MEANING MAKING AMONG FAMILIES OF

INDIVIDUALS WITH INTELLECTUAL AND

DEVELOPMENTAL DISABILITIES: COPING WITH

TRANSITIONS ACROSS THE LIFESPAN

By

SAMANTHA JO JOHNSON

Bachelor of Science in Human Development & Family Science

Oklahoma State University

Stillwater, Oklahoma

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Thesis Approved:

Jennifer Jones

Thesis Adviser

Kami Gallus

Carolyn Henry

Name: SAMANTHA JOHNSON

Date of Degree: JULY, 2017

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Abstract: Families of individual with intellectual and developmental disabilities (IDD)
experience many stressors associated with transitions across the lifespan. One
way to explore how families adapt to transitions is to explore meaning making
surrounding transitions. The current study utilized the phenomological method
and the process of retroduction analysis to understand how families make
meaning over time within the specific context of life long transitions unique to
individuals with IDD and their families. The family resilience model (FRM)
(Henry, Morris, & Harrist, 2015) was used as the lens to review the data for
themes surrounding family meaning making and an inductive analysis was
allowed for new themes to emerge. Using a sample of 23 family members from
19 qualitative interviews, the research question examined included: how do
family members of relatives with IDD make meaning over a lifetime of risk and
transition (e.g., initial diagnosis, institutionalization, and deinstitutionalization.
Family members shared eight themes, six of which fit within the FRM.

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CHAPTER I

INTRODUCTION

Over the past century, families of individuals with intellectual and developmental

disability (IDD) have experienced significant transitions. For many families, transitions began

with initial diagnosis of their relative with IDD, and then moved to institutionalization of the

family member, followed by the trend of deinstitutionalization (Berry, 1995). While individuals

with IDD transitioned out of institutions and into community living, families still continue to be

engaged in the caregiving process (Jones & Gallus, 2016). Although families' involvement with

the individual with IDD is life long, policies and professionals have shaped many aspects of

families and individual with IDD lives.

Beginning in the first half of the twentieth century, decisions in the United States were influenced

by a medical model and parents were often told by practitioners to place their relative with an

IDD in an institution (Smith, Noll, & Wehmeyer, 2013). Due to lack of services and supports in

the community, families often placed their relative with an IDD in institutions from a very young

age (Berry, 1995). During the latter half of the twentieth century, parents began to open training

centers, and the Education for All Handicapped Children Act of 1975 (now known as Individuals

with Disabilities Education Act) mandated schools to provide services to children with disabilities

(EHA, 1975). With a growing number of services in the community, lack of adequate care in

institutions, and negative attention in the media, families, professionals and policy makers began

to look for other alternatives of care for individuals with disabilities (Smith et al., 2013). Deinstitutionalization and the introduction to community living began nearly 50 years ago in the United States (Jones & Gallus, 2016) and many states have followed the national trend of downsizing, or closing all together, their state run institutions (Berry, 1995; Hewitt, Nord, Bogenschutz, & Reinke, 2013). Although deinstitutionalization and a shift of receiving services in the community is considered best practice for individuals with IDD, deinstitutionalization is often met with opposition from many family members (Tabatabainia, 2003)

Many families of individuals with IDD experienced institutionalization and deinstitutionalization in their lifetimes, which present unique significant risks and transitions to individuals with IDD and their family members over time and throughout the life course. With the field of IDD continuing to move toward strengths based approach when researching families of individuals with IDD, the family resilience perspective, which has grown out of family stress and coping theories, is used to understand how families adapted and made meaning throughout their life time of transitions of their family member with IDD (Henry, Morris, & Harrist, 2015). Although research has been conducted to examine family resilience and meaning making specific to autism (Bayat, 2007) and how families make meaning of a relatives' chronic disability in early childhood (Patterson, 1994), little research has been done to understand how families make meaning over a lifetime of transitions. Understanding families' experiences, how they make meaning and successfully adapt to transitions can inform research and families of individuals with IDD on how to better equip themselves through other transitions moving forward throughout their lifetime. To further explore the phenomena, the research question addressed is how do families of relatives with intellectual disability make meaning over a lifetime of risk and transitions (e.g., initial diagnosis, institutionalization, and deinstitutionalization)?

CHAPTER II

REVIEW OF LITERATURE

Historical Context and Meaning Making Overview

This literature review broadly explores the historical context and events surrounding initial diagnoses, institutionalization and deinstitutionalization of individuals with intellectual and developmental disabilities and their families. Moreover, this literature review will include an overview of existing literature of family stress, coping, and resilience theories used to understand how families adapt to stressful transitions over time, which are considered a significant risk to the family members. The family resilience model (FRM), which grew out of the works of family stress theory and individual resilience theory, will be reviewed to provide an overview in the literature on adaptation and how this could have positive or negative impacts on the family, which will assist in understanding family members meaning making over time.

The number of individuals with IDD is increasing due to longer life expectancies because of advanced medical practices and the number of aging baby boomers (Factor, Heller, & Janicki, 2012; Heller, Caldwell, & Factor, 2007). In the United States, approximately 4.8 million individuals have an intellectual disability (Reynolds, Gotto, Agosta, Arnold, & Fay, 2015), which has an exponential impact on American families and their functioning. Previous research has focused on a deficit model to examine families of relatives with IDD. The field of intellectual disability is now moving towards a strengths based approach to study people with disabilities and

their families (Wehmeyer, 2013). Thus, by looking at family meaning making we can understand how family members of individuals with IDD make meaning, cope and adapt to stressors and the transitions associated with initial diagnosis, institutionalization and deinstitutionalization over time.

Context of Initial Diagnosis

How society has viewed individuals with IDD has experienced major shifts over the past century. The way in which families react to disability diagnosis is attributed to the socio-historical context of the time period in which the individual with IDD was born (Ferguson, 2002). The larger social attitude contributes to the families' perspective and how the family perceives and attributes the diagnosis to their family context. With this in mind, unique stressors occur throughout the lifespan for parents of individuals with IDD. For some, this stress starts with the disability diagnosis (Cuzzorcea, Murdaca, Costa, Filippello, & Larcan, 2016). Bingham, Correa, and Huber (2012) discussed how diagnosis of the child's disability is a stressful event due to the managing of emotions, introduction to a new language, and certain requirements and decisions that need to be made. Additionally, the time of the diagnosis could be a stressful event, due to whether the child is diagnosed before birth, after birth, or years later (Bingham et al., 2012). Because medical professionals were unsupportive and often lacked empathy, mothers' coping strategies were negatively influenced (Poehlmann, Clements, Abbeduto, & Farsad, 2005). Although research has moved toward a more strength-based approach for family members of relatives with disability, Ferguson (2002) states literature has yet to move to emphasize positive family adaptation.

Long-term impact on families. Adapting to the relatives disability and initial diagnosis is complex and often a life-long experience for parents and siblings (Poehlmann et al., 2005; Seltzer & Teller, 1997). The way in which families react to their relatives' disability varies throughout the lifetime of the individual with IDD, with positive experiences often coinciding with negative experiences (Glidden, 2012; Hastings & Taunt, 2002). Some parents cope well and

adapt to the family members' disability, while others have a more difficult time due to the demands of care, context of life circumstances and physical and psychological demands (Seltzer & Heller, 1997). Poehlmann et al., (2005) conducted interviews with 21 mothers, 10 of which had a child with Down syndrome and 11 of which had a child with fragile X syndrome. The children ranged from 11 to 23 years of age. After conducting qualitative interviews with each mother, Poehlmann et al. (2005) concluded four themes emerged within families when focusing on the child's birth, diagnosis and development: (a) the importance of context in the coping process, (b) mothers variability in emotional reaction to the child's diagnosis and developmental concerns, (c) specific strategies mothers used to cope with the child's diagnosis, and (d) how families emotional reactions to child's diagnosis evolved over time. Within the theme of mother's variability in emotional reaction to the child's diagnosis and developmental concerns, subthemes emerged which included uncertainty, prolonged distress, a mourning process, as well as, feelings of relief and hope. Parents experience many different transitions over their relatives' life course, and the context in which the families were informed of the disability diagnosis impacts how their families transition and adapt to the initial diagnosis and support thereafter. Prior to the 1930s and 1940s, before parent groups were started, families that had children with IDD were alone and often left with options provided by professionals (Wehmeyer & Schalock, 2013). Little was known about what caused IDD or the conditions, and there were no supports in the community for families with the development and care of their loved one (Wehmeyer & Schalock, 2013). There was not a positive perception of disability in the public during this time period, so families often lacked support from others and faced stigma from society.

Context of Institutionalization

During the late nineteenth century to mid-twentieth century, institutionalization was considered the norm for individuals with IDD (Smith et al., 2013). The number of people institutionalized in the US grew to 140,000 in the 1950s (Smith et al., 2013). IDD was defined by the medical field, and medical professionals were the people parents looked to for advice on their

child with a disability. Physicians made the decisions regarding people with IDD, not the parents (Wehmeyer, Bersani, & Gagne, 2000). Societal views of people with IDD as feebleminded and mentally deficient during this time period added to the view that people with IDD should be sent to institutions to protect them, as well as society (Noll, Smith, & Wehmeyer, 2013; Wehmeyer et al., 2000). Many of today's aging caregivers were having children during this time period, and families were told by professionals that institutionalization was the best option for their child (Noll et al., 2013). Because there were a lack of supports and services in the community for families to keep their child at home, professionals told families that institutionalization was the best and often only option (Smith et al., 2013). There were many reasons families may have chosen to institutionalize their relative. In a study conducted by Spreat, Telles, Conroy, Feinstein, and Colombatto (1987), 110 parents and siblings of individuals residing in state run institutions were given a questionnaire and asked what factors were associated with decisions to institutionalize their relative. They reported difficulty of physical care, advice from clergy, physician, or other professional, need for non-medical service, protection from harm and managing behavior as factors that influenced institutionalization (Spreat et al., 1987). Tabatabainia (2003) conducted a qualitative study with 22 family members with a relative with IDD living in an institution examining their perspectives and attitudes about institutionalization and deinstitutionalization. When asked how they came to the decision to institutionalize their relative, family members cited adverse impacts on the family's own life, relatives' lives and impacts on the community as reasons to do so (Tabatabainia, 2003).

