These disability related themes offer additional dimensions not commonly considered in professional circles. The research question, though answered well, is one that the researcher would now rephrase, excluding the use of the word disability, following the parents’ lead. Parents did not use words of diagnosis or disability to describe their children except as they were compelled to when clarifying things for educational or medical needs of the child. As a professional and as member of a global community, the researcher was forced to come face to face with the conundrum of this indiscriminate naming, even in the
researcher’s own research question and disability references used throughout the study. Parents in this study explored their lives with their children with special needs. In so doing, they found that their children had provided impetus to stretch parent boundaries in perspective, values, ethics, and priorities. Parents often stretched their aptitudes and skills; endurance and stamina; patience and tolerance; adaptability and resilience.

They took on characteristics of their children, experiencing disability with them, emerging as advocates and humanitarians. Many parents had changed vocations, choosing ways to optimize their time for their children, put off dreams as they cared for them, lived through pain and fatigue as the tolls of care increased. They laughed, cried, and prayed. They were angry, discouraged, and disillusioned at times, but that did not define them. In their sorrow, they may have questioned their own acceptance of their lives after all, but none stayed there. They did not like getting mired by negativity. This was part of their success. In fact, they did succeed. That was something they may have questioned at times in the process, but their determination, commitment, and gained competencies served them well. It was a hard life: the hardest thing they ever faced, most said. They followed that always with the worth.

After their children grew up, in many cases, many expressed new dreams that involved understandings of their children’s diagnosis, their caregiving, guardianship, and research needs. Many chose careers in health care. Eight still had enough uncertainty about the future that they were still on high alert.

This study’s results may lead readers to a new understanding of parents of children with congenital disability as they are rearing their children toward adulthood. The understanding may be one that fits better those parents who, in the end, found a way
to make it work. For certainly these families did that. The worldviews parents revealed in this study are dimensional themes that appeared bound to neither realities nor ideals. The themes instead were parts of themselves, their families, their lived worlds, their skills and resourcefulness, and their on-going stories. Parents framed disability in terms that were lively and deep: anything but disabled, in terms that were neither afraid of impairments nor occasional mistakes. Parents and children had often worked hard for their triumphs, but they celebrated those with deep satisfaction.

Parents stretched normal to embrace family, both at home and on the roads that they adapted and forged. Their children who had been born with special needs were central in that stretch. In the process of living the life that was theirs, parents identified with their humanity, with pride, reflectiveness, resilience, adaptation, and creativity. Their children, who they described as the pride and joy of their lived lives, had emerged successfully as young adults. Through tears, trials, thick, and thin, parents stood by them and had their backs. The parents are moving forward with their lives, having ushered them into adulthood. For most parents, this is an unfinished business. Most still ponder what comes next for their young adults as each seeks to become integrated and successful in a world that may or may not be ready to receive them. That story is unfolding, but someone will have to ask to know the ending.
APPENDIX A:

BRACKETING MODEL
Bracketing

Epoche is a relationship between the researcher’s past experiences and the data. Data provide units of meaning but it cannot be interpreted without symmetrical input of the researcher. The synergy of both sources, as they are integrated, moves the data toward the researcher’s interpretation (Bednall, 2006).

This model presents a researcher’s past experiences as part of the qualitative meld of data derivation. It provides a means of understanding the inevitable symmetry of inputs from researcher and data as they move toward interpretation.
APPENDIX B:

FAMILY SYSTEMS MODEL
Family Systems Model. Critical aspects of family systems theory expected to contribute to parental and family responses. These are contrasting traits that describe two different dynamics of family function, the drive to differentiate and the inclination to project. Both need to be considered in family system perceptions and opinion. Differentiation of self is an aspect of healthy individual functioning. Differentiation of self has two meanings conceptually speaking, describing both a person’s capacity to recognize and balance his or her own differences of feeling self and thinking self and to separate from other family members to distinguish his or her own constituencies and strengths/weaknesses. The thinking self represents the ability to look objectively at personal reactions, biases, opinions, and tendencies. The feeling self is the part of self that provides information about the relative significance of personal and interpersonal matters.

Differentiation implies an ability to separate emotionally, mentally, and physically from family of origin in a way that preserves objective relatedness, emotional ties, and connection without being constrained by them. Projection is a parental defense that targets their own children because they are vulnerable. A parent may project anger, frustration, competition, distrust, or any other emotional or cognitive state. Children may begin to possess these projections as if they are personal to them. Such children can become more emotionally reactive. Projection runs counter to healthy differentiation, compromising individual development (Carter & McGoldrick, 1989).

Healthy families need insight to develop healthy and lasting adaptations in their dynamics and relationships, problem solving, and growing in desired directions.
Reflective discussions among members can create insight regarding individual and family patterns (Walsh & Harrigan 2003).

Descriptions and expose` of the tensions between differentiation of self and projection of self are beyond the scope of this paper but are included in this appendix because they are expected to contribute to an understanding of parental emotional responses when framing disability. The evolution and work of parental and family member insight are considered part of family modifications essential to the family system as a whole as well as to the research process.

(Allen, Cornelius, & Lopez, 2007)
APPENDIX C:

FAMILY SYSTEMS INTERVENTION MODEL (FSIM)
Model for assessing the direct and indirect effects of different predictor variables on parent-child interactions and child development. (Trivette et al., 2010)

In this model, therapists are added to family systems in the capacity of capacity builders, help-givers, and as interventionist using family system sensitive practices. While the relationship of therapist impact to child and family outcomes is not the primary subject of the proposed study, the model suggests that it is a contributor. The interjection of related services to family systems yields a model of interest to the cumulative factors commonly associated with child outcomes. The authors of the study often cite that therapist outcomes are both direct and indirect, because of the filter and primacy of parent and family to the child.
APPENDIX D:

ECOLOGICAL MODEL, BRONFENBRENNER
Ecological Model

- **Microsystem:** Institutions with direct impact on a child's development including family, extended family, school, churches, neighborhood, and friendships.
- **Mesosystem:** Relationships between microsystems,
- **Exosystem:** Outside systems or settings that indirectly influence the child
- **Macrosystem:** The contemporary culture of the child.
- **Chronosystem:** Patterns of developmental time

In this model, each system has dominant norms, roles, and rules. It is anticipated that the environment interacts with the personal in ways that impact development of child, parents, and family systems.

Environmental structures range from the family to institutions to economics to relevant politics. Structures — have come to be viewed as part of the life course from childhood through adulthood.

APPENDIX E:

DISABILITY STUDIES - THE SCOPE OF PERSPECTIVES
Disability Studies

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<thead>
<tr>
<th></th>
<th>Major premises of the disability theories.</th>
<th>Experiential Phenomenological (sociological, social, environmental) Ethical/Political</th>
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<tr>
<td>B.</td>
<td>How PIWD’s function, dysfunction, and change in rehabilitation are explained.</td>
<td>See below for general trends</td>
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<tr>
<td>C.</td>
<td>Strengths and weaknesses of theory</td>
<td>See below for trends</td>
</tr>
<tr>
<td>D.</td>
<td>Prevalence in rehabilitation literature</td>
<td>ICF models used often, but disability theory rarely referenced</td>
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**Experiential including:**

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<th>Function =</th>
<th>Dysfunction =</th>
<th>Changes in function =</th>
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<tr>
<td>1. Difference</td>
<td>Atypical</td>
<td>Usual</td>
<td>Improvement</td>
</tr>
<tr>
<td>2. Universal</td>
<td>Eventual</td>
<td>Part of norm</td>
<td>Envir/personal</td>
</tr>
<tr>
<td>3. Typology</td>
<td>Reactionary</td>
<td>Depends</td>
<td>Match needs</td>
</tr>
<tr>
<td>4. Embodiment (stories)</td>
<td>Individual</td>
<td>Depends</td>
<td>Custom</td>
</tr>
<tr>
<td>5. Resistance</td>
<td>Militant</td>
<td>Formative</td>
<td>Global</td>
</tr>
</tbody>
</table>

