

A LIFETIME OF AMBIGUITY: UNDERSTANDING  
THE EXPERIENCES OF FAMILIES IMPACTED BY  
INTELLECTUAL DISABILITY

By

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Abstract: Families are a valuable resource for individuals with intellectual disability (ID). However, the experiences of such family members are often overlooked. The services and supports that states provide are typically designed exclusively for the individual with ID, leaving family members with limited support of their own. Family members of individuals with ID are often called upon to provide support for their children and siblings well into their loved ones' adult years. Therefore, it is important to better understand the lifespan risks of families of individuals with ID in order to move toward a transferrable model of family supports for today's families facing their own unique societal and policy changes. Using grounded theory methodology, the current study explored the experiences across the lifespan of parents and siblings of adults with ID. This unique sample of 23 family members experienced not only the institutionalization of their loved ones but also, years later, state-mandated deinstitutionalization. An in-depth analysis process revealed five common categories of intra and interpersonal processes shared among family members across the lifespan that took place during difficult transition periods: (a) ambiguous loss, (b) ambiguous roles, (c) ambiguous futures, (d) ambiguous emotions, and (e) ambiguous coping. A theoretical model was developed to represent the ongoing interrelatedness between the experiences of family members of individuals with ID over time. The central category of ambiguity connects the major categories and subcategories and suggests families are often faced with numerous stressors simultaneously and often for extended periods of time. The ambiguous experiences provide evidence of the unique circumstances and potential challenges professionals and clinicians should consider when providing services and supports to family members of individuals with ID. Implications for the unique role clinicians can play when working with such families are discussed, including a reference for exploring the unclear experiences for each member of the family system during various transition periods.

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## CHAPTER I

### INTRODUCTION

Oklahoma's response to changes in state and national policies regarding services and supports and a subsequent push for community inclusion of individuals with intellectual disability (ID) created a unique cohort of families who, over the past 50 years, experienced both the institutionalization and deinstitutionalization of a family member with ID.

Deinstitutionalization refers to the movement of residential support and living arrangements for individuals with ID from state-run institutional setting to community living (Hewitt, Nord, Bogenschutz, & Reinke, 2013). Current literature supporting quality of life and socialization of individuals with ID focuses almost exclusively on individual outcomes of person-centered planning (e.g., formal plans for the future focused on the *individual's* wants and needs) and improvements in lifestyle of persons with ID (Bigby & Wiesel, 2011; Robertson et al., 2007).

Few studies have explored the phenomena and outcomes of institutionalization and deinstitutionalization processes from the perspective of family members. To date, research exploring the lived experiences of family members of individuals with ID is limited to early lifespan phases, primarily exploring the psychosocial outcomes of siblings and the emotional and

psychological impact on parents of receiving initial diagnoses and raising a child with a disability (Goff et al., 2013; Heller & Arnold, 2010).

Research is needed that explores later lifespan phases of families of adults with ID and the phenomena of institutionalization and deinstitutionalization many years after their loved ones with ID have left the family home. Not only is it important for researchers to explore the impact of such transitional points on family functioning, but it is also necessary to examine the risk and resilience factors for these families across the life course. Thus, to capture a more holistic image of the influence of having a loved one with ID and better understand risk and resilience factors for such families, researchers must take a broader look at the unique experiences families face across the lifespan. To address the gaps in the literature, the current study explored the unique patterns of stress and coping of family members of adults with ID in order gain a better understanding of the unique experiences of said families from a life course perspective.

The purpose of the study is to make the first steps toward developing a transferable model of risk and resilience for families of individuals with ID. Using grounded theory methodology, the current study aims to provide a theoretical framework to help better understand the risk and resilience processes that take place for families of individuals with ID. The new understanding and framework will assure that mental health professionals, state agency personnel, and policy makers are better informed about the unique challenges families often face and better equipped to provide adequate services and supports for such families.

## CHAPTER II

### LITERATURE REVIEW

Exploring existing literature is necessary in order to make comparisons and provide a general foundation for the overarching theory. To better understand the experiences of adults with ID and their families, it is important to begin by defining quality of life for individuals with ID. Additionally, the following section will review the existing literature on risk and resilience factors for families of individuals with ID, including receiving initial diagnoses and the unique processes of institutionalization and deinstitutionalization. Current literature on Ambiguous Loss Theory and the Family Resilience Model will also be reviewed in order to provide additional information about potential risk factors while also providing support of the selected methodology and purpose of the study.