In the mid-twentieth century, a shift occurred in which parents began to challenge and question professionals about what practices were best for their children (Wehmeyer & Schalock, 2013). As institutions began to deteriorate and were gaining increased negative exposure by the media, parents began to demand more control and a say in the lives of their relative with IDD (Wehmeyer & Schalock, 2013). This led to a shift from the professional movement to the parent

movement. Through the 1950s to the 1980s, parents began to keep their relatives at home due to the decreased nature of institutions, and increase in legislation and social policies which added more supports in the community (Blacher, Baker, & Feinfield, 1999; Noll et al., 2013). The lack of adequate living conditions in institutions and mistreatment of residents of these institutions led to the deinstitutionalization movement. This was not met without opposition, as family members of relatives with IDD had concerns about finding appropriate places to live that would sustain their life style, safety and respect for their relative (Tabatabainia, 2003). Although family members were often advised to place their relative with IDD in an institution, this does not mean it was an easy process or experience for the family. The act of placing the relative in an institution can have long-term effects on parents and be a traumatic experience for families (Blacher et al., 1999; Slobody & Scanlan, 1959).

Long-term impact on families. Society advocated for institutional placement through national policies and funding, and gave the perception to parents that this is how they should cope with their child (Berry, 1995). Because families could not get the services needed, such as attendance to public schools and sufficient health care options, families turned to institutionalization to fulfill their needs. While making the decision to institutionalize their family member and after institutionalization, families often felt guilt, separation anxiety, and sorrow (Conroy, 1985). Families expressed feelings of ambiguous loss and an unclear form of physical loss after placing their loved one in an institution, but still described their emotional presence (Richardson, 2016). Following the transition of their relative with IDD to an institution, parents and siblings experienced various emotions of grief and resentment that occurred and different points in the transition and co-occurred with numerous emotions at the same time (Richardson, 2016).

From the late 1800s until the 1960s,the vast majority of families placed their relatives in institutions as this was strongly encouraged by professionals and resources to remain in the

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community were not available (Smith et al., 2013). However, some families experienced conflicting feelings of the relative's well-being. Conroy (1985) describes how families attempted to reduce this cognitive dissonance by choosing to believe that their family member was unable to obtain goals or development outside of the institution, building their own perception around the institutions quality, rejecting new ideas for placement, and forming an understanding that this is what their relative needs medically. Placing a relative with IDD outside of the home was a difficult decision that left long-term impact on family members, which caused similar feelings to resurface during the process of deinstitutionalization (Conroy, 1985).

Context of Deinstitutionalization

With the national trend of deinstitutionalization, individuals with IDD are moving out of large state run institutions and into community living settings (Hewitt et al., 2013). This movement began nearly 50 years ago, and is a continuing issue for families of individuals with IDD and professionals (Jones & Gallus, 2016). Between 1977 and 2012 the number of individuals living in institutions has drastically decreased by 80% and a primary force in the change from institutions to community living is the freeing of funds of the Medicaid Home and Community-Based Service (HCBS) (Hewitt et al., 2013). This move from institutionalized care to more individualized care in the communities has shifted the responsibilities to Direct Support Professionals (DSPs) and families of relatives with IDD to take on greater roles such as providing greater medical support, behavioral interventions, and community participation (McLaughlin, Sedlezky, Marquand, & Hewitt, 2015). Relatives with IDD are living longer, leading to life-long caregiving of parents and siblings (Heller et al., 2007). Family members of relatives with IDD are called upon to assume guardianship and overseer of care for their relatives, something some families have not done for 30 or more years. Previous research clearly indicates that although relatives with IDD may not live in the family home, families are still engaged in the caregiving process (Jones & Gallus, 2016).

Sibling of relatives with IDD also are taking on a greater role in providing care for their relatives with IDD due to aging parents and because they are the longest lasting relationship that the person with IDD will have (Hewitt et al., 2013; Holl & Morano, 2014; Reynolds et al., 2015). Some siblings reported their role shifting to more parent like responsibilities when their relative transitioned to living in the community (Richardson, 2016). When taking on the role of a caregiver for relatives with IDD, families report positive and negative effects on relationships, support, leisure, and personal satisfaction in families who care for an adult relative with IDD (Yoong & Koritsas, 2012). While there is satisfaction in the role, life-long caregiving creates unique stressors for families of relatives with IDD. Families experience numerous ambiguous emotional experiences and stressors simultaneously with each process being interrelated with others across multiple transition events (Richardson, 2016).

Long-term impact on families. Deinstitutionalization presents many concerns to family members of people with IDD. These concerns often mirror previous concerns of institutionalization. Some of the major challenges include the desire to find and sustain a safe, sound, respectful, caring and permanent residential place for their family member with IDD (Tabatabainia, 2003). Researchers also revealed fears family members have such as training and education for working with their relative, disruption of family life, physical care and protection, appropriate living situations, recreation and companionship and problems in the community (Spreat et al., 1987). Families become uncertain about their future for themselves and their family members. Larson and Lakin (1991) reported 74.2% of family members were against their relative with IDD moving into the community. Although many family members were originally opposed to deinstitutionalization, studies show the families move to satisfaction with community placement over time (Tabatabainia, 2003). This does not mean families do not experience stress after community placement (Larson & Lakin, 1991). Certain long-term stressors (e.g., disability diagnosis, finances, health concerns) are unique to families who have relatives with IDD (Weiss, 2002) and will continue throughout their relative's lifetime.

Families' wants and needs are central during the process of deinstitutionalization. Jones and Gallus (2016) interviewed parents and siblings of individuals with IDD who were in the process of a state mandated deinstitutionalization. Following the trend of deinstitutionalization, Jones and Gallus (2016) found that most family members eventually moved from opposition to satisfaction. However, regardless of satisfaction or opposition, families shared six themes emerged across family members' narratives regarding what they desired and valued during the deinstitutionalization process. These themes included (a) respect our relative's history, (b) collaborate: make us feel like we are a part of the process, (c) provide quality care, (d) provide consistent care (e) include my relative in the community, and (f) remember we are family. Although the themes were found within the context of deinstitutionalization, families experience additional and unique stressors and transitions associated with their relative with ID (e.g., financial stress, shifts in long-term services and supports). Understanding how families make meaning amidst these stressors and events can inform research, policy and practice aimed at improving family well-being.

Family Resilience

Understanding how families make meaning of unique stressors associated with developmental disabilities hold potential to guide professionals and researchers in identifying the supports and services families need across their lifespan (e.g., initial diagnosis, institutionalization, deinstitutionalization, financial stress). To guide this understanding, family resilience is examined through the perspectives of family stress and coping. Families of individuals with IDD experience significant risk throughout the lifetime aspects of caregiving for their loved one late into adulthood, whether it is making financial decisions, or through requesting specific services for their family member. Despite feelings of stress, families' knowledge of certain factors, such as coping styles or adaptation, promote resilience when facing certain significant risk and major adversities. When faced with significant risk, understanding how families are resilient and make meaning could provide insight into better understanding the

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adaptation process of families through times of transitions. Resilience is defined as doing well in the face of adversity and significant risk (Patterson, 2002). Evidence for resilience is based on the outcome after the significant risk and the type of adaptation, such as maladaptation or bonadaptation (McCubbin & Patterson, 1998; Patterson, 2002), which can be moderated by a protective mechanism (Rutter, 1987). Like individual resilience, family resilience is defined as the "processes and outcomes associated with resisting, managing, or restoring family system equilibrium after significant risk occurs" (Henry et al., 2015, p. 24). Protective mechanisms, such as family meaning making, play an important role in how families experience the risk. These mechanisms also reduce the effects of risk and decrease the reaction to the risk, which promotes resilience and adaptation (Rutter, 1987). Families may adapt to a risk in one point in their life, then react differently to the risk during a different part in their life if circumstances have changed (Rutter, 1987). What once was a form of protection for the family, such as resources, process or mechanisms, could now be a vulnerability to the family. When families experience vulnerability, this could cause hardships associated with the risk.

Family meaning systems involve the family worldview, family identities and family shared meanings that arise about specific stressors (Patterson, 2002). Family level meanings are constructed collectively by the family through interactions, experiences, and shared time together (Patterson, 2002). Shared meanings emerge, and families begin to process the risk based on their shared meanings of their experiences (Patterson & Garwick, 1994). Families define the situation based on the families' experiences and redefine them as a part of adapting to the risk (Henry et al., 2015; Patterson & Garwick, 1994). Family identity, a key dimension of family meaning systems, describes the collective family views about who is in the family, the internal boundaries within the family relationships, which roles members take on within the family, and behavior among members (Henry et al., 2015; Patterson & Garwick, 1994). Family identity is important when discussing boundaries and what roles within the family individuals take on when a stressor event happens, such as when a relative is diagnosed with a disability. Family worldview is the

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way members of the family view themselves toward the outside world and how they interpret

their reality. They focus on the assumptions they make about the environments in which they are

surrounded and their beliefs about their family (Patterson & Garwick, 1994). Family worldview

assists in adaptation within the broader ecosystem and has the potential to connect them to

something greater (Henry et al., 2015).

Family Resilience Model

Henry et al. (2015) discuss three waves in which the resilience perspective was formed,

adapted for certain families, and how the perspective can increase its potential through

consistency and application of a new model to provide successful intervention. The family

resilience model (FRM) indicates family resilience occurs when family risk, family protection,

and vulnerability lead to positive, rather than negative interactions and lead to family adaptation

at the family system level (Henry et al., 2015). The FRM encompasses key aspects from

individual and family resilience and systems perspectives to create a multilevel, multisystem

model for research and application (Henry et al., 2015). The four basic elements introduced

(family risk, protection, vulnerability, and adaptation) help capture the complexity of a family's

environment. Family risks include (a) vertical on going stressors (genetic abilities and disabilities,

poverty, family emotional patterns, and religious beliefs and practices), or (b) horizontal stressors

which are disruptions that occur (relative's diagnosis, institutionalization, deinstitutionalization,

economic stress) to family interaction patterns (Henry et al., 2015; McGoldrick & Shibusawa,

2013). These elements of the FRM, together with family situational meaning, interface with

ongoing family systems in key domains of family life, including the family meaning system

(Henry et al., 2015). FAS occur in response to family interactions and the families' response to

stressors (e.g., risk). When a stressor does occur, adaptive family meanings enable families to

approach these stressors and challenges with coherence and hardiness (Henry et al., 2015). In

turn, when a negative family meaning system occurs, the families heighten their risk for negative

outcomes. With this knowledge, it is important to consider family resilience when focusing on

families' adaptation and meaning making to understand and better equip families with tools to create smoother transitions and understanding of significant risk.