Copyright © Sheryl L. Holt 2016
<table>
<thead>
<tr>
<th><strong>Phenomenological including:</strong></th>
<th>1. ‘Normative’ prevention</th>
<th>Broken or ill-repair</th>
<th>Prevention, healing, fixing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Biomedical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Social body</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Social construct</td>
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<tr>
<td>3. Environmental</td>
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<tr>
<td>4. Sociological</td>
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<tr>
<td>5. Community or school inclusion</td>
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<td></td>
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<tr>
<td>6. Integrated biopsychosocial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethical/Political</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Ethic of caring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Socio-political</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Religious views</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Educational*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Qualified by…</td>
<td></td>
<td>Definition</td>
<td>Re-defined</td>
</tr>
<tr>
<td>3. Participatory if</td>
<td></td>
<td>Non-participatory</td>
<td>Adaptation either way</td>
</tr>
<tr>
<td>4. Contextual fits</td>
<td></td>
<td>Contextual misfits</td>
<td>Acceptance or rejection</td>
</tr>
<tr>
<td>5. Hybridization</td>
<td></td>
<td>Custom fits</td>
<td>Back to normal</td>
</tr>
<tr>
<td>6. Enlarging</td>
<td></td>
<td>Normative</td>
<td>Helping toward independence</td>
</tr>
<tr>
<td>1. ‘Normative’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Qualified by…</td>
<td></td>
<td>Definition</td>
<td>Re-defined</td>
</tr>
<tr>
<td>3. Participatory if</td>
<td></td>
<td>Non-participatory</td>
<td>Adaptation either way</td>
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<tr>
<td>4. Contextual fits</td>
<td></td>
<td>Contextual misfits</td>
<td>Acceptance or rejection</td>
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<tr>
<td>5. Hybridization</td>
<td></td>
<td>Custom fits</td>
<td>Back to normal</td>
</tr>
<tr>
<td>6. Enlarging</td>
<td></td>
<td>Normative</td>
<td>Helping toward independence</td>
</tr>
<tr>
<td><strong>Ethical/Political</strong></td>
<td></td>
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<tr>
<td>1. Ethic of caring</td>
<td></td>
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<tr>
<td>2. Socio-political</td>
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<tr>
<td>3. Religious views</td>
<td></td>
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<tr>
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<td></td>
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<tr>
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<td></td>
<td>Definition</td>
<td>Re-defined</td>
</tr>
<tr>
<td>3. Participatory if</td>
<td></td>
<td>Non-participatory</td>
<td>Adaptation either way</td>
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<tr>
<td>4. Contextual fits</td>
<td></td>
<td>Contextual misfits</td>
<td>Acceptance or rejection</td>
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<tr>
<td>5. Hybridization</td>
<td></td>
<td>Custom fits</td>
<td>Back to normal</td>
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<tr>
<td>6. Enlarging</td>
<td></td>
<td>Normative</td>
<td>Helping toward independence</td>
</tr>
<tr>
<td>1. ‘Normative’</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2. Qualified by…</td>
<td></td>
<td>Definition</td>
<td>Re-defined</td>
</tr>
<tr>
<td>3. Participatory if</td>
<td></td>
<td>Non-participatory</td>
<td>Adaptation either way</td>
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<tr>
<td>4. Contextual fits</td>
<td></td>
<td>Contextual misfits</td>
<td>Acceptance or rejection</td>
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<tr>
<td>5. Hybridization</td>
<td></td>
<td>Custom fits</td>
<td>Back to normal</td>
</tr>
<tr>
<td>6. Enlarging</td>
<td></td>
<td>Normative</td>
<td>Helping toward independence</td>
</tr>
</tbody>
</table>

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## DISABILITY SEEN AS:

<table>
<thead>
<tr>
<th>Hybrid</th>
<th>Able bodied majority</th>
<th>Oppressed group</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Integrated Model</td>
<td>Function = Variable +</td>
<td>Dysfunction = Variable +</td>
<td>Reasons vary</td>
</tr>
<tr>
<td>2. Grassroots model</td>
<td>By community responsibility</td>
<td></td>
<td>Group success-failure</td>
</tr>
<tr>
<td>3. Rehab</td>
<td>Continuum</td>
<td>Disabling</td>
<td>Enabling</td>
</tr>
</tbody>
</table>

### Strengths vs. Weaknesses

- **Difference**
  - Differences that could and should be acknowledged in PlwD; prevent lumping all together and missing some key realities
  - Can open dialogue to learn

- **Universal**
  - Recognizes that a large number of people will become disabled in the course of their life spans and are only temporarily able bodied people
  - Can seem irrelevant while the majority of people are in the ruling classes, in the media, and governing the politic of school & work are able bodied

- **Hybrid**
  - Can label as weak or Femme
  - Can create conceptual dichotomies
  - Can create power differentials

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<table>
<thead>
<tr>
<th>Typology</th>
<th>Offers some textural component to the very real mixture of personalities within the disabled population. Helps define a continuum of normal responses to both disability &amp; its social/rehab processes and contexts.</th>
<th>Can lead to stereotyping and Limited expectations Can foster labels that limit Can minimalize</th>
</tr>
</thead>
<tbody>
<tr>
<td>Narratives</td>
<td>Individual and interesting Voice</td>
<td>Can reduce to satisfy able bodied versions and be uninformed of meanings</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(Phenomena ) Social Models Disability=Sociological concept</th>
<th>(Strengths )</th>
<th>(Weaknesses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Biomedical a. Social body</td>
<td>Organized Progressive Powerful Preventative</td>
<td>Labels Categorizes Blames</td>
</tr>
<tr>
<td>2. Social construct</td>
<td>Perspective change Exposes social realities/ barriers common to PwD</td>
<td>Limited Does not account for impact of disabling condition</td>
</tr>
<tr>
<td>3. Environmental</td>
<td>Establishes focus on the environmental biases common to society</td>
<td>Cannot account for impact of disabling condition</td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Creates universal designs</td>
<td>Does not allow for social contexts as easily</td>
</tr>
<tr>
<td>4. Sociological-→</td>
<td>Dynamic</td>
<td>Hard to impact</td>
</tr>
<tr>
<td>created identity</td>
<td>Links with other groups that have experienced oppression</td>
<td>Dominant groups persist</td>
</tr>
<tr>
<td>Or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity as a construct</td>
<td>Fosters self-examination of societal values</td>
<td></td>
</tr>
<tr>
<td>5. Community or</td>
<td>Attempts to de-segregate PwD</td>
<td>Too much classification</td>
</tr>
<tr>
<td>school inclusion</td>
<td>Well intended and often progressive team</td>
<td>Too much political mandate</td>
</tr>
<tr>
<td></td>
<td>Visibility of PwD issues</td>
<td>without supports to school based or community based team</td>
</tr>
<tr>
<td></td>
<td>Identification of child as qualifying for this service</td>
<td>Creates resentment if placement is sub-optimal</td>
</tr>
<tr>
<td></td>
<td>suggests “difference”</td>
<td></td>
</tr>
<tr>
<td>6. Integrated</td>
<td>More comprehensive- ICF framework minimizes impairment role in person</td>
<td>Requires coordination of task forces and specialties</td>
</tr>
<tr>
<td>Biopsychosocial</td>
<td>Dimensions of function become critical assessment</td>
<td></td>
</tr>
<tr>
<td>Hybrid Models</td>
<td>Strengths</td>
<td>Weaknesses</td>
</tr>
<tr>
<td>------------------</td>
<td>-----------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>INTEGRATED</td>
<td>Offers all the strengths of all models</td>
<td>The strength may be hard to ‘rein in’ in real life</td>
</tr>
<tr>
<td>REHABILITATION</td>
<td>Attempting to make impairments less central</td>
<td>Connection with medical model, orientation often to norms</td>
</tr>
<tr>
<td>BIOPSYCHOSOCIAL</td>
<td>Symptom management</td>
<td>May be challenging to implement and get funding</td>
</tr>
<tr>
<td></td>
<td>Recovery and Rehabilitation</td>
<td>Cannot guarantee positive patient</td>
</tr>
<tr>
<td></td>
<td>Self-esteem and Confidence</td>
<td></td>
</tr>
<tr>
<td>Social identity and role</td>
<td>responses</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>Promoting activities and participation</td>
<td>Cannot force social issues without political influences</td>
<td></td>
</tr>
<tr>
<td>Social inclusions and functioning</td>
<td>Governing ethic unclear</td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APENDIX F:

CONSENT FORM FOR STUDY
Consent to Participate in a Research Study

Retrospective *framing* of disability by parents of children with disability, based on their lived experiences from their child’s early infancy to adulthood: a phenomenological study

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You are being invited to take part in a research study about *Parent perceptions of rearing their child who had a disability to adulthood*. The research is based on the observation that parents who have children born with physical disability often have invaluable experiences and unique perspectives to share. Parent knowledge and actions are critical to family and child outcomes. This is true at home, in therapy, in school, and in regard to a child’s taking part in the community. The *lived world* of parents of children with disability has not been investigated extensively, especially having parents look at their experiences once the child is grown. How parents frame their lived experiences may help others better understand what it is like to parent a child over time and how they may relate to that process more sensitively. Other parents, health care providers, community members, family, and friends may need or desire to learn about critical aspects of family and child life, the challenges and joys of ordinary days, perceptions, and needs.

Because you lived the experience of rearing your child from infancy to adulthood, you are being invited to take part in this research study. We invite you to write out, map, and speak to the processes and experiences you have had. If you volunteer to take part in this study, you will be 1 of about 8 parents to do so.

WHO IS DOING THE STUDY?

The person in charge of this study is Sheryl L. Holt of University of Kentucky, Department of Rehabilitation Science in the College of Health Sciences. Sheryl is a doctoral student completing her dissertation, and is being guided in this research by Susan Effigen, PT, PhD and Peggy Wittman, OTR/L, EdD who are acting as her co-advisors.
WHAT IS THE PURPOSE OF THIS STUDY?

The aim of the study is to develop a larger view or a framework about what parents have learned as their child grew up into adulthood. A part of the purpose is to invite specific meanings that parents may have placed on their experiences. A primary objective is to learn about and understand details of the lived experiences of parents of children with disability.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?

There are a few reasons not to participate. It is acceptable for you to choose not to be part of this study. For instance, you may believe your views are private or personal. Thinking about past experiences may put you in touch with unwelcome emotions related to them. Even if they are welcome emotions, not all of them may be positive. Negative perceptions you have or had could create some mental or emotional stress for you. In cases where your memories are associated with times that were a struggle for you, your recollections may be uncomfortable or undesirable. If these or other matters outweigh positive aspects of the study, you may not wish to take part.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The research procedures will be conducted at each participant’s home. Participants in this study are expected to be from Ohio, West Virginia, Pennsylvania, or Kentucky. The researcher will arrange to come to your home two different times during the study. Each of those visits will take about 45 minutes to 1 hour. The total amount of time you will be asked to take part in tasks for this study can depend on how much time it takes you to complete some of the written materials. However, as a whole, participation is unlikely to be more than four total hours over the next 6 months.