#### **Quality of Life**

For the past 30 years, a major goal of legislative bodies, service agencies, advocacy organizations, and families has focused on improving the quality of life of individuals with ID (Brown & Faragher, 2014; Brown, Hatton, & Emerson, 2013). Quality of life is defined as the social, material, and healthy wellbeing of individuals and includes the evaluation of basic

needs and the opportunity for individuals to pursue personal goals (Brown & Faragher, 2014; O'Brien, Thesing, Tuck, & Capie, 2001). Schalock (2004) highlighted eight core domains of quality of life that he has found over time in his research on quality of life among individuals with ID. These domains include (a) emotional well-being, (b) interpersonal relations, (c) material wellbeing, (d) personal development, (e) physical well-being, (f) self-determination, (g) social inclusion, and (h) human and legal rights (Schalock, 2004). Additionally, self-perceptions of life satisfaction and the functional behaviors in many life domains of the individual with ID are considered important areas that influence overall well-being and quality of life (O'Brien et al., 2001).

Studies have found that the recent shift from institutional care and medical interventions (e.g. nursing, pharmaceuticals) to more person-centered and individualized supports for individuals with ID significantly influences the quality of life for both individuals with ID and their families (Bigby & Wiesel, 2011; Brown & Faragher, 2014; Brown et al., 2013; Robertson et al., 2007). The shift towards more individualized care fueled the push for person-centered planning for individuals with ID. The goal of person-centered planning is to increase supports tailored to meet the personal needs and desires of the individual with the disability (Robertson et al., 2007).

Towards the end of the 20th century, research exploring quality of life of individuals with ID expanded to include the concept of family quality of life recognizing the impact of disability on the nuclear and extended family (Brown & Faragher, 2014; Zuna, Brown, & Brown, 2014). Previous literature has primarily focused on three broad factors that influence family quality of life, including (a) stress and caregiver burden, (b) overall family functioning or family involvement, and (c) the accommodations and adaptations families often require when caring for loved ones with ID (Summers et al., 2005). While research exists that provides support for the conceptualization of family quality of life for families of individuals with ID, research that

explores how to apply such information to families in order to benefit them is lacking. Zuna et al. (2014) found six consistent themes that influenced the quality of family life among families of individuals with ID. First, families value experiences with their family members. Family relationships are important; therefore, when family members are able to engage in shared experiences with one another, their overall quality of life is positively impacted. Positive and supportive careers and schooling for family members and individuals with ID also impacts quality of life. Themes that emerged from the study that had negative implications on quality of family life included the lack of satisfaction with services for loved ones with ID, financial challenges and health issues, and a lack of interaction and integration in the community. Additionally, families who experienced low levels of support from their extended families, neighbors, and peers reported lower levels of quality of life (Zuna et al., 2014).

### **Risk Factors Impacting Families**

A small body of research has investigated numerous risk and resilience factors that impact families of individuals with ID across the life course. Families of individuals with ID often encounter an array of unique stressors across the life course that disrupt family functioning. These stressors often include receiving an initial diagnosis of ID, shifts in parenting roles, long-term caregiving demands, access to social support, availability of local and state services and supports, financial decisions and management, guardianship, and family relationships and satisfaction (Roper & Jackson, 2007). In general, the research has focused on two major risk factors: receiving initial diagnoses and long-term caregiving. In this section, these two risk and resilience factors will be defined along with details regarding how each has been assessed in the literature.

**Receiving initial diagnoses of ID.** Intellectual disability is a compound, often overwhelming condition that occurs in approximately one to three percent of the population and has a large impact on the individual's family and friends across the lifespan (Makela, Birch, Friedman, & Marra, 2009). Parental reports of adjustment to receiving their children's initial

diagnoses of ID suggest parents, specifically mothers, of individuals with ID often experience higher levels of depressive symptoms and stress compared to parents of children who do not have disabilities (O'Brien, 2007). Goff et al. (2013) found that many parents described receiving their children's initial diagnosis as overwhelming, which provoked an array of emotions including fear, anger, guilt, denial, and grief (Goff et al., 2013). It is important to note that these findings were specific to the diagnosis of Down syndrome. The research remains limited, especially with respect to the experience of parents receiving other diagnoses that result in ID. For approximately 30 to 50% of individuals with ID, there is no known cause (Makela et al., 2009). Thus, research has found that the experiences of parents with known etiology of their child's disability often differ from those who learned of the cause prenatally or shortly after birth (Jones, Oseland, Morris, & Larzelere, 2014; Makela et al., 2009).

Two major factors that moderate the association between the impact of receiving the initial diagnosis of ID of a child and parental adjustment are the severity of the disability and the family's social support (O'Brien, 2007). Research has found that parents who focus their energy on problem-solving and are accepting of social support report more positive adjustment outcomes compared to parents whose attention is focused on denial and avoidance of challenges associated with having a child with a disability (Glidden, Billings, & Jobe, 2006; O'Brien, 2007).