Meaning making. Families of an individual with IDD have often been examined in the literature through a deficit model, but in recent years there has been a turn to examine such families with a strengths based approach (Ferguson, 2002). Other ways in which families make meanings of events is through coping and family stress theories (Hill, 1958; Patterson, 2002; Patterson & Garwick, 1994). Families begin to process the stressor events by constructing meanings (Patterson & Garwick, 1994).

Bayat (2007) interviewed 175 parents and biological caregivers of children with autism aged two to 18 to examine factors of family resilience in families of children with autism. Families who were resilient and adapted to the child's disability made positive meanings out of the child's disability and discussed an altered world view to look at life positively. Although families discuss their adaptation and altered views, some of these perspectives by families did not come until years later (Bayat, 2007). Patterson and Garwick (1994) discussed how family meaning could change due to a diagnosis of a chronic illness or disability. As families begin to talk with each other about the situation or stressor, they begin to construct similar meanings around the event, which are family situational meanings. Through this, families reported positive aspects of having a child with intense medical needs, such as the family unit pulling together to manage the stressor, child's warmth and responsiveness, and perseverance of the child (Patterson & Garwick, 1994). How families view themselves is defined as family identity. Having a family member with a chronic illness or disability can alter the way in which a family views their family unit. This could be due to demands of family member and interruption in routine. The families worldview is their orientation to the outside world (Patterson & Garwick, 1994). Families world view can change due to the changes in orientation to the outside world. Families whose communities express positive attitudes and beliefs toward a child with disability adapt and adjust, where as families who encounter negative attitudes struggle with isolation and sense making.

Current Study

Oklahoma began serving individuals with IDD in 1909 with the opening of their first state-run institution. For 70 years, from 1909 until the 1980s, institutionalized care was the primary model used to serve individuals with IDD (Oklahoma Department of Human Services, n.d.). Due to a class action lawsuit brought on by seven parents in Oklahoma (Homeward Bound v. Hissom Memorial Center, 1985), the state was compelled to close the Hissom Memorial Center and provide the Homeward Bound Home and Community Based Services waiver for individuals with IDD to live in the community (Oklahoma Department of Human Services, n.d.). This propelled the deinstitutionalization movement in Oklahoma. In November 2012, Oklahoma Commission for Human Services announced its mandated closure of the two remaining state run institutions Northern Oklahoma Resource Center of Enid (NORCE) and Southern Oklahoma Resource Center (SORC) and charged Developmental Disabilities Services (DDS) with the task of transitioning individuals at NORCE and SORC into the community. Together, the institutions housed 234 individuals and over a two-year time period, individuals were transitioned to communities across Oklahoma (Oklahoma Department of Human Services, 2012). In July of 2015, the last resident was moved from SORC and Oklahoma officially closed its state-run institutions.

The current study builds on the work of Jones and Gallus (2016), which investigated families of individuals with IDD who experienced state mandated deinstitutionalization. In addition to the six common themes families shared regarding deinstitutionalization, Jones and Gallus (2016) discuss the need for developing and implementing models of support for families during times of transitions due to the continued shifts to community inclusion in other contexts (e.g., closure of sheltered workshops). Jones and Gallus (2016) recommended future research, policy and practice address the need for intentional supports for families during times of transitions and be mindful of the difficulty of the process of deinstitutionalization for individuals with IDD, family members and professionals. The authors also encouraged professionals to

develop intentional collaborations and supports with families who are experiencing transitions in combination with proving supports and services to individuals with IDD.

A secondary data analysis completed by Richardson (2016) using the qualitative Grounded Theory methodology examined the same family members unique experiences across their life span to help move toward a transferrable model of supports for families. Richardson (2016) found five common categories of intra and interpersonal processes shared among family members across the lifespan: (a) ambiguous loss, (b) ambiguous roles, (c) ambiguous futures, (d) ambiguous emotions, and (e) ambiguous coping. Clinicians and professional should consider these ambiguous understandings families experience through out their lifetime when working with such families.

With these studies in mind, the current study examined meaning making across the lifespan of families with a relative with IDD. There is little research to understand how families make meaning over time within the specific context of life long transitions unique to individuals with IDD and their families. Although only certain families with relatives with disabilities experience the transitions of institutionalization and deinstitutionalization, every family experiences other types of stressors and transitions (e.g., financial stress, transitions from sheltered workshop to community employment, or attending school to not attending school). Research that explores how families make meaning over a lifetime of stressors (e.g, initial diagnosis, institutionalization, and deinstitutionalization) could also be applicable to other stressful transitions across the life course.

CHAPTER III

METHODOLOGY

Introduction

       The current study is part of a larger two-phase mixed method study, which examined the

impact and experiences of parents and siblings whose relative with intellectual and developmental

disabilities (IDD) transitioned from Northern Oklahoma Resource Center of Enid (NORCE) and

Southern Oklahoma Resource Center (SORC) in Pauls Valley to community living. Phase 1

included a quantitative questionnaire with a sampling frame that included 153 parents and

siblings whose relative recently transitioned from NORCE and SORC. After Phase 1, a subgroup

of participants were invited to participate in Phase 2 of the study that included a qualitative

interview.

       The qualitative interviews from Phase 2 were used in the current study, which is a

secondary data analysis focusing on meaning making of family members of relatives with IDD

and how they use meaning making to adapt to transitions across the lifespan (e.g., initial

diagnosis, institutionalization, and deinstitutionalization). There is little research to understand

how families make meaning over time within the specific context of life long transitions unique

to individuals with IDD and their families. Thus, the phenomenological perspective was used to

analyze the lived experiences of family members about the specific phenomena (Cresswell,

1998). To further explore the phenomena, the research question addressed is (a) how do families

of individuals with intellectual and developmental disability make meaning over a lifetime of risk and transitions (e.g., initial diagnosis, institutionalization, and deinstitutionalization)?

Introduction to Phenomenological Method

The phenomenological method aims to describe the meaning of a phenomenon of individuals lived experiences and seeks to understand the meaning the individual places on the specific experience (Cresswell, 1998). The purpose is to understand the essence and underlying meaning of the experiences that individuals describe. These are then reduced to statements and analyzed for their specific meanings, which are then turned into themes that provide a general description of the experience through the lens of the participants (Cresswell, 1998). Because the goal of this methodology is to understand the meaning of how individuals are experiencing the phenomena, it is important for the researcher to have a framework or perspective that informs and orients the individuals experiences.

Qualitative interviews were used to explore and understand the essence of the specific phenomena of families of individuals with IDD. Because of the unique significant risks experienced by the families of individuals with IDD, the phenomenological method was utilized to understand the meaning families place on the experiences and significant risks through the lens and words of the family members.

Researcher Identity

Discussing researcher identity is critical in qualitative research to reflect on researcher bias and how the researcher orients the interpretations of a study (Cresswell, 1998). I am a second year masters student at Oklahoma State University studying Human Development and Family Science with a specialty in Child and Family Services. Additionally, I have served in a number of roles with individuals with IDD and their families, such as direct care staff at a day center for adults with IDD where I helped individuals to promote independence and choice in their daily lives. I also worked as a research and teaching assistant on projects centering around individuals with IDD who receive state funded services in Oklahoma. Through my studies and experiences, I

hold a theoretical lens of family resilience theory, which grew from the work of family stress theory and individual resilience perspectives. I believe that the general systems, such as policy and communities, impact and play an important role in how families function. The family functions systematically and each individuals interactions impact the family system as a whole. Lastly, I am interested in how policies affect the lives of families' and individuals with IDD and how they cope and make meaning through different lifetime transitions.

Sample and Procedures

   Recruitment. The sampling frame of Phase 1 of the study included 153 parents and siblings whose relative recently transitioned from NORCE and SORC. All parents and siblings were guardians of the relative with IDD at the time of the study. Information was provided for potential participants by Oklahoma Department of Human Services—Developmental Disabilities Services (OKDHS-DDS), and 135 participants were mailed a quantitative questionnaire to complete during Phase 1 of the study. Eighteen parent and sibling guardians were removed from the sampling frame due to living out of state or moving their relative with IDD to a facility outside of Oklahoma. After completion of Phase 1 of the study, a subgroup of parents and siblings were contacted via telephone by trained members of the research team and were invited to partake in Phase 2 of the study, which included a qualitative interview. Research team members explained the purpose of the study and potential participants were given the opportunity to ask any questions related to the study. Once the purpose of the study was explained, the research team invited the parent or sibling to participate in the study and schedule an appointment with the participant.

   Participants. Participants in the current study included parents and siblings whose relative recently transitioned from living in a state-run institution to living in the community. Parents and siblings were given the option to invite others to join them for the interview resulting in a total sample of 23 family members across 19 interviews. All family members in the current study were legal guardians of their relatives with IDD.