WHAT WILL YOU BE ASKED TO DO?

As part of a three phase study, you will share your thoughts, feelings, opinions, and ideas in several different ways. If you wish, you will be invited to share pictures or media that are personally meaningful. I will ask you to share information in live interviews, journal keeping,
filling out a MAP (diagram), and by answering written questions. Some of these tasks will be done on your own. At all times of the study, I will be able to be reached by phone, text, or emails. I can help you with any part of the study. Each person may also keep a journal during the study, but this isn’t required. It’s up to you. The journal can be used for any purpose. It may help you organize your thoughts, feelings, and views. Here are the phases of the study:

**Phase one:** We will chose an agreeable date and time to meet. I will come to your home. The interview will take place in whatever part of your home you choose.

1. I will share the purpose of study.
2. I will review the consent form. If you agree to participate, you will be asked to complete the consent form and sign. If you do not, that is fine.
3. If you have consented, you will fill in information about your family; (e.g., your name, your work, your employment status, your salary, your schooling, whether you are married or single, ways you are involved in your community, how many children you have, extended family information, main support systems, therapies your child received, where they were and distance, means of transportation; child’s school type, where child lives and what child does now, parent birth date, age at birth of child, adult-child’s current age, child’s diagnosis, perceived severity of condition, and perceived visibility of condition).
4. I will give you five questions to answer in writing. I’ll review them with you then leave them. You will write or type your answers to these questions before I return for the next phase of study. This will be 10 days or a little more. I’ll get these questions when I come back.
5. I will give you a journal to track your thoughts, feelings, findings, and questions. This is optional. If you keep a journal, you will write down anything that you wish that comes to mind that you may wish to share. Sharing the journal is not required. If you do share, journal entries may be used in the study.

**Phase two:** You will be asked to participate in a face to face interview. I will ask you questions and you will share what that comes to mind regarding the questions. I will use a written diagram to help me understand some of your support systems and you will help me fill it in. There are no wrong answers.
No questions have to be answered. You are welcome to pass on any part of this study if it makes you feel uncomfortable. Once you provide information, you are not obligated to have that information retained. You will be welcome throughout the study to contact me regarding any part of the study. I am also available by way of email or phone to answer any questions you have once you begin the study. This can occur during or between phases of study.

**Phase three:** Once I have spent time going through your information, I will try to condense your thoughts into themes. I will be asking each of you to look over my findings. You will answer a few questions about my findings to see if what I conclude represents what you have told me.

**Time line.** Phase one will be completed in part while I am in your home. The initial materials I have for you can be completed in 45 minutes to an hour. I will leave a few assignments and a journal for you to complete within 2-3 weeks. I will pick these up on my second visit 2-3 weeks after my first visit to your house. The face to face interview that will last approximately 45 minutes to an hour. Before the final phase, I will allow myself 3-4 months to analyze what you provide me by your answers and materials. After that time, I will be emailing you my study results and asking your opinion, which I will ask you to return by text or email within one week. Your participation in this final phase will conclude your formal participation in the study. Your calls and texts are still welcome after this phase, as they have been between all phases. A final copy of the study will be available to you on request, once the study is final.

**WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?**

There are no known risks or discomforts expected with this study, but as noted earlier, if you do have an emotional response to any question or memories aroused by the study, not all of these may be happy. It is possible you will have some emotional distress associated with re-living certain events in your mind.

<table>
<thead>
<tr>
<th>Possible Risk/Side Effect</th>
<th>How often has it occurred?</th>
<th>How serious is it?</th>
<th>Can it be corrected?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional distress</td>
<td>Past memories can stir up fresh emotional response</td>
<td>Usually of short duration</td>
<td>It self-corrects generally</td>
</tr>
</tbody>
</table>

University of Kentucky
Revised 2/21/14
<table>
<thead>
<tr>
<th>Sadness, regret, or conflict</th>
<th>It occasionally occurs with recall</th>
<th>Usually of short duration</th>
<th>It self-corrects generally</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative associations</td>
<td>Conceivable since some questions will relate to lived experiences over time</td>
<td>Usually of short duration</td>
<td>It self-corrects generally</td>
</tr>
<tr>
<td>Time demands above your comfort level</td>
<td>It is uncommon</td>
<td>It will not impact your overall health</td>
<td>It can be economized and is very short term</td>
</tr>
</tbody>
</table>

While medical treatment for any of these circumstances is improbable and highly unlikely, it is important to remind you that there is always a chance that any medical treatment may have risk.

**WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?**

There is no guarantee that you will get any benefit from taking part in this study. However, some people who have participated in studies like this one have experienced a sense of empowerment and a voice. Your willingness to take part may also benefit others in the future. Because this study will be presented in professional formats at conferences or professional or civic meetings, others will be able to benefit from what we have found. The contents of this study may also be published, making its findings available to health care professionals. In that way, you may help new parents, physical therapists, doctors, and community members. Your information may increase understanding of families and children. It may also improve interactions or interventions that occur during childhood.

**DO YOU HAVE TO TAKE PART IN THE STUDY?**

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits, relational comforts, or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits, relationships, and rights you had before volunteering.

**IF YOU DON’T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?**
If after reading through this study, you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There is no cost associated with participation.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

The primary investigator will see the transcriptions of your interview, the materials you voluntarily give to her. Once the data is received, however, your information will not be associated with your name. That means that no one else will know that the information you give came from you.

To ensure this, I will make every effort to keep confidential all research records that could identify you to the extent allowed by law. Audio files from our interviews will be retained only until transcription is completed and completeness is ensured. At this time, the audio files will be deleted from the researcher’s computer.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private. We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is.

Data collection procedures will include collection of written forms to be hand collected and stored in briefcase in transit to locked file cabinet. Live interview will make use of Dragon, Naturally Speaking, by Nuance ©. This will convert audio files to written transcripts. Both forms of data will be password protected on the primary investigator’s personal computer while in use and copied to password protected encrypted portable storage drive after the study. The computer is used by no other persons. Written transcripts and portable storage drive will be kept in files in
a locked file cabinet which is routinely used for protecting confidentiality of data including paper records, computer records, and portable storage devices.

You should know, however, that there are rare circumstances in which we may have to show or discuss your information to or with other people, such as officials from affiliated universities, the University of Kentucky, Eastern Kentucky University, and Wheeling Jesuit University. This is a matter which can be explained further to you when this study is discussed.

CAN YOUR TAKING PART IN THE STUDY END EARLY?

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study. The individual conducting the study may need to withdraw you from the study. This may occur if you are not able to complete the research protocol, or if they find that your being in the study is more risk than benefit to you, or for reasons related to the primary investigators’ inability or other infeasibility of completing the study. Your data will still be protected as if you were in the study.

ARE YOU PARTICIPATING OR CAN YOU PARTICIPATE IN ANOTHER RESEARCH STUDY AT THE SAME TIME AS PARTICIPATING IN THIS ONE?

You may take part in this study if you are currently involved in another research study. It is important to let the investigator know if you are in another research study. You should also discuss with the investigator before you agree to participate in another research study while you are enrolled in this study.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will not receive any rewards or payment for taking part in the study.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Sheryl Holt At 330-844-1027. If
you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity between the business hours of 8am and 5pm EST, Mon-Fri at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428. We will give you a signed copy of this consent form to take with you.

WHAT IF NEW INFORMATION IS LEARNED DURING THE STUDY THAT MIGHT AFFECT YOUR DECISION TO PARTICIPATE?

If the researcher learns of new information in regards to this study, and it might change your willingness to stay in this study, the information will be provided to you. You may be asked to sign a new informed consent form if the information is provided to you after you have joined the study. This is not at all anticipated.

POTENTIAL FUTURE USE

The use for the results of the study are initially to complete dissertation requirements, but are anticipated to be part of one or more publishable articles. If the results can are believed to be beneficial to any constituency, whether other parents, families, community members, educators, health care providers such as therapists, nurses, doctors, or social workers, it is possible that a book chapter or handbook may be created with the information derived in the qualitative study.

Contacting Research Subjects for Future Studies

As a current research subject, we value your participation greatly. Please indicate if you are willing to be contacted by the principal investigator regarding future studies regarding this or other related topics. Do you give your permission for Sheryl L. Holt to contact you in the future regarding future research opportunities. Note that future studies may continue this current inquiry about you and your child’s life experiences, but other topics are also possible.

☐ Yes ☐ No ________ Initials

Any areas of interest? ____________________________________________

WHAT ELSE DO YOU NEED TO KNOW?
There is a possibility that the data collected from you may be shared with other investigators in the future. If that is the case, the data will not contain information that can identify you unless you give your specific consent/authorization. The Institutional Review Board (IRB) is a committee that reviews ethical issues, according to federal, state and local regulations on research with human subjects, to make sure the study complies with these regulations before approval of a research study is issued.