**Long-term caregiving and planning.** In addition to the experiences associated with receiving initial diagnoses, parents of individuals with ID face unique stressors, including challenges associated with making medical decisions, locating available resources, and planning for the future of their child (Goff et al., 2013; Heller & Arnold, 2010). Research has shown that many of the challenges family members are faced with are because child care responsibilities and caregiving roles continue across the lifespan of the individual with ID and do not diminish once the child transitions into different developmental stages. Often, caregiving becomes more difficult as the child ages and as the caregivers grow older, eventually leading to a point where parents are no longer physically able to provide appropriate care for their adult children (Griffith & Hastings,

2014; Tabatabainia, 2003). Parents often feel as if their caretaking roles are extended indefinitely and well beyond what they imaged for themselves.

### **Institutionalization**

Institutionalization is the process of admitting an individual with an ID into a large residential facility for extended periods. The goal of institutionalization for most families is for their loved one to have the opportunity to thrive in a setting that offers services that the family might not be able to provide at home (Butterfield, 1977; Tabatabainia, 2003). Many of today's aging parents of individuals with ID gave birth during a time when institutionalized care was highly encouraged. In fact, from the late 1800s through 1960s, the primary model of support for families of individuals with ID was institutionalization (Smith, Noll, & Wehmeyer, 2013). After receiving initial diagnoses of ID for their children, parents often consult others, including extended family and professionals, about options for their child's future. In the past, professionals often encouraged the institutionalization of individuals with ID because of the specific supports and services available within the institutional setting (Burghardt, 2015; Roper & Jackson, 2007; Tabatabainia, 2003). In fact, many family members reported choosing institutionalization because of advice from extended family members and medical professionals (Tabatabainia, 2003). Research has found many factors that impact the family members' decisions to institutionalize their loved ones with ID, including negative beliefs about the adverse impact of residing in the home for the individual with ID, the family, and the community.

**Impact on family functioning.** Family members have varying reasons for placing their loved ones with ID in institutionalized care. Tabatabainia (2003) found that when asked about the decision making process to institutionalize their children, caregivers described numerous concerns for their children when living in the home, including concerns related to the adverse impact on the individual with ID because of beliefs about limited opportunities for inclusive experiences or community outings, lack of independence, and the risk of rejection or threats of safety by other members of the community. Additionally, parents expressed concerns about

adverse effects on the overall family system and the community. Examples of adverse effects on the family include concerns regarding the personal death of family members and worries about what would happen to the individual with ID once the parents were no longer physically present to provide care (Tabatabainia, 2003). Families also have concerns regarding their ability to meet the needs of other family members living in the family home, including siblings of individuals with ID. Family members may also be concerned about lack of boundaries exhibited by their loved ones with ID that might threaten the safety and security of other community members (Tabatabainia, 2003).

### **Deinstitutionalization**

The deinstitutionalization movement that began over 50 years ago continues to create challenges for both families and professionals (Jones & Gallus, 2016). Since the 1970s, drastic shifts regarding living arrangements and residential supports for individuals with ID have occurred (Hewitt et al., 2013). Between 1967 and 2012, the number of individuals with ID residing in state-run institutions for individuals with ID and psychiatric institutions decreased by approximately 86 percent (Larson et al., 2014). Through this process, individuals receiving residential services from the state transition to live in the community, either on their own, with their families, or in other community residential housing (Butterfield, 1977; Hewitt et al., 2013; Lemay, 2009;). While studies have suggested that deinstitutionalization has the ability to increase quality of life of prior residents by providing residential services within the community, few strides have been made to ensure increases in participation in society and fostering of social relationships between individuals with and without ID (Bigby & Wiesel, 2011). Bigby and Wiesel (2011) suggested an overt difference in the "community presence" (i.e., the use of services and supports within the community that are available to all) of individuals with ID and "community participation," which suggests individuals with ID are active participants of thriving relationships within the community that include persons with and without disabilities.

While the goal of deinstitutionalization is to promote community inclusion for



individuals with ID, it also risks disrupting the routines and established relationships of the individuals who reside in the institutions (Butterfield, 1977; Lemay, 2009). Many unintentional consequences occur through the deinstitutionalization process. While researchers have found that many have benefitted from the increased socialization and freedom that accompanies community inclusion, others have experienced the repercussions of poor planning of residential supports, insufficient community resources, and inadequate training of support staff (Krieg, 2001; Lemay, 2009).

While the process of deinstitutionalization may seem to primarily impact individuals with ID, deinstitutionalization also involves the active participation of state employees and legal guardians (frequently parents and siblings) of the adult individuals with ID (Lemay, 2009; Minton, Fullerton, Murray, & Dodder, 2002). Not only is there a shift in role of government and policy, deinstitutionalization also calls for a shift in the roles and responsibilities of family members of individuals who were living within the institutions.