The sample was comprised of 43% (*n* = 10) mothers, 26% (*n* = 6) sisters, 13% (*n* = 3) fathers, 13% (*n* = 3) brothers, and 8% (*n* = 1) was a brother-in-law. Of the 23 participants, 21 reported race: 18 identified as Caucasian, two as African-American, and one as Hispanic. Age of the participants ranged from 51 to 85 years (*M* = 65.33, *SD* = 9.01). Highest level of education for participants included 21.7% (*n* = 5) Master's degree or higher, 8.7% (*n* = 2) bachelor's degree, 4.3% (*n* = 1) associate's degree, 30.4% (*n* = 7) some college, 8.7% (*n* = 2) vocational training, 8.7% (*n* = 2) high school diploma, 8.6% (*n* = 2) did not complete high school, and 8.7% (*n* = 2) did not report their level of education. Of the 19 households, 14 reported family income which ranged from $10,000 - $19,000 (*n* = 1) to above $100,000 (*n* = 2) with families reporting a mean and median income range of $50,000 - $59,000. Family members reported demographic information for their relative with IDD. The relatives consisted of 12 males and seven females, and ranged in age from 35 to 70 years old. Participant's relatives' length of time at NORCE or SORC ranged from 11 to 58 years (*M* = 37.63, *SD* = 12.85). Relative's total time living in an institution ranged from 27 to 58 years (*M* = 43.32, *SD* = 7.99). Intellectual disability (ID) was reported for 18 relatives and included moderate ID (*n* = 1), severe ID (*n* = 6) and profound ID (*n* = 11). At the time of the interviews, relative's transition from institutions to Daily Living supports in the community had occurred within one to three years prior. Daily Living Supports includes supervision by staff available 24 hours a day for up to 3 individuals living in a home (OKDHS, 2010).

Table 1

Contextual Information for Family Members (N = 23) and Relatives with Intellectual and Developmental Disabilities (N = 19)

Family Member Pseudonym	Relationship	Family Member Age	Relative Age	Relative Years in Institution	Relative Gender
Matt	Brother	51	55	47 years	Male
Catherine	Sister	56	57	50 years	Male
Andrew	Brother	62	56	47 years	Male
Laura & Keith	Sister, Brother-in-law	62, 56	64	48 years	Male
Julie	Mother	71	41	39 years	Male
Jim & Katie	Father, Mother	61, 61	35	27 years	Female
Rosa	Sister	64	58	51 years	Male
James & Martha	Father, Mother	71, 68	37	32 years	Male
Joseph	Brother	59	61	52 years	Male
Jackie	Mother	72	47	36 years	Female
Holly	Sister	56	46	40 years	Male
Emily	Mother	70	49	41 years	Female
Debbie	Mother	63	44	36 years	Male
Courtney	Mother	85	62	56 years	Male
Brett & Michelle	Father, Mother	80, 77	50	44 years	Female
Amanda	Mother	74	48	45 years	Female
Whitney	Mother	59	42	33 years	Male
Rachel	Sister	54	66	50 years	Female

Interviews

The qualitative interviews were semi-structured and open-ended consisting of 47 questions for parents and 43 questions for siblings. The semi-structured interview guides used in the study (see sample interview questions, Table 2) were piloted with parents and siblings not associated with the study. Each interview was conducted in person by trained graduate and undergraduates and ranged from 36 minutes to 139 minutes. The interviews were audio-recorded, transcribed verbatim by an undergraduate and graduate research team, and checked for accuracy. During the interviews, six family members cried, one of whom requested the audio recorder be turned off for a brief period while she regained her composure. Fourteen of the interviews were conducted in the family member's home, three interviews were conducted at the family member's work place, and two interviews took place at a restaurant of the family member's choice.

Table 2

Sample Qualitative Interview Questions

Questions

Tell me what it was like for your family to learn that [your relative] had a disability.

How do you think [your relative]'s disability influenced/changed your family?

How did your family decide to have [your relative] live at NORCE/SORC?

How has your role in [your loved one]'s life changed now that he/she is in the community?

What are your fears for [your relative] in the future?

What are your hopes for [your relative] in the future?

Qualitative Analysis

The 19 qualitative interviews were analyzed using Colaizzi's (1978) seven-step phenomenological method to ensure trustworthiness and rigor. Wave 1 of the analysis was

completed in June of 2016 and included the completion of Steps 1 and 2 (Acquiring a Sense of Each Transcript and Extracting Significant Statements). The data was coded inductively and I extracted statements on how family members coped and adapted during specific events when specific transitions occurred throughout the relatives with IDD life (e.g., initial diagnosis, institutionalization, deinstitutionalization and other). Before reading and listening to each interview, I read through literature that defined coping, coping styles, and different types of coping (Aspinwall & Taylor, 1997; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Reuman, Mitamura, & Tugade, 2013). I also carefully reviewed different models of coping; 4 Phases of Crisis Development (Caplan, 1994), Family Adjustment and Adaptation Response Model, (Patterson, 2002), and the Double ABCX Model of Family Stress and Adaptation, (McCubbin & Patterson, 1983). Then following Step 1, I read through each interview to gain a better understanding of the participants' experiences. I kept a detailed log of reflective processing after reading each interview. While reading and listening to the interviews simultaneously, I then began coding the interviews for coping. After meeting with my thesis committee and discussing my initial impressions of the data, I narrowed my focus from coping to meaning making. I read through the interviews again and began Step 2 of Colaizzi's method—extracting significant statements. I extracted significant statements from the interviews focusing on meaning making surrounding the relative's disability diagnosis, institutionalization, and deinstitutionalization. My thesis advisor served as my research supervisor given her extensive knowledge in the field of IDD. In order to ensure reliability, my research supervisor carefully reviewed significant statements and agreed that I was capturing the significant statements. I was then instructed to continue coding using the same process for the remaining transcripts.

In January/February of 2017, before beginning Wave 2 of the data analysis, I met with a thesis committee member versed in qualitative analysis to discuss my plan to continue analyzing the interviews. I acknowledged that after becoming immersed in the literature on family

resilience, I viewed the data through a family resilience and family meaning making lens. This led to the use of the Henry et al. (2015) table as a codebook on family meaning making to deductively review the data again for themes that emerged related to family meaning making (i.e., family situational meaning, family identity, family worldview). Because of the inductive and deductive analysis, we decided to move forward with the retroduction process of analysis (Burr, 1973). This allows for the use of family resilience and meaning making as a framework to use during the data analysis, while also allowing new themes to emerge.

In March of 2017, following committee approval, I began Wave 2 of my analysis and organized my extracted significant statements from Wave 1 into the family level meanings using the Henry et al. (2015) table as a codebook (see Table 3). These categories include: family situational meaning-initial diagnosis, family situational meaning-institutionalization, family situational meaning-deinstitutionalization, family identity-initial diagnosis, family identity-institutionalization, family identity-deinstitutionalization, family world view-initial diagnosis, family world view-institutionalization, and family world view-deinstitutionalization. After organizing the significant statements into these nine categories, I continued on to Step 3 of Colaizzi's method, Formulation of Meanings. I read through each individual extracted significant statement and formulated 59 general restatements or meanings from each statement across the nine categories (see Table 4 in appendix). A colleague with experience in qualitative research and knowledge in the field of IDD who is not involved in the larger study served as my external auditor. During Step 3, my external auditor reviewed all extracted significant statements and my categorization of statements and formulation of meanings. My external auditor provided detailed suggestions on the extracted statements and formulation of meanings, such as discussing meanings she thought could be turned into overarching themes, meanings that could be collapsed together, and redirection of significant statements that could fit under different meanings. I reviewed the suggestions together with my research advisor and made revisions as needed.

Table 3

Family Meanings Codebook

Term	Definition	Reference(s)
Family situational meaning	family definitions of situations based on family experiences and interpretations; families often redefine as part of resilience process; constructing meanings about the stressor event of the pile-up of demands, as well as their capabilities as a family to manage demands	Hill, 1958; Patterson & Garwick, 1994
Family identity	families perceptions of their uniqueness within their ecosystems (e.g., , family themes and legacies); how families view themselves	Patterson & Garwick, 1994
Family world view	abstract beliefs of the world and how things work in families and ecosystems; often reconciled with family responses to stressors and the pile-up as part of resilience; family members' orientation toward the world outside the family; how they interpret reality, core assumptions of environment, existential beliefs such as families purpose in life	Patterson & Garwick, 1994

In April 2017, I began Step 4, Organizing Formulated Meanings into Clusters. I began to collapse my 59 formulated meanings into theme clusters. The 59 theme clusters were reduced to 23 and brought to my research supervisor. She then instructed me on how to organize my theme clusters into over arching themes. After this feedback from my research supervisor, 23 themes

(see Table 5 in Appendix) were collapsed into eight overarching themes with eight subthemes.

(see Table 6). Following Step 5, Exhaustively Describing the Investigated Phenomenon, I then

organized the data and incorporated the salient themes to describe the family members'

experiences. I returned the descriptions of the salient themes to my research supervisor and

external auditor. They provided feedback such as providing more descriptive details within

brackets to provide more contexts for the family members' quotes and to organizing the themes in

a more chronological order.

Table 6

Qualitative Interview Themes

Theme/subtheme	Number of interviews in which themes emerged
I can deal with what I know, I have a hard time dealing with what I don't know	12
I think we got to be more caring	9
Shifting Family Roles	16
Inability to fulfill the parent role	8
Family members took on caregiving role to help parents	13
Listening to the Experts	17
You just need to put him away and forget about him	7
It was like pulling my heart out	15
Strong Sibling Connection	6
I just want him to be happy	14
Learning to Adapt	16
It brought us closer	13
Family lacked support	11
Higher Power Taking Care of Relative	10
Gods plan	8
Afterlife	3

Trustworthiness and Rigor

Shaping a qualitative study to be trustworthy, accurate and useful to others besides the people who participated in the study is an important aspect to qualitative research (Cresswell, 1998). During Wave 1 of the data analysis, I completed detailed notes and created an audit trail to reflect decisions I made regarding the analysis in order to enhance my creditability of the choices made throughout the analysis process (Koch, 1994). To assure trustworthiness and rigor, I spent

June and July of 2016 immersed in the data where I read each interview once, listened to each interview once, then read and listened to the interviews simultaneously. When pulling significant statements, I used verbatim accounts from the participants, and utilized my research supervisor and external auditor to discuss the ongoing analysis and findings. Throughout the analysis and moving forward, I engaged in reflexivity to self-reflect about my researcher bias (Johnson, 1977).