*This study is neither funded by any outside institutions nor does it promote materials associated with an outside agency or institution.*

________________________  \________________
Signature of person agreeing to take part in the study       Date

________________________
Printed name of person agreeing to take part in the study

________________________  \________________
Name of [authorized] person obtaining informed consent       Date

________________________
Signature of Principal Investigator or Sub/Co-Investigator
APPENDIX G:

INSTRUMENTATION
Underlying Strategies of Interviewer

Introductory phase 1*:
Introduce studies by orienting parents to areas if interest: Demographics were gathered using descriptors that impact care giving capacity of parents, e.g., support systems, community setting, socio-economic status, single versus two parent home, number of siblings, birth-order, perceived severity of disablement, age of parent at birth of child, age of child when he moved from home, etc.. Part of this phase, after discussing purpose of study is an open-ended written questionnaire, left with parent to jump start reflective processes associated with the child’s growing up. Self-selected family valued child-specific milestones over time are part of the strategy.

Phase 2- Open ended face to face Interview*

The following were follow-up research questions. Each are listed with their theoretical or evidence based structures. These questions served as a partial guide to various directions the researcher considered for the research investigation of “parental framing of disability” in parents of a child with a disability. The also represent the potential bias that may have been interjected into interviews or analysis. These are thus listed as part of the researcher’s reflexivity. Parent responses to the research instruments, written and oral, served as the predominant guide. These are not the interview questions but rather the researcher’s questions and sub-questions of interest.

How do parental disability frameworks develop over time? How does environment interact with parental perceptions of disability? How does a parental framing of disability correlate with established disability theories, models, studies, and identities, including the disability rights movement?
How does a parental framing of disability relate to aspects of their own identified family culture? Does a parent’s frame of "disability" prove unique to their family culture and system dynamics?

How do parents of a child with a disability interpret impact of disability on their child who lived with a disabling impairment, other siblings, parents, and family as an entity?

How do parents believe that society has influenced their disability perspectives?

How do parents believe that the medical field has influenced their disability perspectives?

How have their child’s own perceptions of his or her ability and/or well-being influenced parental disability perspectives?

How does a parent of a child with a physical disability describe the evolution of feelings he or she experienced over time in giving birth, caring for, rearing, developing a family around, and transitioning the child to adulthood? What have parents learned from their parenting journey?

After revisiting the experience of rearing a child with disability, with what ideas and perceptions do parents create a summative “frame for disability”?

How do they describe key things they have learned from their lived experience of disability? What perspectives have they developed by the time their child has grown up? Has disability changed their worldviews? What did they share with the medical team? What do they think the medical team should know about family perspectives? What do they think the medical team should know about disability, the word, the use of the word? What do parents consider as the critical structures that led to their frame?

How does a parent of a child with a physical disability describe the relationships of their over-all disability perceptions and their experiences/memories/identified key child and family milestones?

How do variable demographics interact with parent perceptions? How does a parental framing of disability relate to unique disability identities? How does a parental framing
of disability relate to family system identity*? Do social and biomedical models of
disability influence parental experience of disability and/or related perspectives?

How does a parent of a child with a physical disability describe the evolution of
feelings he or she experienced over time in giving birth, caring for, rearing, developing a
family around, and transitioning the child to adulthood? How does the adult outcomes of
a child impact disability frame?

Examples of potential follow-up of patient questions:

How do you believe your family identity has impacted upon your child’s disability? How
do you believe your child’s disability has impacted your family identity?

Please expound on how your view of disability as developed over time. In what contexts
have you felt most minimized? Why?

Help me understand the way you as a parent and family member have experienced what
your child has faced, living with a disability?

Looking back, what has disability come to mean to you? At the end of face to face
interview, I asked each participant if he or she has any questions.

**Phase 3- Member Check**

Review of thematic findings with members, Strategy to let them examine the fit as
chapters of themes of what they shared. Perhaps they are not complete or accurate, so let
them share ideas.

Regarding what was derived in analysis, ask parents “how do these ring true?” See what
resonates with them among the themes. Emphasis can then be added.
What would you change or add? The parent perspective will be modified as needed.

What are we missing? While additional ideas may complicate the study timeline, this question is essential for parents to hear? The strategy is to engage a final look at the topic.

Anything else you’ve thought of since we last talked that relate to this study? This is to see if there are questions or concerns in addition to thematic member checking.
Study Instrumentation

Phase one, part one

Introduction

Although most study participants have received some materials or discussed study
informally with researcher post IRB approval, phase one is set aside as a formal
introduction to study.

Checklist for each participant:

1. Review of study purposes and aims.
2. Review of procedures and commitments.
3. Disposition of study outcomes.
4. Treatment of data sources, and files.
5. Questions from the parents.
6. Signing the consent form.
7. Enter phase one, part two.

Phase one, part two

Demographics were gathered. These included: parent’s name (which were whited
out once research number was assigned), parent’s vocation, parent’s employment status,
socio-economic status, level of education completed, marital status, community
involvement, number of other family children, description of extended family, main
support systems, therapies child received including where they were and distance, means
of transportation; child’s school type, where child lives, what child does now, parent birth
date, age at birth of child with disability, adult-child’s current age, child’s diagnosis,
perceived severity, perceived visibility.
Demographics

Name:___________________
Parent age:(25-29)_____(30-39)____(40-49)____(50-59)_____ (60-69)_______(70 or above)______
Parent age at birth of your child with disability___________
Parent highest level of education completed/year :_____________________
Parent(s) vocation/work:__________________________________________________________
                        Status: active full time______, active part time______, retired______, n/a______
Yearly income: Less than $25,000/yr___ $25-50,000/yr____ $ 50-99,000___ Over $100,000___
Marital status during child’s growing up___________ marital status at present___________
Community involvement

Child’s diagnosis:_________________________________________
Perceived severity: (Severe, Moderate, Mild); Perceived visibility of impairments: (High, Medium, Low)
Child’s current age:___________ Age at diagnosis: _______Age at transition to adulthood______
Child’s living situation/work/school:

Child’s highest level of education completed:____________________ Special Education? ____ Therapies received in school?_____ if yes, which therapies?
Surgeries or medical procedures?
Outcomes: (Excellent, good, fair, poor, awful). Health of child: (Excellent, good, fair, poor)
Number of other family children:______________; Birth order of child with disability______
Where did you find your greatest support during early childhood?_________________________
How would you describe your own health over the years: (Excellent, good, fair, poor)

(Enter Phase one, part three).
Phase one part three  Perceptions of the child’s own key milestones and transitions, defined as personally relevant to child or family, not as part of a standardized list of typical milestones

Parents are asked to identify five areas they identify as significant family milestones: these are relevant or valued highlights of their child’s life. They were asked to share five impressions they associate with their experiences in facing their child’s label of disability. They were asked to describe their child’s five greatest attributes and strengths and their child’s five hardest struggles.

Phase one, part three- A written questionnaire

As parents, our knowledge of our child is great, especially during their early development. One of the areas that parents most look forward to with the birth of a child are the achievements of what are often called milestones. Children with disability also achieve their own milestones, sometimes on a much different plane than children who do not face life with impairments. Even if, to the waking world, children with disability are considered delayed, the delays are according to standards that do not account for their challenges. For that reason, this questionnaire wants to focus on the individual or family milestones that your child achieved that were most important to you. What five areas do you recollect over your child’s life that truly represents a hallmark or milestone of achievement? (These can be personally important to you as a parent, something that made you proud OR something you know was important to your child). Please list the milestones below and why they were special.

<table>
<thead>
<tr>
<th>Milestones</th>
<th>Importance and to whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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<tr>
<td>2.</td>
<td></td>
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<tr>
<td>3.</td>
<td></td>
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<tr>
<td>4.</td>
<td></td>
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<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>

The first time parents hear that something is wrong with a child, parents are known to be in shock; they get rattled, disoriented, and worried. Over time, ways to cope and adjust may ameliorate some of the pain, sadness, or uncertainty. Sometimes, there are cases when a child’s survival is so significant that it masks some of those early responses as a parent holds to life. Everyone has a story to tell about the beginnings of a journey. For this question, please consider five experiences and five impressions regarding your child and the discovery that they had special needs, a so-called disability, something “wrong” that put them on, for a time, a grid that was different. It could be the time a diagnosis was shared, an evaluation, a random comment.
These experience/impressions can be experiences with great inspiring impressions or the very opposite. They can be whatever you wish to share. Please share five impressions you associate with your experiences in facing your child’s label of disability

<table>
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<tr>
<th>The experience</th>
<th>The impression</th>
</tr>
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<tbody>
<tr>
<td>1.</td>
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<td>4.</td>
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</table>

As parents, it is always hard to watch as your child faces challenges that a bit above his or her ability or means. On the other hand, it is almost always a thrill when they face life and find joy in what they do, accomplish, feel, dream of. Please take a moment and try to recall what you would consider five of your child’s strongest attributes and five of their weakest links, areas of struggle. Share only those things with which you are comfortable.

<table>
<thead>
<tr>
<th>Strongest attributes</th>
<th>Weakest links</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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<tr>
<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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<tr>
<td>5.</td>
<td></td>
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</table>

Thank you. You can return this in the stamped enclosed envelope or retain until the next interview. Your time and feedback are very important to me. Thanks for sharing.
Phase two, part one: face to face interview

The researcher instructs the parent participating in the interview to share anything he or she wishes to help the researcher understand more about his or her retrospective reflections on life with their child, particularly how disability framed that experience. Each parent was given the freedom to respond in any fashion he or she chooses; the interviewer sought to listen in an active and interested way, conveying the importance of each of the views expressed. Any thoughts expressed were considered valid data and parents were told that ‘there are no wrong answers’.