**Impact on family functioning.** Many of the same concerns that arose and influenced family member's decision-making concerning institutionalization seem to be present for family members when the idea of deinstitutionalization is first introduced. Tabatabainia (2003) found that many family members were initially opposed to the idea because of worries about adverse effects on the family system and their loved one with ID. Additionally, family members reported concerns about inadequate community care and residential supports and believed that the state facility where their loved one had lived for many years was providing adequate care. Therefore, many family members believed there was no need for deinstitutionalization. This lack of understanding for the purpose of deinstitutionalization led to mixed feelings from families, which resulted in many family members serving as passive participants in the process while others were very vocal about their position on the issue to policy makers and legislative officials (Lemay, 2009; Tabatabania, 2003).

Research exploring families' attitudes toward deinstitutionalization has found that while

families may initially oppose deinstitutionalization, the majority later report satisfaction with their relatives' care in the community and often prefer community living to institutionalized care (Grimes & Vitello, 1990; Larson & Lakin, 1991; Lemay, 2009). Jones and Gallus (2016) found in their study of family perceptions on the deinstitutionalization process that the majority of family members reported satisfaction with community living despite their initial opposition. Although the initial move to the community was challenging, most families expressed overall satisfaction with the outcome of community living for both them and their loved ones with ID (Jones & Gallus, 2016).

During the process of deinstitutionalization, many family members are expected to be active in the decision-making process regarding community care and serve as the legal guardians of their adult loved ones with ID (Jones & Gallus, 2016). However, family members may be ill prepared to take on such caretaking roles and responsibilities they relinquished to the state many years ago. This unexpected change to the family system often brings about unresolved issues from the past (e.g., denial of their child's disability, disagreements about the decision to institutionalize), as well as monetary and legal challenges for many families (Butterfield, 1977; Lemay, 2009). Because many individuals with ID spent the majority of their lives residing within the walls of an institution, most of the individuals transitioning into the community are well into adulthood. Most of their aged parents are physically incapable of providing care for their loved ones, and many are no longer living or able to make decisions regarding living arrangements or guardianship (Lemay, 2009). Therefore, siblings often play an important role in the lives of individuals with ID through the deinstitutionalization process (Coyle, Kramer, & Mutchler, 2014).

Jones and Gallus (2016) explored the perspectives of parents and siblings who had recently experienced the deinstitutionalization of family members with ID and found that many parents and siblings who were initially opposed to community living for their family members eventually reached a place of satisfaction. Although the deinstitutionalization process was

described as unique for each family, Jones and Gallus (2016) found six primary themes consistent among family members who had experienced the transition to the community within one to three years, regarding what they valued or desired through the deinstitutionalization process. These themes included: (a) a desired respect for their loved ones' history and experiences when at the state institution, (b) a need to be included in the moving and decision-making processes, (c) concerns regarding consistent care when in the community, (d) concerns related to the quality and type of care after moving to the community, (e) community involvement of their loved ones with ID, and (f) a desire to be treated like family members rather than professionals through the transition process. These findings indicate that deinstitutionalization is an emotional and stressful process for the whole system.

### **Ambiguous Loss Theory**

The most severe family stressors result from changes to the family that are unclear and nearly impossible to resolve (Boss, 2006). These stressors often lead to varying forms of ambiguity and loss for family members (O'Brien, 2007). An ambiguous loss is a unique type of loss that is externally caused and traumatic in nature because of the vague and imprecise quality of the loss (Boss, 2006). According to Ambiguous Loss Theory (Betz & Thorngren, 2006; Boss, 2006; Boss, 2010), families can experience ambiguous loss in two forms: (a) the psychological presence but physical absence of a loved one, or (b) the physical presence but psychological absence of a loved one. With the first form of ambiguous loss, the individual may not be physically present but he or she continues to play an emotional role in the family and remains constant in the thoughts of family members. The latter form is often more confusing for family members because the emotional presence of their loved one feels distant causing family members to question whether their psychologically absent family member is in fact a formal member of the family system (Betz & Thorngren, 2006). This form of the phenomenon of ambiguous loss has primarily been studied with families of deployed military personnel and during times of war and natural disasters. Boss (2006) found these unrecognized and intangible experiences as natural

disasters. Boss (2006) found these unrecognized and intangible experiences as traumatizing for family members because of the lack of control and knowledge of their loved ones' whereabouts.