CHAPTER IV

FINDINGS

The current phenomenological study explored how family members of relatives with intellectual and developmental disabilities (IDD) made meaning over a lifetime of transitions and significant risk (e.g., initial diagnosis, institutionalization, & deinstitutionalizations). This study builds on previous work (Jones & Gallus, 2016; Richardson, 2016) and expands the literature by using the family resilience model (FRM) as a lens through with which to analyze the data. Across the families' experiences a total of eight salient themes emerged 1) I can deal with what I know, I have a hard time dealing with what I don't know; 2) I think we got to be more caring; 3) Learning to Adapt 4) Shifting Family Roles; 5) Listening To the Experts; 6) Strong Sibling Connection 7) I just want him to be happy and 8) Higher Power Taking Care of Relative.

Theme: ***I can deal with what I know, I have a hard time dealing with what I don't know***

During the qualitative interview, parents and siblings were asked to recall facts and feelings surrounding their relative's diagnosis that took place decades prior. Many family members made meaning of their relatives' initial diagnosis by describing it as a shock to their family and discussed a lack of understanding regarding disability conditions and the process of the disability diagnosis. Parents questioned if there was something they had done to cause the disability, and described frustration at the lack of explanations they received. They discussed the difficulty of not having answers. Jim said of his daughter's diagnosis, "There wasn't anything in our lives that pointed the same way. We didn't do drugs, we didn't drink, you know, there weren't any traumatic injuries or things like that. There were no explanations." Some family

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members made meaning around the lack of understanding of how their relative came to have a disability and what was the cause. Family members described multiple hospital visits and tests to try to gain an understanding about what was happening with their relative. James shared his hopes for his son after receiving an initial diagnosis, "…we sent him to every place you could send him for every kind of test you can have and um, it became evident that he wasn't ever going to get better. Uh, but we spent a whole lot of time to see if he could." Family members discussed the process of coming to an understanding of their relatives disability diagnosis, and the realization that they would not be cured of the disability. Some siblings described how their parents may have felt guilty. Rosa reflected on how her parents may have felt when her brother was diagnosed,

> I think as a parent probably [there was] always is a little bit of guilt. "Did we do
> something to cause this?"…"What if we hadn't been so greedy to have another
> child,"…all of those things that I think any parent questions …

For Rosa's parents, not knowing what caused the disability led to feelings of guilt and having a difficult time understanding if there was something they could have done to prevent their child's disability. Some family members described the process of what it was like for the other members of their family to learn of the disability. Amanda said,

> My older son, I was concerned that he might have…guilt and [feel] she was all his fault.
> And sure enough, around eight…we talked it out quite a bit. "Listen. This was a natural
> thing that happens and sometimes it just works out this way." So, I don't think he's
> grown up with that. It's the guilt factor and you don't know what all the other people in
> the family are feeling.

Some family members also discussed feeling relief when they learned about their relatives' disability after searching for answers. Julie stated after finding out about her son's disability,

It brought some peace to me because I knew for a long time that something was wrong and for someone to finally go ahead and tell me, at least I had an answer. I knew…I've always said I can deal with what I know. I have a hard time dealing with what I don't know.

Theme: *I think we got to be more caring*

Families also seemed to make meaning of their relatives' disability by describing how their family became more caring, knowledgeable, and compassionate. Family members felt they learned empathy and had more insight into people who were different from them. When asked how her sister influenced or changed her family, Hannah stated, "I think we got to be more caring and stuff… .We were considerate and caring about people that were, you know, had disabilities." Some family members described gaining not just a compassion for people with disabilities, but greater empathy towards all people. Courtney said her son taught them "not only an awareness but understanding of what was going on and the challenges that particular persons [are] going to have to face because of what's going on in their life."

Many family members felt they were motivated to be more sensitive towards others. Two mothers specifically stated their relatives opened up their hearts to others. Debbie shared, "[Son] has been a blessing to the world [cries] and that's when he's not being a little royal mischief-maker [laughs] cause he has his trying moments, but…I think [having a relative with a disability] helped [siblings] open their hearts in ways that they might not have otherwise." Julie stated of her other children, "I just think it…it opened a part of their heart that a lot of kids don't have happen until they're older." Interestingly, although Julie discussed her belief that her other children are more compassionate due to their brothers disability, she also described the long process it took for her to get to the place of her own understanding and discussed how her family members helped her. She shared, "I finally decided that my four boys were [here] to help me learn to love the basically unloved and unlovable."

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Theme: *Learning to Adapt*

      Family members made meaning of their experiences by describing adapting to their transitions. Family members described their experience of having a relative with a disability through the subtheme *It Brought Us Closer* by discussing how their relatives' diagnoses made them adapt to the disability collectively. In contrast, in the subtheme *Family Lacked Support*, other family members felt isolated and felt they did not get support from not only extended family, but the outside world and their larger ecosystem. They made meaning of their adaptation as a family by discussing experiences with extended family members and other individuals who were not supportive of their relatives' disability. Although these subthemes at times appear to be in contrast to each other, they illustrate the complex adaptation processes families experience.

      It brought us closer. Many families described their experiences of transitions across their relative's lifespan as bringing them closer as a family, and in some cases closer to their relative. For some, these families were a collective experience. Jim described the meaning they placed on their daughters initial diagnosis stating,

> I don't know, …you know a lot of times we were told this, that we, she was diagnosed with her problems [and] a lot of times, parents split up, get divorces and things like that. It's brought us closer together. And—we just both took care of her. I mean, and I wasn't afraid to take care of her.

Katie, Jim's wife, also described their family felt isolation due to the lack of understanding and knowledge about disability from others, such as teachers or babysitters. She went on to state, "We just drew together, and it was just a part of our…it was just the two of us. If we didn't have each other, we had nobody." Some families described that not only did it bring them closer, but also navigating their relative's disability diagnosis was something they would experience collectively. When asked how their family unit changed when her son came along, Debbie replied "… probably the most that I could say at this point in time would be that it gave us something that we

were all learning together." When discussing the process of deinstitutionalization and moving into the community, some family members discussed their satisfaction at continuing to build that relationship with their relative and expanding it to other members of the family. Regarding the transition to the community, Laura explained that

> Doesn't bother me a bit. I posted his—the video on Facebook, and we've just got in contact with people in Florida that are our family and some other family members and some others that say "Thank you for posting your visits," 'cause they hadn't seen him in a long time. So, I'm hoping to get, they will bring [brother] wherever I want.

Family members also described what it meant to have them in the community with Holly stating, "nothing else matters to me and him, it's like wow, we're together again." After their years of living apart, the transition allowed Holly the ability to see her brother and not only be close to him physically, but continue to build their relationship.

Family lacked support. Although some families describe support they received from other family members and their experiences bringing them closer, other family members described the lack of supports from other family members, as well as the larger ecosystem. When asked about her relationship with other people after finding out about her son's diagnosis, Julie explained,

> My mother and I had some problems there for a while because she wanted me to give him back to DHS… I said, "No, he's my son. Would you give your son back, to them?...She just came to an understanding that this was just going to be this way, and…Oh there's things I've noticed over the years you know. People will ask, "How's your daughters? How's [youngest son]?" But they don't ask about [son]. And… you know that's their problem, not mine.

Julie continued to formulate her meaning about others' perception of her relative's disability and comes to an understanding that not all people will deal with the situations in a similar manner, and it takes others longer to come to an acceptance of disability.

> But I have noticed that it gets…you know everybody… some people just can't deal with things, and it's their loss. But…that's one thing I've noticed but I never did make a big deal of it because I think people …you have to find your own understanding… and maybe they just haven't gotten there yet, so.

Some family members explained that while their family members are supportive, they have had limited interaction with their relative with a disability through the years. Laura said some extended family members placed blame on her mother for her brother's disability stating,

> Some sides of the family, I think blamed my mother. I think back then there was little known as to cause of… a chromosome irregularity and so they blamed her for not taking care of herself.

Family members discussed just a lack of overall understanding of their relatives with a disability and the perception they placed on their loved ones contributed to the lack of support.

Theme: *Shifting Family Roles*

Some family members made meaning of what their different roles were in the life of their relatives. These meanings were broken down into the subthemes of *Inability to Fulfill the Parent* Role, and *Family Members took on Caregiving Role to Help Parents*. Family members described how they felt about the *Inability to Fulfill the Parent Role*, and how this affected their adjustment to transitions, either from learning of the initial diagnosis, to the process of institutionalization. In *Family Members took on Caregiving Role to Help Parents*, other family members described what it meant to have support and assistance from their other children and extended family.

Inability to fulfill the parent role. Family members described what it meant to them to have their role change after the diagnosis of their relative, and how they made meaning of their

adjustment. Amanda reflected on the time immediately following her daughter's birth and diagnosis and the influence her daughter's disability had on the decision to have more children,

> I came home first and she was there [at the hospital] another two weeks. So we had some time to adjust to how unusual this was going to be. And then after a couple of years of her being gone [to the institution] we had the second son, so… it was just kind of like I needed to have that baby. I needed to have a healthy baby after I'd had her. And I didn't realize that was going on in my brain, but I knew something had to happen like that.

Some family members reflected on the meaning of placing their relative in the institution and having others be her son's primary caregiver. Debbie described relief at not having to make the decision to institutionalize her son by herself stating,

> I was glad that [ex-husband] and I came to the decision to put [son] there before we were divorced. Because, that ridded me of guilt of thinking that I would have done it as a single mom because I was either unable to be the kind of mom I needed to be or that anyone, I don't care what anyone thinks, but just thinking that I was using that as an out to try and make my life not so hard. So I was glad that those decisions had been made prior to the divorce.

Other family members described what it meant for them and their family to be told someone else could provide better care for their relative than they could. Rosa reflected on her mother's reaction to institutionalizing her brother and how she perceived her mother might have felt about placing him,

> I remember [the day they dropped brother off at the institution] but maybe more so as I've gotten older. How hard, you turn your child over to the care of strangers…. She couldn't provide the home. Somebody else was doing the job that maybe she should've been doing. And that she felt inadequate… that she could not do that. Through no fault of

her own… so just like any mother, she would think… "am I not being a good mother?