Questions followed dominant themes regarding disability constructs of difference, family system considerations such as family culture, family identity and the merger with disability identity and systems. Roles of interventionists in disability frameworks were also visited. Models of family and disability that guided considerations for these instruments are in appendices A-C. When phrases or concepts are brought up by parents which include ideas within these models/paradigms, follow-up questions are to be inserted.

The first contains a model of intervention which places the practices of help giving and capacity building in relationship to family quality of life and child outcomes. Family system models follow with information on the dynamics of family differentiation and healthy outcomes as a child transitions into older ages. It includes concepts of self-differentiation, parental projection, and variations in outcomes that examine parent-child emotional ties with or without emotional constraints. The models of disability display bio-medical, social, and hybrid models that represent aspects of disability that are
personal, phenomenological and political. Disability identities are often based on *differences*. That concept is one which this investigative interview sought to uncover. The total interview process is designed to aid the parents in gaining further appreciation and understanding of themselves, affirming and empowering them in their lived experiences and perspectives, especially in those areas in which they have not explored. Both intentions are consistent with qualitative research (Glense & Peshkin 1992).

**Questionnaire:**

1. (Difference) Consider how your lived experience of disability as it relates to your child growing up with a disability. One theme commonly associated with disability is “difference.” When you hear this sort of statement, I wonder about your sense of your child being the same as other kids versus different.
   i. In what ways did you perceive of your child the same as/different from other children?
   ii. In what ways did you perceive of your child’s choices the same as/different from other children?
   iii. In what ways did you perceive of yourself the same as/different from other parents?
   iv. In what ways did you perceive of your life choices the same as/different from other parents?
   v. Can you answer the questions for your family as a whole?

2. (Ability versus disability) Consider how your lived experience of disability as it relates to your child growing up with a disability. Another theme commonly associated with disability is … well…ability versus disability. When you consider your child’s life, I wonder about your sense of your child being able versus dis-able…
   i. In what ways did you perceive of your child able, competent, whole?
   ii. In what ways did your child experience dys-ablement?
   iii. In what ways did you or other members of your family sense ablement, competency, wholeness?
   iv. In what ways did your or your family sense disablement, treatment of incompetency, or handicap?
3. (Family systems) Family systems are dynamic, especially over time. It is said that each family has a sense of identity and culture. People with disability also develop a rich sense of identity and culture and have written extensively about who they really are. I am wondering if you have experience one or both of these.
   i. What can you tell me about your family identity and culture prior to your child’s birth? What were the strengths and weaknesses of those?
   ii. After living with your child over the years, did disability alter your culture or identity as a family?
   iii. How your family culture and sense of identity influence your child’s disability experiences?

4. (Interventions) You and your child probably participated in plenty of different doctor or specialist visits, therapies, and such. Some of the effort among researchers in the field of rehabilitation science is to understand how pediatric specialists work through and with the family. One of the thoughts is that they build parent capacity. At the same time, they provide help. Both are meant to have a positive impact on your quality of life as a family and your child’s outcomes. I am curious what your experience was with your teams over the years, in your home, clinics, hospitals, schools…
   i. Can you describe the way interventions shaped your views on your child, his choices, his impairments, and his potential?
   ii. How did your team address the notion of “disability?”
   iii. Looking back, how did your doctors and therapist impact you as a parent of a child with a disability?

5. (Retrospective frame of disability) Your child has grown from infancy to adulthood. If you could look at all the pieces of that process and reconstruct them into a new frame, something you could use to teach others what you know, what you learned, how would you frame disability to:
   i. Your family
   ii. Your friends, acquaintances, peer group
   iii. Your community
   iv. Your health care providers
   v. A new family facing the same challenges as you did as a new parent?
MAPS: (introduction)

Guiding Thoughts or Questions for filling out form

Who Did I Spend My Time With?

- Think about all of the people who were important to your child.
- Think about the people who you wanted to have enter your child’s life.
- Think of those people who spent quality time that made a big difference.

Where Did I Spend My Time?

- Where were the places that your child spent time that he/she really liked?
- Were there places in your community where your child didn’t go, but you wished he or she could have spent time there?
- Would you have liked to see your child spend more time in the community?

What Did I Spend My Time Doing?

- What did your child like to do?
- How did other members of the family spend their time?
- What were the things that other members of the family did that you wanted to see your child enjoy as well? Did that happen?
- What were school days like?
- What were the most important things your child learned?

Information derived from this query will be used to facilitate the completion of the MAP form (next page) that sets up the contextual background of the parent’s looking back.
Things that worked for us:

Regarding what I have written... Actions I have taken (or wanted to take)
- Describe your child’s temperament.

- How does your child respond to being with other people?

- How do other people respond to being with your child?

- What have you learned from your child?

- How is the world better because of your child?

If these questions were answered previously, parents were able to simply state that. These questions were largely integrated into the interview but reinforced through the final phase.
Phase three: member check (randomly selected members, post data analysis)

1. Upon completion of data analysis, three separate parents from the study provide feedback regarding thematic findings. This purpose is to validate the findings of the research.

2. The second purpose is for parents to add additional understanding or corrections to the existing data.

3. A fourth parent, not involved in study, will review themes for face validity.

The themes were sent by email. This was parent preference. The parents who received these themes for review was instructed to focus on whether the themes represent the opinions and perspectives that they shared in the interview materials and face to face interaction. They were asked if they described with adequacy their own framing of disability. In other words, were the proposed themes representative of their perspectives? Their responses guided the final phases of data analysis. Sample questions include: Do these themes ring true? What of these themes ring truest? What areas are not accurate? What would you change or add? What are we missing? Anything else you’ve thought of since we last talked that relate to this study?
## Coding journal and process summary

### Summary of Research Process

<table>
<thead>
<tr>
<th>Tasks</th>
<th>What</th>
<th>Researcher process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transcripts</td>
<td>Interviews completed with handheld tape recorder or audio heat set. These audiotapes of all nine parents were retained in either mp3 files or as part of Dragon software files. The handheld was tested prior to official interview start to ensure conversation was being captured. Transcripts also developed from written questionnaires and MAPS, added to data pool</td>
<td>After interviews were completed, all tapes were listened to from beginning to end to verify that content was usable. Dragon transcribed audio files of first five clients. I personally transcribed last four after Dragon Software malfunctioned. Transcripts were read alongside audio tape playing to provide notes on inflection, pauses, laughter, crying, or other noted affect.</td>
<td>Transcripts completed. Audio files associated with Dragon software became corrupted. Even with work with their help team, could not recover. Written transcripts had already been converted into Word © and were retained. All four audio files retained from handheld recorder are in password protected file. All transcripts, complete with field notations are retained.</td>
</tr>
<tr>
<td>Coding</td>
<td>174 pages of transcript data from interviews. 69, generated by Dragon software © and the 105, generated by hand from hand-held recorder recorded transcripts. 68 pages of transcripts from Written questionnaire and MAPS. For all, columns created on both sides of collected data to allow highlighting, line-drawing, and needed writing/typing of codes.</td>
<td>Individual analysis followed by one researcher. The coding process was done after all data was transcribed. Coding was completed line by line, page by page. Most code descriptions were written in long hand in the order they were derived from data. Some codes were typed in text boxes. Data were regrouped once list was completed for all pages. Like codes were combined. Some codes were singular.</td>
<td>1243 individual labels were derived from data. Data reached saturation on all initial codes, representing entire data pool. The 1243 initial labels were synthesized into 85 collective codes</td>
</tr>
<tr>
<td>Categorizing</td>
<td>85 codes were retained after synthesis of all codes and assessed for potential categories. Based on theoretical basis of study, preliminary categories were selected that included disability perceptions across persons, lived experiences, times, and environments. These were modified to fit all data.</td>
<td>Data fit to categories was considered an essential step. The categories were refined from preliminary categories to invited all codes. The final categories used to derive themes included: Doing and being in places/systems; time; family; child; teams; others (near and far); Status changers&lt;disability. One researcher rebuilt study data. Bracketing of preconceived ideas was practiced throughout, returning researcher to data. All efforts were made to let data led analysis.</td>
<td>None of codes were considered mutually exclusive and could be included in more than one category. All codes were re-categorized in one or more categories, with quotes to support. Pre-theme chunking of recurring ideas were recorded and retained prior to deriving themes.</td>
</tr>
<tr>
<td>Deriving Themes</td>
<td>By re-reading rebuilt data and reviewing selected quotes as well as those from original transcripts, certain streams of thought, chunks of ideas led to preliminary themes, which began to emerge with repeated frequency. Preliminary themes were handwritten and retained. These ideas were synthesized into four primary themes</td>
<td>Preliminary themes were handwritten next to categorical data with a question mark. These were in short phrase form. E.g., Living with difference? Fighting difference? Ignoring difference? Final themes were synthesized from these potential ideas as all were re-read and matched with parent words/quotes. Match with parent quotes was considered a form of verification. Final themes were reviewed as a phase of the study (member check) by three parents from the interview group. Themes were affirmed unanimously. Parenthetical thoughts were added to themes to reflect their inputs to the question of whether anything needed added.</td>
<td>Relevant quotes fit well into final themes: themes were neutral and multidimensional across categories allowing for presence and absence, perceived accomplishment or perceived needs regarding persons, experiences, time frames, and contexts. Themes were considered validated after final parent review and discussion with faculty mentors.</td>
</tr>
</tbody>
</table>
APPENDIX I

SAMPLE OF COMPLETED STUDY COMPONENTS
SAMPLE of COMPLETED study components

Phase one, part three- A written questionnaire

As parents, our knowledge of our child is great, especially during their early development. One of the areas that parents most look forward to with the birth of a child are the achievements of what are often called milestones. Rose Kennedy is known for the quote: “It is not the milestones, but the moments.” This questionnaire is based on that ideology. For the sake of this study, we will consider life’s MOMENTS for your child that stand out as important to you. This questionnaire wants to focus on the individual or family moments that you recall with your child that stand out. What five moments do you recollect over your child’s life that are personally memorable to you as a parent, something that made you proud OR something you know was important to your child). Please list the moments below and why they were special.