Ambiguous Loss Theory (Boss, 2006) was originally intended to study and explain the experiences of families of individuals with neurocognitive disorders, such as dementia and Alzheimer's disease. However, more recent research of ambiguous loss has expanded this theoretical framework to include other forms of exceptional and indescribable experiences, including military deployments (Huebner, Mancini, Wilcox, Grass, & Grass, 2007; Maguire, Heinemann-LaFave, & Sahlstein, 2013), Prisoners of War (Shalev & Ben-Asher, 2011), and intellectual and developmental disabilities (Goff et al., 2013). Because of the stressful and unclear nature of ambiguous loss, typical mourning processes are often complicated by feelings of unending anguish (Betz & Thorngren, 2006). Families who experience such losses often feel helpless because of the lack of clarity and security of the future.

More recently, researchers studying ambiguous loss have turned their attention to families of individuals with disabilities or severe mental health diagnoses. Existing literature finds that parents often describe the experience of receiving the initial diagnosis of a child's disability as an ambiguous loss marked by the psychological loss, but physical presence of their child (e.g., Goff et al., 2013). This poses the question of whether or not families of individuals with ID who have experienced the process of institutionalizing their loved one may have experienced both forms of ambiguous loss simultaneously. Prior to the experience of institutionalization, the child's cognitive impairments related to his or her disability may be viewed as the physiological absence of the child while still having him or her in the family home (Roper & Jackson, 2007). Moreover, once the child was placed in institutional care, parents and family members likely experienced themes consistent with ambiguous loss, in that their loved one remained emotionally present and in their minds, but was physically absent from the family home (Roper & Jackson, 2007).

### **Family Resilience Model**

Families of individuals with ID often face numerous stressors throughout the lifespan of

their loved ones. Not only do these families have to make decisions regarding the care of their loved ones and the overall functioning of their households, but they also work closely with outside resources including medical professionals, state agencies, caseworkers, lawyers, and educators. Family members are faced with difficult decisions and changes to their family system on a regular basis, and these responsibilities are typically lifelong and continue well into the adult years of their loved ones with ID. Therefore, in order to work towards the development of a model that encapsulates the interrelation between different systems across the lifespan for families of individuals with ID, it is important to begin by forming a theoretical foundation using existing research on family risk and resilience.

Why certain families are able to adapt to adversity more successfully and in less time compared to others remains a constant question in the field of family science. Resilience is defined as the ongoing process that requires continuous growth and adaptation in the context of repeated challenges (Ouellette-Kuntz, Blinkhorn, Routte, Blinkhorn, Lunskey, & Weiss, 2014). Brief repeated exposure to negative experiences allows individuals to successfully navigate future challenges (Ouellette-Kuntz et al., 2014). Families, like individuals, are also seen as having the potential for resilience when faced with adversity. Family resilience is defined as the processes and outcomes associated with resisting, managing, and reestablishing balance within a family system when faced with significant risk (Henry, Morris, & Harrist, 2015). Resilience involves ongoing, mutual relations at multiple levels, ranging from individual emotional, cognitive, and biological systems to interactions within the broader ecosystem (e.g., community, culture, environments; Henry et al., 2015). A family's resilience reflects the family's perception of control and adaptation to adverse events and the level of confidence that the family can overcome further challenges (Ouellette-Kuntz et al., 2014).

The Family Resilience Model suggests that family resilience occurs when stressors (i.e., family risks), family protective factors, and vulnerabilities interact in ways that produce positive outcomes (Henry et al., 2015). These positive outcomes (i.e., adaptations) occur at multiple levels

of the family system, including the overall family system, specific subsystems, and individual family members (Henry et al., 2015). Further, the model defines family adaptation as the competence of individuals, family systems, and the family's relation with the ecosystem after experiencing significant risk (Henry et al., 2015).

The Family Resilience Model includes four basic elements: (a) family risk, (b) family protection, (c) family vulnerability, and (d) family adaptation. Family risk includes family stressors and perceptions of stressors that disrupt family functioning and increase the risk for negative outcomes (Henry et al., 2015). Family protection is defined as family resources or processes that counter family risks and facilitates the family's ability to restore balance. The stressors associated with family risk can be either vertical (e.g., chronic stressors, including physical or mental conditions or environmental factors) or horizontal (e.g., acute stressors, such as life cycle transitions, trauma, or family restructuring). Family protection includes both family protective processes and factors (Henry et al., 2015). Conditions where family systems are more likely to experience hardships associated with family risks are known as family vulnerabilities. These can often be a result of cumulative risk or ongoing exposure to repeated risk (Henry et al., 2015). Family adaptation is defined as a family's level of competence after such risk exposure (Henry et al., 2015).