Have I not made enough sacrifices? What else could I do?"

Julie felt like she could find comfort and empathize with how mothers were feeling about placing their child in the institution. She stated,

I felt like I could relate to the feelings of those mothers because I knew how it felt. To feel like someone else could care for my child better than I could and so consequently, that's how they felt, and I knew it.

Family members took on a caregiving role to help parents. Many participants, particularly siblings, described how they or extended family took on additional caregiving roles . Most family members described this was what family members did to help with the demands of caring for a child with a disability and how they made meaning of the demands as a family. Andrew describes helping his mother by stating, "well I took care of him when he was born, too you know, 'cause all of us boys had to learn how to do all the chores that men don't do you know, so ironing, sewing, everything. So I kind of took care of [brother], helped mom take care of [brother]. You know, all of us boys did." Family members described how they collectively took on duties to provide care for not just the relative, but the upkeep of the household.

Many siblings and family members made meaning of taking on the role of the caregiver by explaining their family member was not going to live forever, and someone needed to step up to assume the role. Most siblings described it as a natural progression or discussed taking on the role of the caregiver and guardian when their parents aged and could no longer assume the responsibility. Catherine spoke of her mother's inability to have her brother come home for visits stating, "…it was just too much for mother, I said, 'Well Mom, why don't you just let me start doing it. I would love to do it.' So I started doing that back in the early 90s". She then transitioned into the role of guardian for her brother.

Theme: *Listening to the Experts*

Throughout the course of their relative's life, family members have had professionals advising them on what is best for their relative. Some family members described advice they received from others about how to care for their relatives when they were first diagnosed, while others discuss how it felt to leave their relative in the care of others. Within the subtheme *You Just Need to Put Him Away and Forget About Him* many family members made meaning of following professional advice was by telling themselves the professional knows best, and trusting what they said would be right for the whole family. Family members described their reaction they had to following the professional advice of institutionalization in the subtheme *It Was Like Pulling My Heart Out*.

You just need to put him away and forget about him. Family members reflected on the advice or comments they received from professionals surrounding their relative's initial diagnosis, and circumstances surrounding placing their relative in an institution. They made meaning of the advice given especially when professionals, such as clergy or doctors, warned of the negative experiences family members encounter when they have a relative with a disability. Family members were often informed that keeping their relative at home would be detrimental to their family. Katie recalled what she was told when her daughter was in the hospital,

> Well when they diagnosed her, in the city, at the Children's hospital, the first thing the clergy did, was call us into a room and tell us… oh, the percentage was ungodly high. 85 percent of parents with a special needs child, when they find it out, one or the other of them can't handle it.

Family members made meaning of the initial diagnosis described by professionals as a weight on them and their first perception of the disability was negative. Family members also described professionals advising them to place their relative in an institution for the betterment of their

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family. When asked about how her family made the decision to institutionalize her brother, Catherine explains,

> Based on their professional observations and opinions, they [parents] believed that the best thing for the family to do for the family was to put him there. They believed that was the best thing for the family. That seemed to be the common thread—it is for the family.

Although family members had reservations about placing their loved one in an institution, some family members reiterated that they listened to the advice of the professional to do what was best for their family.

Some family members were told once they left their relative at an institution, they should forget about them. James described, "Yeah, but the professional advice we were given early on is that you just need to put him away and forget about him. And that's not the way we are…" His wife Martha continued, "Well I cannot imagine, I know, I mean they told me 'You just need to put him away and forget it." James finished, "That was the advice we were given, 'You need to put him away, forget about him, and go about your business'". James and Martha, along with other family members, stated that although this was the advice they received, they were not the type of family to leave their relative and forget them.

It was like pulling my heart out. Many family members reflected on how it felt to place their loved one in an institution, the process, and what it meant for them as a family. Family members appeared to make meaning by reconciling the heart wrenching decision they made to transition their relative to an institution by cognitively reconciling "the professional knows best". Most family members described crying the day they dropped their relative off at the institution, with several family members crying during the interview when retelling and describing their experiences. Family members discussed how it felt when they first dropped off their relative, and the first few years following.

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Brett and Michelle reflected back on the day they took their daughter to the institution. Brett stated, "...when she went there that was hard too. They said you have to take her there and you could not see her for two weeks period, just take her". Michelle then commented, "That was hard". Brett followed up this conversation describing, "I'll never forget the feeling", with Michelle finishing stating, "Yeah…it was like losing a child." Many family members described the day they took their loved ones to the institution as horrible. Julie stated, "…that was really painful and leaving him there and coming back home …I think that…well, that was harder than burying my first child." Family members described this experience as devastating, with two mothers stating, "it was like pulling my heart out". When describing the day she and her husband took their daughter to the institution, Katie said, "We cried all the way home. We both said, as soon as we pulled out of the drive, that, uh, it was just like someone reaches in, grabs her heart out, pulls it out. You know, it just, it was bad." When discussing what happened shorty after dropping off their daughter, Martha stated,

> For about a month…I'd get the girls up and out—and I would go back to bed. And I'd stay there until I heard the school bus come and then I'd get up and make the bed and act like I'd been up all day.

Family members were faced with a lack of choices, and mentioned that all though it was a horrible experiences, they went through with their decision to do what they had been told was best for their relative. Emily explains, "…when she went to Pauls Valley…you know, I cried every day… [cries] I wanted what was best for her… [cries]." Some parents described how their other children made meaning of the institutionalization of their sibling. Amanda reflected on how her son without a disability understood the institutionalization by stating,

> The other thing about him was then when we had to put her somewhere, it was like well we got to get rid of this one. This one didn't work. And you know, I didn't know what his young mind was thinking. But I've tried my very hardest just to keep him level as far as

normal because it wasn't normal for him. …this little baby's born and then we give her

away. How does that look?

Catherine described the reaction she and her other sibling had when their parents initially told them they were placing their brother in an institution. She stated, "Obviously I'm bitter" and went on to reflect on how she and her brother "begged" their parents to keep him at home indicating,

I wish the decision hadn't been made. I wish that for myself and my brother, and I'm

going to lose it. I know… [cries], that we begged. We begged them not to take him. I can

remember many times me and my brother were angry at our parents, and I can remember

sitting on the floor and just sobbing and sobbing, you know, "Please!" But on the same

hand, I was a little kid, and I had no knowledge of, you know, what they had to deal with.

She then unpacked how her parents must have felt not only about placing one child in an institution, but the reactions she and her other sibling displayed once learning the news. She described,

And now when I think about that and I think about how my brother and I reacted, and

how they had to deal with the emotional pain that they had, [cries more heavily]. I'm so

sorry. And so, for then my brother and I to respond, and ours was just true and honest we

weren't trying, we were just begging "I'll be the nicest little girl." You know, "I'll do

whatever I need to do, don't take him," and so coupled with how we felt about it, and

then how they felt about it, I just cannot imagine the turmoil that they had to deal with in

making the decision that they had made.

Once Catherine's brother was placed in an institution, she described the visits as traumatic for her family. She felt that it was a negative turning point in their family relationships. Although this is how she initially describes the experience, she later goes on to describe she learned from the experience,

There was a point in time, but the reason I say that is, I think had we stayed together as a

family, there would not have been that emotional separation, I don't know that that's

making any sense…there was that emotional separation for me for a while…and I hate

that, but I learned from it, I learned where it came from.

Catherine described how she and her family constructed meanings around two different time

periods, first when she was younger, then later on in life reflecting back on their experience with

institutionalization. She explained how on the one hand when she was a child,

institutionalization, she believed, was "dangerous" for her family. Catherine finished stating that

although it was "dangerous" for her family and contributed to their emotional separation, she

constructed a meaning and learned from their experience.

Theme: *Strong Sibling Connection*

Six of the eight siblings interviewed described having a strong connection with their

sibling over their lifetime. Two parents also spoke about their other children having a strong

connection with their children who were institutionalized. Some siblings described the meaning

around the connection they shared with their relative when they were younger, while they were

institutionalized, and after when they continued to stay involved in their relatives' life. Holly

describes,

I know [brother] better than anybody does. More than even my own parents

would…because the honesty of it is, and I'm sharing with you, that I raised [brother].

[Brother]'s not an issue with Sis. I've been up in the bed and held onto him when it

looked like a death angel was pulling him right up out of that bed.

Throughout her interview, Holly continued to describe how she provided care for her brother at a

young age, and although she holds resentment toward her parents for that responsibility, she

stated,

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What I was angry about, about my childhood being deprived of me, was probably one of

the greatest journeys of my life. That actually, [brother] became my teacher. And it

helped me later on in life, to facilitate, to become a counselor…. The betterment of [me]

was [brother].

She described learning valuable lessons from her brother that although were difficult at the time,

she learned later on would prove to her benefit. Some relatives described, even after the move to

the institution, they were able to spend meaningful amounts of time with their sibling. Rosa

stated, "and then as I said after he moved we stayed connected…", and was encouraged by her

parents to continue her relationship with her brother.

Parents described the positive relationship their child with a disability shared with their

sibling, and reflected on their future relationship. Whitney described her son's reaction to what a

future would look like without his brother. She stated, "Yeah, he's worried about his brother. He

said, 'I don't know what I want to do if someday, he had to go,' [when] he would have to die, he

said 'I don't know what I'm going to do.'…he loves his brother, it's the only one he [has]." Katie

reflected on memories of her daughters and their time spent playing together. Her daughter

without a disability wanted her daughter with a disability to do things she could do, and felt it

unfair that she sometimes could not. Katie stated about going to their grandparents house, "She

didn't like to come down [to her grandparents' house] as much because she wanted to stay with

[her sister], and they didn't take [her sister] so she didn't want to go."

Theme: *I just want him to be happy*

Many family members desired for their relatives to live out a good life and emphasized

their desire for positive wellbeing for their relative. When asked about what their hopes for the

future regarding their relative, family members discussed their hope for them to be happy.