<table>
<thead>
<tr>
<th>Moments</th>
<th>Importance and to whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When he was first able to speak</td>
<td>Encouragement in the midst of gut wrenching pain and uncertainty. My husband and me (wife)*</td>
</tr>
<tr>
<td></td>
<td>I asked myself why am I not falling apart? When he talked, I wasn’t just on autopilot-</td>
</tr>
<tr>
<td></td>
<td>I was able to do what I needed to do but I could have little celebrations</td>
</tr>
<tr>
<td></td>
<td>Consumed with getting Josh better (Doctors and specialists, therapists)</td>
</tr>
<tr>
<td>2. Learning to walk</td>
<td>So he could be independent. Important to Josh, family, therapists.</td>
</tr>
<tr>
<td>3. School work</td>
<td>Josh seemed always behind in academics, but his teachers bent over backwards helping him get through. Important to Josh, family, therapists.</td>
</tr>
<tr>
<td>4. Getting home his first over night</td>
<td>A new level of joy and excitement. A sign he was growing up. Important to Josh and his friends, our church family.</td>
</tr>
<tr>
<td>5. His first experiences with Functional E-Stim</td>
<td>Helps him believe he can get his left hand to work for him. Seems vital to his self-image at times. Therapist is very supportive.</td>
</tr>
</tbody>
</table>
The first time parents hear that something is wrong with a child, parents are known to be in shock; they get rattled, disoriented, and worried. Over time, ways to cope and adjust may ameliorate some of the pain, sadness, or uncertainty. Sometimes, there are cases when a child’s survival is so significant that it masks some of those early responses as a parent holds to life. Everyone has a story to tell about the beginnings of a journey. For this question, please consider five experiences and five impressions regarding your child and the discovery that they had special needs, a so-called disability, something “wrong” that put them on, for a time, a grid that was different. It could be the time a diagnosis was shared, an evaluation, a random comment. These experience/impressions can be experiences with great inspiring impressions or the very opposite. They can be whatever you wish to share. Please share five impressions you associate with your experiences in facing your child’s label of disability.

<table>
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<tr>
<th>The experience</th>
<th>The impression</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wanting to have a heart to heart with my husband about what was going on</td>
<td>Husband couldn’t handle it. Was like a zombie.</td>
</tr>
<tr>
<td>with Josh at the beginning. Wanted to receive comfort of a close friend.</td>
<td>Little help. Frustration.</td>
</tr>
<tr>
<td></td>
<td>Knew they couldn’t understand what I was going thru.</td>
</tr>
<tr>
<td></td>
<td>Felt completely alone.</td>
</tr>
<tr>
<td></td>
<td>Grief stricken, depressed. Emotionally and physically exhausted.</td>
</tr>
<tr>
<td>2. Realizing I lost the little boy I had held on to</td>
<td>A permanent loss. Still love my child.</td>
</tr>
<tr>
<td></td>
<td>Lost my ability to empathize with others.</td>
</tr>
<tr>
<td></td>
<td>Don’t see that I have time for friends.</td>
</tr>
<tr>
<td></td>
<td>Centered around therapy and school needs of son.</td>
</tr>
<tr>
<td></td>
<td>Feel dependent on a higher power. Josh’s sisters lost their parents for the</td>
</tr>
<tr>
<td></td>
<td>early years.</td>
</tr>
<tr>
<td>3. Josh learning to walk</td>
<td>Thankful Josh is with us. Of course I love him.</td>
</tr>
<tr>
<td></td>
<td>Duties make it seem like he grew up overnight.</td>
</tr>
<tr>
<td></td>
<td>Has to wear a brace on his left foot because he cannot pick it up without it.</td>
</tr>
<tr>
<td></td>
<td>Can hike and have fun with others.</td>
</tr>
<tr>
<td>4. Success in school</td>
<td>The school was accommodating and helpful.</td>
</tr>
<tr>
<td></td>
<td>Was homebound teaching and tutoring when he needs it. Is doing very well.</td>
</tr>
</tbody>
</table>
As parents, it is always hard to watch as your child faces challenges that a bit above his or her ability or means. On the other hand, it is almost always a thrill when they face life and find joy in what they do, accomplish, feel, dream of. Please take a moment and try to recall what you would consider five of your child’s strongest attributes and five of their weakest links, areas of struggle. Share only those things with which you are comfortable.

<table>
<thead>
<tr>
<th>Strongest attributes</th>
<th>Weakest links</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Good sense of humor</td>
<td>His left side. He still uses a brace on leg. Cannot use his arm normally.</td>
</tr>
<tr>
<td>2. Enjoys a great variety of sports and outdoor activities</td>
<td>Can understand subtle inferences. Has to have someone explain when they are joking</td>
</tr>
<tr>
<td>3. Able to complete his schooling in spite of struggles</td>
<td>Academic holes. Intelligence is there but just not like everyone else</td>
</tr>
<tr>
<td>4. Commitment to his church groups and their activities. Participates like a member of a valued group.</td>
<td>Impatience with his limitations. Anxiety with new situations when he is not with close friends or family.</td>
</tr>
<tr>
<td>5. Joy with simple achievements. Finding a pair of sandals he can keep on his feet without them coming off his left makes him ecstatic, feeling like everyone else.</td>
<td>Grows weary and demotivated with therapy</td>
</tr>
</tbody>
</table>

Thank you. You can return this in the stamped enclosed envelope or retain until the next interview. Your time and feedback are very important to me. Thanks for sharing.
**Excerpts derived from MAPS**

**Who did I spend my time with?**

**Close relationships:** Maternal grandmother. Sisters, one older, one younger; therapists, husband & wife; **Extended families, nuclear family, church family, work friends;** Paternal and maternal grandmothers; kindergarten teacher. psychologist, church families, there were always 2 or 3 in each congregation; All the aunts, uncles, cousins; youth leaders at church; teachers from school; YMCA counselors; pastors, especially the youth pastors; grandparents; siblings; my mom (mom), Big momma (grandmother); grandpa; school teachers (select), Hope house (respite); mother daughter, other moms whose daughters were in respite care. My mom mostly called on the phone. Never kept Anna. Anna’s nurses at respite. Step dad, cousins, aunts and uncles. Didn’t hang out with other moms.

**Friendships:** Very few friendships except church and family; hard since time at premium; office staff; Two close friends (lifelong), family, all took time and stayed transitory as did my work record; family and school friends, they spent a lot of time at our house; family oriented, church friends more than anywhere else. Friends from J’s work. We’d travel with one or two of them. Family, work friends, and child’s school friends and online acquaintances (as a young adult); parents of children with disability at hope house (formed support system); limited acquaintances. Three moms. We stuck together. From school, R’s clubs and band. Church.

**Where did I spend my time?**

**Community**- Relationships very hard, moved a lot, 9 times in 19 years; **joined in outings with MRDD, group home;** church community- I had to know I could trust people before I opened up; **academics, mission trips, music, art, out of doors, YMCA, church, fitness and walks for a cause**

Has her own peer groups of kids with varying needs. Still lives at home and pays rent; goes everywhere she needs to go by bus; **Miracle League;** anywhere I would want to go, I took Anna in her stroller, her wheelchair, or car seat. Enjoyed Museums, sporting events, arts.

**Participation**- Church, School, Fishing, Hiking with Dad; went with me to work during summer vacations; church youth groups, library time with his mom, hikes with his brother; **sports, academics, mission trips, music, art, family routines and vacations;** work and social outings, visits to her father’s and grandparents; out to eat with mom, shopping. She took field trips when she was little, but after I started to home school, it was her and I. Church, debate club, science projects

**What did I spend my time doing?**

**School**- special ed; special ed, therapies; special ed; regular ed, accommodations in driver’s ed, typing; special education, dozens of calls a month. **Spec Ed. Pulled from school after leg was broken there.** School was too overwhelming. I home schooled her and had her do therapies. (OT, PT, and speech). Regular education, APE.
Parent Work- (father) teacher, substitute teacher; farming for first nine years until we felt we needed to get nearer to resources, then wife transitioned to primary provider, administrative assistant and office manager; Ministry, educational ministry, teaching; stay at home mom, father sales and retail; administrative assistant at a large university; odd jobs, child full time job; nurses’ aide. Did not have a career, went back to school when R. was young adult. Nursing.