The Family Resilience Model represents the trajectory from family risk to adaptation, whether positive or negative, while emphasizing the influence of vulnerability and protection on family adjustment (Henry et al., 2015). Further, the model suggests these elements are impacted by broader factors, including the ecosystem, the family's adaptive system, and the family's meaning-making abilities (i.e., family situational meaning). When risk influences family functioning, families have the potential to adapt positively based on available protective factors at the family and ecosystem levels (Henry et al., 2015). Henry et al. (2015) suggest families respond to vulnerabilities and protections in relation to risk factors in ways that yield variation in family adaptation. Therefore, we learn from this model that family adaptation in the face of risk

factors expands beyond individual members of the system. Thus, it is important that we explore not only intrapersonal factors but also outside resources that influence family resilience.

The Family Resilience Model suggests family members develop shared meanings regarding stressors and adverse situations, family identity, and mutual worldviews (Patterson, 2002).

Family meaning has the potential to influence how the family responds to adversity, how they utilize internal and external resources, and how the family views the stressor, which can affect family adaptability over time (Patterson, 2002). How the family makes sense of potential risks influences adaptive functioning, which can lead to increased vulnerability (e.g., maladaptation) or increased competence and the utilization of resources (e.g., bonadaptation; Patterson, 2002).

### **Current Study**

In 1909, Oklahoma opened its first state-run facility for individuals with ID. Over the next 70 years, the model of care for individuals with ID across the state focused almost exclusively on institutionalized care (Oklahoma Department of Human Services, n.d.). The deinstitutionalization movement in Oklahoma began in the 1980s in response to litigation (i.e., *Homeward Bound v. Hissom Memorial Center*, 1985) and the creation of Home and Community-Based Services (HCBS) waiver programs (Oklahoma Department of Human Services, n.d.). In 2012, the Oklahoma Commission for Human Services mandated that Oklahoma close the two remaining state-run institutions for individuals with ID. Over the next two years, Oklahoma Developmental Disabilities Services (DDS) oversaw the deinstitutionalization of 234 adults with ID. In July 2015, Oklahoma officially closed its two remaining state-run institutions for individuals with ID (Oklahoma Department of Human Services, n.d.).

Families are a valuable resource for individuals, and while the state provides services and supports to individuals with ID, the experiences of their families are often overlooked. Family members of individuals with ID are often called upon to provide support for their children and siblings well into their loved ones' adult years (Ouellette-Kuntz et al., 2014). Therefore, it is important to better understand the lifespan risks of families of individuals with ID in order to

move toward a transferrable model of family supports for today's families facing their own unique societal and policy changes. The Family Resilience Model provides a stable foundation for understanding the pathway from family risk when influenced by family meanings and adaptive systems within broader ecological contexts (Henry et al., 2015). Further, Ambiguous Loss Theory provides support for understanding the emotional and psychological challenges that often accompany receiving initial diagnoses and the process of institutionalization. However, no model branches out to include unique and chronic stressors, such as the experiences of families of individuals with ID face across the life course.

Additionally, a model is needed that explores the normative processes, such as aging and development, and additional non-normative processes (i.e., having a loved one with ID), that often take place for families simultaneously across time. Further, the life expectancy of adults with ID has increased significantly in recent years and is currently much closer to that of the general population (Coyle et al., 2014). At the same time, their aging caregivers continue to age, and yet, are expected to continue providing long-term care for their adult child or sibling. Aging family members are often faced with challenges associated with providing quality physical care for their loved one with ID. Thus, it is important that such a model incorporate a lifespan perspective that considers both the normative and non-normative transitions of families of individuals with ID. By exploring the lived experiences of families across the state of Oklahoma who have experienced numerous transitions throughout their lives, including the deinstitutionalization moment, the current study aims to understand the risk and resilience patterns that take place for families of individuals with ID.



## CHAPTER III

### METHODOLOGY

Understanding the unique experiences of family members who experienced both the institutionalization and deinstitutionalization of a loved one with ID is a complex process. Therefore, analyzing single variables through a deductive theory-testing model did not seem to capture the complexity of such experiences. As a result, qualitative methodology, specifically grounded theory methodology, was found to be most appropriate to provide a more holistic understanding of the lived experiences of family members of individuals with ID.

#### **Introduction to Grounded Theory**

The development of a grounded theory includes an inductive process of generating theory from data. Rather than test the validity of a given theory, grounded theory methodology analyzes raw data in an attempt to discover new ideas and patterns, thus fostering the development of a newly formed theory (Hylander, 2003; Strauss & Corbin, 1998). With this method, the researcher avoids preconceived ideas and allows research questions and theory to emerge from the data. Strauss and Corbin (1998) suggested the purpose of grounded theory research is to provide insight into specific phenomena, increase understanding, and provide a guide for future action and application. The purpose of this methodology is aimed at creating a working model based

on the meanings made through individuals' lived experiences (Hylander, 2003). The foundation underlying this method of research is that important concepts and patterns that emerge from the data could be overlooked by using an existing theory (Hylander, 2003).