Michelle stated, "My hope is just that she can stay as well off as she is." Family members

discussed they hoped for their relatives to find joy. Rosa wished "…that he would be able to have

some enjoyment in his life, like we all expect to have. Some joy, everybody deserves to have some joy." Catherine also discussed wanting joy for her brother, but recognized it would be different now that he lives in the community, "I just want him to … I know he's not ever going to have the same joy that he had before because life is different. I understand the seasons that we go through and the changes that we have to make but I just want him to be happy." In addition to relatives' wellbeing, family members described hope that their relative will continue to receive quality care. Andrew said, "I just pray that at this point on he just lives out his life where he's at and with the care that he's getting…that's all you can hope for." Family members also desired others to empathize with their relative with Rosa stating, "And I just want him to have—I want him to be happy and comfortable and feel that—he has feelings I think we think people think they *don't* [emphasis added]."

When family members were asked what they would tell other parents or siblings of a loved one with a disability, many mentioned the importance of expressing love to their relative. Hannah advised, "I guess I'd just tell them … to love them as much as you can, enjoy them while you got them, and don't let anybody try and turn you against them." Other family members discussed the difficulty and sometimes struggle they face with having a child with a disability. Catherine stated, "Just love them and try to make them happy and just love them and, you know, I understand it's hard."

Theme: *Higher Power Taking Care of Relative*

Many family members described leaning on a Higher Power or their spirituality as a form of support during their times of transition with two subthemes emerging. Within the subtheme *God's Plan*, family members discussed how they made meaning of what God's plan was for their relative through out their lifespan. In the subtheme *Afterlife*, family members discussed what meaning they placed on the afterlife for themselves and their relative.

God's plan. Some family members felt it was God's plan for their relative to have a disability and understood that He knows what He is doing and will provide adequate care. Courtney states, "I think things happen for a reason and for the most part they happen the way they're supposed to happen….It [is] God's blessing on [son that] people love him. But I also think [son] is… is a blessing to the world because he blesses their lives as well." Debbie recalls her stepbrother's reaction to her son's diagnosis being very different from her own. Her stepbrother was mad at God. She challenged this by stating, "I didn't understand that. And I said, you know 'God didn't do anything to me'…now, it's a perfectly logical reaction. It just wasn't my reaction. I have a baby boy, you know."

Afterlife. Family members also reported looking forward to an afterlife with their relative. Matt described, "… I have some hopes that in the afterlife for him to be able to have some normalcy." Matt also describe that in the afterlife, he hopes to be able to communicate better with his brother stating,

> If you're someone that believes that in salvation and afterlife and all that, you would hope
> that in the afterlife, [emphasis added] *bam* chains are released. [Brother will say] "I've
> been wanting to tell you this shit for 60 years!"

Matt seemed to make meaning around what it will be like to have a conversation with brother after all of these years especially to be able to know what his brother wants to communicate.

Holly emphasized how she often talked to her brother about the afterlife and what it would mean for them. She said,

> When I tell my brother, and I look him in the face, and I say [brother], one day we're
> getting out of here, and we're going to see Mom and Dad. If you think he does not
> understand what I'm saying, be there with me, he will tear up. He is *not* [emphasis added]
> insane. He has the ability to *think* [emphasis added]….just because there is a severe a
> disability there.

One mother, Julie, discussed what she hopes for her son in the afterlife, "It would mean peace for him, and I believe when you die, no matter what's wrong with us here, we become a whole person to God and that would be a fulfillment of my dream for him. So, that's my hope for him." Julie goes on to say that she hopes to outlive her son so that she can continue to oversee his care on Earth "For now, whatever will be will be, but I hope before I go, he does, so I can finish my last bit of care."

CHAPTER V

CONCLUSION

The purpose of this study was to describe the phenomenon of how family members of relatives with intellectual and developmental disabilities (IDD) make meaning surrounding a lifetimes of transitions. Qualitative data was analyzed using the family resilience model (FRM; Henry et al., 2015) as a framework to better understand the meaning family members place on their experiences surrounding initial diagnosis of their relative, institutionalization, and deinstitutionalization. Although there has been research conducted to examine family meaning making and family resilience around specific diagnosis such as autism (Bayat, 2007) and chronic disability in early childhood (Patterson, 1994), there has been little research done to explore the transitions of families across the lifespan of transitions unique to family members of relatives with IDD.

Previous Research

Consistent with previous literature (Glidden, 2012; Hastings & Taunt, 2002; Poehlmann et al., 2005; Seltzer & Teller, 1997), findings from this study conclude that adapting to relatives' disability is a lifelong process with positive and negative experiences coinciding throughout the lifespan of family members. Similar to Wehmeyer and Schalock's (2012) research, this study found that families felt they lacked information and understanding regarding disability diagnosis at the time because little was known about what caused disabilities at the time of their child's diagnosis. This left parents questioning if they contributed to the disability, and similar to Poehlmann et al. (2005), left many parents with feelings of uncertainty and distress surrounding

the diagnosis. Family members also described feelings of isolation from other family members, friends and the community regarding when their child was diagnosed with a disability. According to Wehmeyer and Schalock (2013), this finding could be in part due to the time period in which relatives were diagnosed with a disability and the negative perception of disability surrounding the period of the 1930s and 1940s. Interestingly, family members in this study described the feelings of isolation from others due to their relatives' disability diagnosis as bringing them closer as a family, and they were able to gain a better understanding of others through having a relative with a disability. Consistent with other findings surrounding religiosity and spirituality in family members of relatives with IDD (Michie & Skinner, 2010), family members discussed how a higher power was taking care of their relative and many believed that God was in control.

Findings consistent with previous research regarding institutionalization of relatives with disability included family members reporting they were advised by clergy or other professionals to institutionalize their relative with a disability (Spreat et al., 1987; Tabatabainia, 2003). Family members described experiences with professionals and doctors explaining they were told institutions would best be able to provide care for their relatives and they would not be able to provide adequate care. This finding is reflected in previous literature describing professional's advice that state institutional placement would be best for their family members (Noll et al., 2013; Wehmeyer et al., 2000). Family members discussed meanings of what it felt to have their role change, and what it meant to be told others could provide better care for their relative. As reflected in previous studies surrounding the impact institutionalization has on family members (Berry, 1995; Conroy, 1985; Richardson, 2016), family members in the current study felt guilt, sorrow and ambiguous loss after placing their relative in an institution, with two mothers describing the pain as pulling their hearts out. Also similar to findings in previous studies (Jones & Gallus, 2016; Tabatabainia, 2003), family members described desires for their relatives to

receive adequate care in the community provided by staff. Family members also expressed hope that their relatives would live out happy lives.

Family Resilience Model: Family Meaning Making

The family resilience model (FRM) was used as a guiding framework and of the eight themes, six themes appeared to fit within the FRM (Henry et al., 2015). The FRM includes four basic elements (i.e., family risk, protection, vulnerability, and adaptation). Lifelong transitions of relatives with IDD present a unique risk to the family members of relatives with IDD. Family members used family meanings as a protective mechanism to reduce the risk of the transitions and promote resilience and adaptation. The use of family meaning as a protective mechanism led family members to adapt to stressors by creating meanings surrounding the transitions of initial diagnosis, institutionalization and deinstitutionalization of their relative with IDD. These meanings included family situational meaning, family identity, and family worldview. Themes found within this study fit within the FRM because when family members were presented with a risk, such as transitions across the lifespan (e.g., initial diagnosis, institutionalization, deinstitutionalization), they were able to create meanings around the transitions and used those meanings as a protective mechanism to promote positive adaptation.

Family situational meanings describe how family members define situations based on their experiences and often redefine certain meanings as part of their family resilience (Hill, 1958; Patterson & Garwick, 1994). The theme *"I just want him to be happy"* that emerged in the current study describes how family members construct similar meanings around their relatives' wellbeing and their desire for their relative to live out a good life. Family members desired for their relative to be properly cared for throughout their lives. Family members also described the meaning they made around showing love to their relative and discussed that even though their family members have faced hardships, they are able to adapt. The process of constructing meaning around the stressor event and capabilities to manage demands were found in the theme

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Listening to the Experts. Family members constructed meanings around placing their relative in an institution and described details of the demands this had on their family members, such as describing the pain of leaving their relative in the institution. They also described how they managed the stressors and demands, with many describing that although placing relative in an institution and listening to advice of professionals was a hurtful experience for their family members, they learned from the experiences and reconciled it was what was best for their family members at the time. Although managing the demands of placing their relative with a disability in an institution was discussed as a protective mechanism by which family members adapted, for some during previous times in family members lives, this was seen as a vulnerability and hardship for the family.

Family identity includes family members' perception of their uniqueness within their ecosystems, such as patterned interactions and legacies (Patterson & Garwick, 1994). Several themes that emerged in the current study reflect family identity and how family members viewed themselves. Within the theme *"I think we got to be more caring"*, family members described how they became more passionate, caring and empathetic toward others because of what their relative with a disability taught them. Family members made meaning of their identity surrounding their relatives' diagnosis as more caring not only to each other, but within their ecosystem. They were able to create meaning surrounding the risk of their relatives' diagnoses and used that meaning as a protective mechanism to adapt. The theme *Shifting Family Roles* is also reflective of how the family members viewed themselves and made meaning of the transitions of initial diagnosis and institutionalization. Family identity consists of boundaries and roles family members take on when a stressor event occurs, and how their roles could change when a risk, such as disability diagnosis or institutionalization is presented. Within this theme, family members narrated their inability to fulfill certain roles and how they made meaning around their identity to adapt and adjust to changes in their roles. This is consistent with previous research where family members

with relatives with disability can alter the way the family views their unit (Patterson & Garwick, 1994).

Family members discussed their abstract and existential beliefs of the world and how they responded to a risk within the theme *Higher Power Taking Care of Relative*. This is consistent with the family world view with many participants in the current study describing *God's Plan* and their view of the *Afterlife*. Family members were able to find an understanding and make meaning around God being in control of their own and their relatives' lives. Family members described how they felt at peace with what the afterlife will bring for their relatives and shared a positive outlook on what the afterlife will bring for their relatives. The positive meanings formed surrounding their relatives' disability assisted in their adaptation and understanding of their relatives' disability. Family members often discussed their orientation to the outside world and ecosystem in the theme *Learning to Adapt*. Their relatives' disability helped shaped the family members view of the outside world and they collectively built an understanding and made meaning surrounding their relatives' disability. In the subtheme *Family Lacked Support*, relatives described their understanding and acceptance of their relatives' disability within their family of origin and how their view differed significantly than that of members of their extended families. Family members explained their family of origin has a different understanding and perception of their relatives' disability than their extended family, and they understood and made meaning that the different understandings were acceptable.