Recreation – youth group, church; group home and school outings, family outings; youth group, family and work parties; adaptive sports, biking, swimming; on-line gaming, animals, long walks; music and people watching; shopping, movies, eating out, parades, local sports games. Not big on personal involvement, but great spectator of most major sports.

Adult transition- habilitation center, apartment with a transition aide through voc rehab; large group home with 6 other adults, weekends at home with us; classes, supported living, part time structured work; College, work, coaching, having a family; has a job as a vet tech. Lives at home independently in own apartment, pays rent; made at 21. Participates in shelter tasks, some work, some social. Group home. Group home, home, and respite depending on her health. Business degree, got married, no kids.

Actions I have taken or wanted to take, having to do with what I wrote: Trying to find work. We moved frequently for “work”, staying 1-3 years. This started us with home schooling and help from local specialists who helped us through local school systems. Our family shared responsibilities. I entrusted our son to our church youth leaders too as he loved being part of that group. Tried respite care, my girls did not like this, essential at times, limited visits; I was always adapting to change, lack of change. I was trying to meet the needs of the whole family. S. was central, but I had the marriage to think of, the girls, church, work, and all their business. I loved S. My experiences with her convince me that there are dimensions that are different when your child lives outside normal. Her abilities were ones new to all of us. Her language. We really used a lot of friends and family to problem solve what to do. When my husband left, I blamed it on S. at first, but time showed that J would probably have left anyway. He had his own issues. He and S. have developed their own relationships now that she is older and I had to let that happen. I had to learn to advocate and also as S. got older to know when she could speak for her self. I had to protect but protect less. I had to honor S. and her unique inclinations. I also had to support paths and expectations that would let her succeed in being an adult, so she had to deal with work issues. This took finding a work site that would work with her as she is. Back to school. Want to have my own life. My life goal is to research daughter’s diagnosis and what to do. Research assistant. Serves on board for MRDD. Thinks about opening day program for children with disability who cannot work mainstream. I think that I want to help kids like her. I work at a center with respite care and love those kids. I learned to stand on my own two feet. I am truly an advocate and have researched everything about his condition. (Myotonic dystrophy)

What worked? Our family shared responsibilities, helping our son when each of us needed to. The girls, one older and one younger needed to spend time with same age peers, so I often took the responsibility of doing everything so they could have normal
experiences. As our son got older, my husband adjusted; and was able to take him fishing or camping. I entrusted our son to our church youth leaders too as he loved being part of that group. **Office staff loved S. Accepted her, welcomed her there;** St. somewhat changed our family dynamics. We all did one on one with St. – his brother, D., his mom, his grandmothers, even his teacher, who we had to our home often. I had my close circles, but he was not part of them. It was like we all took care of our selves. And we all took care of each other. We were committed and close to each other. But we didn’t move in units. It just worked better that way. I decided that my whole life would be mobile enough to adjust to St’s needs as they changed. I changed with him. So did my map. So did St.’s map. We just followed the good advice that came in and tried to live healthy and happy. It was a journey for us. The map would have been fun to keep from the beginning. It had a lot of zigs and zags. **Our world was kind to us. Those who said rude or irrelevant things were in the minority.** We had a bad experience with the medical professionals. They really just seemed to create more problems than solutions. I don’t really blame them, but S. had problems that lasted her whole life from a botched surgery and a staph infection she got in the hospital. Anyway, we found those places where we could feel both at home and challenged to grow as individuals and family. You figure it out. Then everything changes. We had our people and places we went to and counted on. I would say that we quit trying to change S. Even though I want her to want to have a more involved life in our town, I have to let her be an adult. She is in charge of S. except for curfews since she lives here. **School transportation was awful, always stressful.** Special services in school were very inconsistent and sometimes incompetent. Medical team was severe at times, non-accepting of and discrediting toward parental stressors. She was my angel. R. was very successful, has his own family, and makes me happy every day. Was quiet, sweet, fun, funny, and shy, patient, observant. The world is better because helps people stop and smell the roses. We developed out of tragedies. We found hope in each other.

**What didn’t work?** Finances were very hard, marriage struggled at times, having a sick husband and sick child on; **My husband could not manage stress.** He quit being a provider for us when S was 9. Routines were tough and I couldn’t do everything every day. Respite care helped but the girls did not like it, so we stopped. The girls needed our home to feel like our home; did not do well in noisy or demanding settings – preferred to read and have on-line friends; **We outpaced therapists and doctors after she became a teen, except when she was really sick.** In retrospect, I’m not sure surgery was a good idea. It definitely just added pain, infections, and different problems. Structures of school and work without negotiations are impossible. S. can’t work with anyone or any job that doesn’t allow for open communication and mutual effort. My work also has to accommodate. My marriage fell apart. Our issues were many but goals for our daughter were central. **Anna’s father could not handle her disability at all.** Did drugs. Left us. My own mom was not warm or demonstrative. She did the best she could but I always felt alone with Anna. My father was never known to me. **We home schooled.** Anna got lost in the system. Tensions in family discussions about whether my son should have kids. Really? The docs went more with textbook definitions than my son’s progress who was sitting in front of them. For some reason, the sibs never connected. I think it was more about different fathers than the disability.

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**Participant Profiles**

**Family One: Rebecca and Tyson, son Josh.** Both parents were in their forties currently and had their child when the mother was 23 and the father 24. The father was the breadwinner, a sales professional with a large software firm with income reported as a bit over 100,000 annually, but this was not the case when their son was growing up. They reportedly moved often, 9 times in 19 years. The mother reports that she became a stay at home mom by choice: she believed that Josh’s needs were significant enough that she needed to prioritize being there for him. And, though finances were a challenge at different times, they could afford it. Josh was one of three children, one older and one younger sister. The mother describes a familiarity with tragedy and loss that started with loss of her brother and father and then a tumultuous marriage, with job losses, moves, and challenges. Josh had a number of frightening disability related surgeries. Over time, their family became stronger. The father ended up with chronic lung disease, though, strengthening the father son relationship, as they related to each other more than to others in the family.

Josh was…a reticent, sincere, and committed child who worked hard to succeed at school. The way his mind worked created holes in his success. He had a quirky sense of humor, probably because he was prone to interpret the world literally, missing its subtleties. He valued his social groups, especially his church youth group. He also loved the outdoors, camping with his father. He often became impatient with his left sided weakness and could get quite down. He liked his vocational experiences and had dreams of college or specialized training. He had a hard time staying motivated in therapy because nothing stuck, but found new things of interest, like an e-stim trial with his left
hand. He lives in an assisted living apartment, but *likes to spend weekends* at home. He lived with left hemiparesis.

**Family Two: Ken and Susie, daughter Steffie.** Both parents were in their sixties at the time of the interview, and were 32 (mother) and 33 when their child Steffie was born. They described themselves as *farmers* until farming *became impossible* due to a lack of resources and supports. Still, the *farm ethic* remained a part of their family *identity*, even after they had had to move to the city and developed a life there. In this family, the wife transitioned into the *role of bread winner* after their child’s first 9 years on the farm. Their income grew progressively once the mother’s career in insurance took off and together with her husband’s part time work, was enough to stay *above water*. There were two younger sisters in addition to Steffie, who grew up with her and *included her* in everything. Church and faith were *very integral* part of family life. Trusting in *God* enhanced their coping strategies, *cohesive* world view and *like-minded* support system. The school team was also *family to Steffie*. They were *so close to her* and *so helpful* that her transition to adulthood seemed *unbearable*, having included the severance of their roles.

Steffie was… an *old soul* from her earliest moments. She entered life under *duress* and *seemed fragile* off and on into adulthood. She was *challenged visually* and *in all her arms and legs*. She was *beloved* by everyone in the family, *especially her younger sisters* who made *loving on her* part of their daily routine. She would have moments when she could not seem to calm herself, but the family *learned to handle her* in ways that *let her relax*. She enjoyed going to school, work, and social outings of our family. She struggled *getting enough nutrition* and eventually got a PEG tube. This *brought her*
new levels of energy and enjoyment. Wherever she went, her influence was positive. She exuded strength, peace, and love. She was dependent but never demanding. As she turned 24, she transitioned into long term care near to the family home. She comes home almost every Sunday and on holidays. Her sisters have families of their own now, but they are still very close.

Family Three: Carlos and Tori, son Stephen. Both parents were in their mid-fifties and had their second son, Stephen, when the mother and father were 29 and 28, respectively. Prior to their second son’s birth, Carlos was a minister. His own family worried that he’d never find his soulmate, because he was single until his late twenties, but then he found Tori. Several years after their son first displayed early childhood physical and behavioral issues, he left the ministry as he began to identify with his son and with the role of father more than his role as pastor. Vocationally, he switched to teaching. The father answered all study questions, written and oral. As Stephen matured, Tori found that she shared certain attributes with him, attributes associated with sensory integration problems. This was affirming for her and she developed a close relationship with Stephen. Carlos states that he related better with their older son, but after leaving the ministry, he tried to study Stephen and learn what made him tick. The family’s financial status was modest and was generally under 50,000/year, but the family always found a way to make do. The older brother of the family had a lot of responsibility with Josh that Carlos regretted as he looked back on this.