When using grounded theory methodology, it is recommended to conduct exploratory research that avoids a specific theory that potentially explains the experiences in question (Hylander, 2003; Strauss & Corbin, 1998). The goal, therefore, is to understand the phenomena from the participants' perspectives in their own environment. This process involves the constant interaction between researcher and data (Hylander, 2003). As a result, the themes and concepts that emerge from the raw data are both a reflection of the personal understandings of the unique cohort being studied, as well as meanings and symbols made by the researcher (Hylander, 2003). This process leads to the analysis of emerging concepts from the raw data and the formation of a substantive theory. (Hylander, 2003).

Because qualitative methodologies allow for more in-depth exploration of data, grounded theory methodology was chosen for the current study in order to better understand the complex experiences of family members of individuals with ID through the eyes of the participants. The purpose of this approach is to establish a theory grounded in the data that resembles the realities of such families.

### **Researcher Identity**

As the principle investigator, I am a second-year master's student at Oklahoma State University studying Human Development and Family Science with specialized training in Marriage and Family Therapy. In addition, I have had specialized training and experience working with individuals with ID and their families. I have served in numerous roles working with individuals with ID, including serving as direct care staff, which included responsibilities with in-home care and daily life skills development for individuals with varying levels of ID, and as a research assistant on projects focused on working with individuals with ID and their families. Based on experience and education, my primary theoretical orientations adhere to Family

Systems Theory, Attachment Theory, and Ambiguous Loss Theory. Thus, I view families as systemic in nature and believe the experiences of one part of the family influences the family system as a whole. Additionally, I view relationships and family dynamics through an attachment lens and value the influence of early attachment relationships and how those mediate experiences as adults and influence later development of intimate relationships. Finally, I am interested in the impact of traumatic stress on families and couples. More specifically, I am interested in the role of unique stressors and unclear losses within family systems. Therefore, a traumatic stress or ambiguous loss lens is often present when working with individuals and families in a therapeutic setting. These underlying theoretical orientations have the potential to influence how the researcher views the current data. Specifically, the data could be analyzed through a systemic and traumatic stress lens, influencing how the experiences and stressful life events of the participants are perceived and how they affect the family system as a whole.

### **Procedures**

The current thesis was part of a two-phase, mixed-method study that explored the experiences of parents and siblings of adults with ID who transitioned from the Northern Oklahoma Resource Center of Enid (NORCE) and Southern Oklahoma Resource Center (SORC) in Pauls Valley as identified by the Oklahoma Department of Human Services- Developmental Disabilities Services (OKDHS-DDS). The initial sampling frame for Phase I was obtained from Oklahoma DDS and included a list of 153 parents and siblings who were legal guardians who resided in Oklahoma. As part of the quantitative Phase I, all 153 guardians were mailed paper questionnaires using contact information provided by OKDHS-DDS.

**Participants.** Participants of the current study were recruited through convenience sampling of all 153 parents and legal guardians. To prepare for possible attrition, a representative sample (i.e., equal distribution of parents and siblings) of 30 participants was drawn from the total sampling pool of 153 guardians and were invited to participate in the qualitative study with a goal of 20 total participants for the study (i.e., 10 parents and 10 siblings). The total sample consisted

of 19 qualitative interviews. Participants were invited to have other family members join them; therefore, the study included a total of 23 participants. All but one family member in the current study had full legal guardianship of their loved ones with ID.

The majority of participants were female (70%). The relationship to the individual with ID varied and included ten mothers (43%), three fathers (13%), six sisters (26%), three brothers (13%), and one brother-in-law (8%). Participants' ages ranged from 51 to 85 years ( $M = 65.33$ ,  $SD = 9.01$ ). Most participants who reported race were Caucasian (85.7%,  $n = 18$ ), followed by African American (9.5%,  $n = 2$ ), and Hispanic or Latino (4.8%,  $n = 1$ ). Socioeconomic status varied among participants: 35.6% ( $n = 5$ ) reported a yearly income of \$40,000 or below, 35.6% ( $n = 5$ ) reported \$50,000 to \$79,999 yearly, and 28.5% ( $n = 4$ ) of participants reported a yearly income of \$80,000 or above.

Family members provided demographics of sons, daughters, and siblings with ID (hereafter referred to as loved ones). Loved ones ranged in age from 35 to 70 years old ( $M = 52.31$ ,  $SD = 10.03$ ) and included 12 males (63.2%) and seven females (36.8%) with ID. Levels of ID varied among loved ones and included moderate ID (5.3%,  $n = 1$ ), severe ID (31.5%,  $n = 6$ ), and profound ID (63.2%,  $n = 12$ ) diagnoses of ID. The total number of years loved ones were institutionalized at NORCE or SORC and other state institutions ranged from 27 to 58 years ( $M = 43.32$ ,  $SD = 7.99$ ). Table 1 includes contextual information regarding family members and their loved ones.