Emergent Themes

Although the majority of the themes fit within the FRM framework, two themes emerged among participants that did not correspond with family meaning making. The theme "*I can deal with what I know, I have a hard time dealing with what I don't know*" describes ambiguous understandings of how family members made meaning of their relatives disability and how they processed and adapted to the disability diagnosis. According to Boss (2006), ambiguous loss is a

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unique traumatic type of loss due to the vague quality of the loss. Parents had difficulty with not knowing what their relatives disability was, or how it was caused, and adapted through making meaning of the ambiguity surrounding their relative. Parents and siblings also spoke of meaning around the connection shared in the theme *Strong Sibling Connection*. This meaning was not found within the family level meanings of the FRM, but may be a part of the family protection at the subsystem level within the FRM. Throughout different stages of siblings' lives, there was a consistent connection between their brother or sister with a disability and the siblings noted by both parents and siblings in the current study. Siblings made meaning of this connection by discussing their different transitions that took place throughout their relatives' life span and discussed the importance of maintaining a close relationship throughout the different transitions.

Strengths and Limitations

Strengths within this study included the methodology used and the systematic process of analysis. The phenomenological method used to provide a description of family members of relatives with IDD lived experiences of a phenomenon (Cresswell, 1998). Colaizzi's (1968) seven-step method was applied to demonstrate rigor, describe each step of the analysis and provide a framework and understanding of how the phenomenon was analyzed. To promote trustworthiness, participants' verbatim statements were extracted and analyzed (Johnson, 1997). Throughout the analysis process, a research supervisor familiar with the study and literature of IDD reviewed the methods, meanings and interpretations of the data and provided feedback (Cresswell, 1998). An external auditor with no connection to the study assessed whether the findings, interpretations and conclusions were supported by the data (Cresswell, 1998). Finally, the study author repeatedly reflected on her research bias to orient what shaped her approach and interpretations of the study.

There were some limitations to this study. First, the study included a small homogenous sample of 23 family guardians, with the majority being primarily white, female caregivers. Future

research should include larger samples with wider geographic locations to validate findings

across different contexts and regions. Second, the interviews were completed at one point in time

and member checking (Colaizzi, 1978) was not included to validate the participants' experiences

and interpretations of those experiences. This step could be used in future research to increase the

validity of the findings.

Implications

Family members of relatives with IDD experience many transitions across the lifespan.

The study can inform professionals and policy makers who assist family members during times of

transitions on what meaning family members place on specific transitions, and professionals and

policy makers can assist family members in positive adaptation through their influence.

Understanding how family members make meaning can assist professionals working with family

members in other transitions unique to individuals with disabilities such as transitioning out of

the school system, employment transitions, and moving to community living. Meaning making

can better equip and inform family members on how to successfully adapt to transitions moving

forward. Due to the nature of aging parents of relatives with disabilities and the roles siblings

play in relatives with IDD lives, professionals should make intentional efforts to include siblings

in transitions and processes regarding their relatives'. Professionals can also remain cognizant of

the multiple and frequent transitions family members experience across their lifespans, and the

meaning they place on adaption to the transitions.

Conclusion

Although there have been studies specifically aiming to understand family resilience and

meaning making of relatives with IDDs diagnosis of specific disabilities, and how family

members make meaning of chronic disability, little research has been done to understand these

transitions across the lifespan of family members of relatives with IDD. Understanding how

family members make meaning through their family situational meaning, family identity, and

family world view can shape perspectives on how professionals and policy makers understand

what is important to family members and aid in successful adaptation during times of transitions.

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APPENDICES

Table 4

Process of creating formulated meanings from significant statements

	Formulated meanings		Formulated meanings
1	Didn't think much of family situation because of lack of information regarding relatives diagnosis	31	Resentment toward the process of losing relative to institution
2	Continued normalcy—did not feel there was a disruption (Similar to Insistence for Normalcy?) "Just part of our family"	32	Resentment toward parents for amount of responsibility
3	Lack of supports in the community—no other options—family turned to other options—to enhance relative with IDDs life	33	Reframing resentment to a positive life experience
4	Professional advice--Not gonna do yourself any favors keeping him at home	34	Traumatic and emotional separation because of lack of preparation
5	Professional advice-deinstitutionalization	35	Loss of control
6	Family lacked support from other members--extended members avoided discussing relative with ID	36	Family as strong advocates for relatives needs
7	Still no supports in the community for relative (after deinstitutionalization)	37	A better life (in the community)
8	Disbelief of disability (Parents or Professionals)	38	What will they do without each other?
9	It brought us closer	39	Oversight and protection
10	Family became more caring due to relatives disability	40	Staff as family/POSITIVE Staff experiences to help transition
11	Deferred/altered life plans due to diagnosis	41	Experiences with staff create NEGATIVE view of move to community
12	Deferred/altered life plans due to deinstitutionalization	42	Relatives needs over families
13		43	Grudge towards other siblings/family members

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Table 4

Continued

	Formulated meanings		Formulated meanings
14	Making meaning of why their relative has a disability--What did we do--What was the cause	44	Ambiguous roles--depending on the circumstances
15	Siblings witnessed and internalized family stress--but didn't want to lose sibling	45	Missed experiences
16	Took on a caregiving role to help parents	46	Consistent relationship throughout lifespan
17	Some of this stuff don't have words to it	47	Worry about retaking responsibility of total care
18	It was [relatives] home. Meant stability for relative and family members	48	Change is hard
19	Emotional toll on leaving family member at institution—it was like pulling my heart out	49	Higher power taking care of relative/family
20	Made meaning of inability to fulfill the parent role	50	What can relative comprehend?
21	Take what they tell you or let it be	51	Shock at appearance of institution
22	It was hard, but he's better over there	52	Empathy for individuals with ID who did not have a family member visit
23	Frustration. Disappointment. Dislike.	53	Intentional about not forgetting relative with ID
24	Integration in the process gave a sense of meaning	54	Resentment and betrayal toward disability diagnosis
25	Larger ecosystem will affect my relatives care	55	Gave up seeing relative with ID because of emotional toll to take care of other family members
26	Meaning of relatives with IDDS well being	56	Family identity was formed around relative with ID--adapted because it was just part of their life

Table 4

Continued

	Formulated meanings		Formulated meanings
27	Supportive family assisted in adjustment	57	Strong sibling connection
28	Family identity was disrupted by absence of relative	58	Grateful for family members health compared to relative--Reflection on their own family
29	Future Plans	59	Guilt—I wish it wasn't that way, but he's our child [relative]
30	Appreciation for popularity of relative with others		

Table 5

Formulated meanings into clusters of themes

	Theme clusters		Theme clusters
1	Professional Advice	14	Emotional toll on family members after leaving relative at institution—it was like pulling my heart out
2	Deferred/altered life plans	15	Higher power taking care of relative
3	Family made meaning by adjusting to disability	16	Roles
4	It was hard, but he's better over there. A better life in the community.	17	Strong Sibling connection
5	Resentment toward transitions	18	Meaning of relatives wellbeing
6	Oversight and Protection: Fear of not being there, what's going to happen when I'm gone	19	It was [relatives] home. It was just a way of life for her.
7	Impact of Staff Experiences	20	Frustration. Disappointment. Dislike.
8	Processed as a family what was best for relative w/ IDD	21	Love for relative as form of coping
9	Continued normalcy—insistence of normalcy	22	Consistent relationship throughout lifespan
10	Family Lacked support (other members, professionals, community)	23	Family became more caring due to relatives disability
11	Family as strong advocate for relatives needs		
12	Making meaning of why relative has disability, what did we do—what was the cause?		
13	Take what they tell you, or let it be		

Oklahoma State University Institutional Review Board

Date: Tuesday, June 28, 2016   **Protocol Expires:**   3/27/2017

IRB Application No: HE1419

Proposal Title: Families and Intellectual and Developmental Disability: Understanding Risk and Resilience Across the Lifespan

Reviewed and   Exempt
Processed as:
                          Modification

Status Recommended by Reviewer(s)   **Approved**

Principal
Investigator(s):

Natalie Richardson	Samantha Johnson	Kami L. (Schwerdtfeger) Gallus
717 N Brush Creek	819 S Knoxville Ave	233 HES
Stillwater, OK 74075	Tulsa, OK 74112	Stillwater, OK 74078
Jennifer L. Jones		
233 HES		
Stillwater, OK 74078		

The requested modification to this IRB protocol has been approved. Please note that the original expiration date of the protocol has not changed. The IRB office MUST be notified in writing when a project is complete. All approved projects are subject to monitoring by the IRB.

☑ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

The reviewer(s) had these comments:

Mod to add Samantha Johnson as a Co-PI and Jennifer Jones co advisor.

Signature :

Hugh Crethar, Chair, Institutional Review Board

Tuesday, June 28, 2016
Date

VITA

Samantha Johnson

Candidate for the Degree of

Master of Science

Thesis: MEANING MAKING AMONG FAMILIES OF INDIVIDUALS WITH
          INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: COPING
          ACROSS THE LIFESPAN

Major Field: Human Development and Family Science

Biographical:

     Education: Completed the requirements for the Master of Science in Human
                  Development and Family Science at Oklahoma State University,
                  Stillwater, Oklahoma in July 2017 (expected).

                  Completed the requirements for the Bachelor of Science in Human
                  Development & Family Science at Oklahoma State University,
                  Stillwater, Oklahoma in 2014.

     Experience: August 2015-June 2017: Graduate Research and Teaching
                  Assistant, Department of Human Development and Family
                  Science, Oklahoma State University, Stillwater, Oklahoma

     Professional Memberships: American Association on Intellectual and
                               Developmental Disabilities