Stephen was… a child that did not enjoy being held or hugged, but he loved being near his parents, often backing up to them and staying right next to them…He was comfortable in the family home, but anywhere else, he was always easily rattled. He
often lost it, meaning his sense of well-being and his composure. He did not enjoy school or church and his behaviors were extreme, often hitting himself, shaking his head, or pulling hard on his ears. Once the family learned how to help him with self-regulation (and his sensory diet), his coping improved. He was quite bright and especially good at organizing things. He could write reports that were perfect. He learned to tell jokes by putting together details the rest of his peers and family missed. He loved to outsmart us when playing board games, on-line games, and even hide and seek. He completed high school at 22 and went into a group home. He has learned to express his feelings to them and us. He still struggles with balance and coordination, even with articulating his words when he talks, but he seems more content now that he has some independence. He enjoys coming home for special events.

**Family Four: Jamie and Molly, daughter Sari.** Sari’s mom and dad were 59 and 67 and had their daughter, Sari, they were 31 and 39, respectively. The father was the provider, working in retail sales, most often in management. Both mother and father answered interview questions, with the mother providing the written summary. The family had three children, the middle which was Sari. Their financial status was modest and was generally just over 50,000/year. Church and education were listed as highly important. Family dinners and extended family at holidays were key parts of family identity. The family did not use the word disability and rarely talked about Sari’s condition, cerebral palsy. Therapies were part of weekly routines during grade school, but by junior high school, mainstream sports and activities were encouraged. Sari was 28, living away from home with two young children, married and working part-time as an athletic trainer.
Sari was…shy and soft spoken. Her confidence was easily shaken by cuts and scrapes. She learned to walk late around age 30 months after many falls. She called herself accident prone as a teenager. As a child, the family said she was always tripping and falling, dropping and breaking things, poorly controlling her bladder, and getting nervous, feeling like she could not think or breathe. She had a wide range of things she liked to do: swimming, softball, basketball, bowling, cycling, poetry, math, animals, and art. She struggled with reading, skating, tripping, gymnastics, dance, skipping, balancing, and using her right hand. She loved to joke and read comics. She and her siblings would act, sing, and do skits impromptu when they were growing up. As a young woman, Sari took an interest in exercise and athletic training. Though college was challenging, she earned a degree in athletic training, got married, and bought a home with her husband.

**Family Five: Patsy, daughter Mara.** Patsy was in her mid-fifties and developing her social life with a significant other. She was 27 at the birth of her daughter, Mara, who was an only child. Mara was 25 and living in assisted living.

Mara’s family was a single parent family from the time Mara was a toddler, during which time the mother and father were divorced. Patsy, the mother, describes herself as a working mother who has made secretarial skills work for her. She has stayed in one job for over 20 years and become indispensable. That gave her job security. She maintained a range of salary from 35-50,000/year throughout that time and has child support from her ex-husband who is an educator. Mara’s father stays in touch with his adult daughter far better than he did with she was young. Pasty describes the support of her extended family as intensely helpful. She doesn’t know what she would do without
them. Mara was….a self-assured child with a penchant for reading which she did at the age of two. She was clumsy and had low tone in her extremities. She reportedly often had injuries because she twisted an ankle or wrist. Besides reading, she loved technology. From the first time she held a remote, she was happy. She has continued to love movies, games, and music online into adulthood. She was always very literal and showed little emotion in her social interactions, but has developed long-term friendships in spite of that. She enjoys animals and works as a Vet tech for a local veterinarian and volunteers at a wild life rehabilitation shelter. She has successfully taken classes at a technical college to help her at her job, and seems to enjoy the challenge.

**Family Six: Carli, daughter Layla.** Layla’s mom Carli was a single mom with a strong extended family support system, big momma and granddaddy, both of whom adored their only grandchild Layla. At the time of the interview, Carli was days away from turning 50. Layla was born when she was 29 and was currently 21. Family income was under $25,000 and support was provided through extended family and waivers. Emotional and physical supports were also provided by a local support group. Interest in her child’s diagnosis led her to start college once Layla completed school. She stated her interest was in research of childhood diagnosis such as Rett Syndrome. Layla was Carli’s one and only. She was diagnosed at age 3. Her transition to adulthood was on-going, and both mother and daughter were adjusting to the changes of Layla moving out.

Layla was…a funny child with a contagious smile at first. Her mom recalls living for her giggle. She had her favorite words and favorite people. Grandpappy was both. Layla was less social with other children than she was with adults and her own family. She had the nickname of Tong Tong and loved to play silly games including burping
contests. She was described as a very persistent child who would try and try to be independent. From the time she was a little baby, Carli saw her determination. Layla had had a favorite teacher in school that she connected with. Carli thought that kept her engaged in school. During her grade school years, however, she had her leg broken during a transfer or re-positioning in her school and never went back. Carli home schooled and arranged therapies. Layla became unable to speak after grade school, but she continued to enjoy family, even though her emotionality and expressiveness had waned. When Carli watched Layla participate in burping contests with a friend of hers, she believed that it demonstrated her underlying spunk.

**Family Seven: Nina and Bradley, daughter Jocelyn.** Nina and Bradley were currently in their late fifties and were both thirty at birth of their first child, Jocelyn who was diagnosed with Rett syndrome. They also had a son, born several years later. The marriage was described as a significant source of support with other supports being very few and far between. Extended family was near during Jocelyn’s youth, but as the grandparents aged, they were able to do less. Nina is a nurse, who works with disabled adults, a degree she pursued and attained after Jocie had reached adulthood. She observes that staying busy is not optional, but rather a necessity. She prides herself for her involvement in Rett Syndrome support groups and disability advocacy. Her husband Bradley is a businessman. Together as a couple, they make nearly 100,000. Jocelyn finished high school through a special education track. She lives at home, but has regular respite care and daily programming, allowing both parents to work. Nina describes herself as a disability advocate. The family still takes yearly family vacations as part of their family routine.
Jocelyn was... ornery and active during her toddlerhood and grade school years. She had a high level of energy and an inquisitive nature which she explored by getting into everything. As she got older, her behaviors began to change, as is common in children with Rett syndrome. Her withdrawal was subtle at first, but proved persistent. She was always happiest when around her family and she loved bright places. Her mood was also better when she had a routine. She loved to eat chocolate. As she got older and began to show more autistic tendencies, the family made necessary adjustments, studying her condition and adapting their expectations and skills. Jess recently turned 28 years old. She is in a wheelchair full time, but still attempts to interact.

**Family Eight: Christina, daughter Anna.** Christina is a 39 year old nurse. Christina was 19 when she had Anna, who was 20. Her move to a group home when she reached adulthood was described as exceedingly heartbreaking as the two of them were very close. Christina was a single mom. Soon after Anna’s diagnosis, her husband realized that their child would not be ok. She would not be a typically developing child. He could not handle that, did drugs to cope, and eventually walked away from both of them, never getting to know his child. Christina describes her mom as emotionally and physically limited in her support both with Anna and her as Anna was growing up. Her mother reportedly was very angry toward God that Anna was disabled. She did the best she could was Christina’s summary. Thus, Christina and Anna quickly became a team, adding to the team with early interventionists. At school age, Anna’s school began to struggle with meeting her needs. At that time, Christina opted to home school and provide therapies. Their income was through Christina’s nursing practice. Her salary was under 50,000/year.
Anna was... a fighter who faced a very challenging medical condition that greatly weakened her heart. Through her tenacity, she impressed others with her great patience, gentleness, and inner fortitude. She loved being near her mom and accompanied her at work, on outings, and homeschooling. She was described as a child with a beautiful kind spirit. She was wheelchair dependent for her entire childhood and had spastic quadriparesis due to static encephalopathy. Her communication was largely through learned vocalizations and eye expressions. She never complained about anything according to her mother.

**Family Nine: Dee Dee, son Roger.** Dee Dee was 18 when she got married. By 19, she was pregnant with her first son. By the time her second son was born, she and her husband were settled in a small apartment, several miles from her extended family. Her third son was born shortly after. He was diagnosed with Down syndrome as an infant.

Roger, her son with Down syndrome, was involved in therapies at an early age, later continuing with home based early intervention. The entire family and two older brothers were described as very close, a family that did everything together. She described Roger as a sweet son, one whom they treated as entirely normal. Roger went to regular education classes at school and had a tutor. He was a member of the band. He participated in church, doing readings and ushering. He also participated in Special Olympics. Family included him in their extended functions, weddings, reunions, outings, and vacations. He was also employed by various businesses, including the movie theater, grocery store, and a video store, each of which he worked on an as needed basis.

He enjoyed school and was known as a joiner, a good sport, and a willing manager of school sports teams, providing assistance on the bench. He is now 27 and
lives semi-independent. He is still very involved in family and community and works on keeping his weight down and fitness up so that he can play sports. He loves being an uncle to several nieces and nephews.
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Professional Presentations

School based Physical Therapists Perceptions of Practice, poster presentation, AACPDM fall annual conference, Milwaukee, WI, 2013

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Grants/Awards
Ohio State University, SMA clinic provision and wheelchair clinic, 1998-2003

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Ohio State University Neuromuscular research division, seating consultant, Columbus, OH
ALS Medical Advisory Board, Acting president, Canton, OH
ALS Care Project, Education, Canton, OH

North Canton Christian Education Committee, 2003-2011

Early Education Board Associate director, 2009-2011
University Program Assessment Committee, representative, subcommittee, 2008-2011

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