**Recruitment.** After the completion of the paper surveys from Phase I, a research team of two trained graduate students in the Department of Human Development and Family Science (HDFS) contacted the family members via phone calls using contact information supplied by OKDHS-DDS to recruit potential participants for the qualitative Phase II of the study. Team members informed potential participants of the purpose of the study and provided the opportunity for family members to ask any questions related to the study. Once the study's purpose had been

**Table 1.** Contextual information for family members ( $n = 23$ ) and their loved ones ( $n = 19$ ).

Family member pseudonym	Relationship	Family member age	Loved one age	Loved one years in institution	Loved one gender
Stella	Mother	70	49	41	Female
Eva	Mother	85	62	56	Male
Anna	Mother	74	48	45	Female
Caroline	Mother	63	44	36	Male
Hattie	Mother	59	42	33	Male
Olivia	Mother	71	41	39	Male
Scarlett	Mother	72	47	36	Female
Charlotte & Owen	Mother, father	77, 80	50	44	Female
Polly & William	Mother, father	61, 61	35	27	Female
Beth & Elliot	Mother, father	68, 71	37	32	Male
Charlie	Brother	59	61	52	Male
Jackson	Brother	62	56	47	Male
Chloe	Sister	-	70	58	Female
Aubrey	Sister	56	57	50	Male
Hannah	Sister	56	46	40	Male
Zoe	Sister	64	58	51	Male
Melanie	Sister	54	66	50	Female
Ethan	Brother	51	55	47	Male
Autumn & Sean	Sister, brother-in-law	62, 56	64	48	Male

explained, team members invited the family member(s) to participate in the study and scheduled mutually agreed upon times and locations for the in-person interviews.

**Interviews.** Participants completed semi-structured, open-ended individual or family interviews conducted by a one of three trained graduate students on the project, including the current researcher. In-person interviews took place in the participant’s home or at a mutually convenient and confidential location (e.g., local restaurants).

Interview questions were developed by researchers from Phase I after a needs assessment survey was conducted with parents and siblings of individuals transitioning from NORCE and SORC to the community. Based on the feedback from the needs assessments, semi-structure interview questions were developed and aimed at exploring the deinstitutionalization process from a family system perspective.

The qualitative interviews included open-ended questions relating to quality of family life and marital status for parents, the transition of their love one with ID to the state institutions,

deinstitutionalization and the transition to the community, legal guardianship, and hopes and fears for the future. Two separate, yet similar versions of the qualitative interview were used for parent and sibling interviews that allowed researchers to address the unique experiences of parents of individuals with disabilities as compared to siblings of individuals with ID. Questions for both versions were worded to target the specific role of the participant. The open-ended, semi-structured qualitative interview for parents consisted of 47 questions; the sibling interview consisted of 43 open-ended questions. See Table 2 for a list of sample questions used in the present study. Follow up questions were asked in order for participants to expand or clarify their responses. A final question that was asked of all family members was *“What would you tell other parents/siblings with a loved one with a disability?”*

**Table 2.** Sample Interview Questions.

Questions
Tell me what it was like for your family to learn that [your loved one] had a disability.
How do you think [your loved ones]’s disability influenced/changed your family?
How did your family decide to have [your loved one] live at SORC/NORCE?
How has your role in [your loved one]’s life changed now that he/she is living in the community?
What are your fears for [your loved one] in the future?
What are your hopes for [your loved one] in the future?

Length of interviews ranged from approximately 24 to 145 minutes. Interviews were audio recorded and electronically transcribed by a research team of undergraduate and graduate students in the HDFS department at Oklahoma State University. Interviews were conducted with family members until theoretical saturation was achieved (Strauss & Corbin, 1998). Theoretical saturation is the process of sampling until each category of data has reached capacity. This can be achieved in three ways: (a) pertinent or new data ceases to emerge, (b) each category of data has specific properties and dimensions that allow variation between categories, and (c) relevant relations between categories are established and validated by the researcher (Strauss & Corbin, 1998).

## **Analysis**

Immediately after initial interviews were completed, interviewers completed post-interview reflections that included thoughts, personal reactions, and any additional information relative to the data. These reflections were included in the initial data for each participant. In an attempt to fully understand the data in order to develop an emerging theory, the coding process will follow a series of three phases outlined by Strauss and Corbin (1998).

**Open coding.** Open coding is the analytic process of developing categories supported by the data and discovering the properties and dimensions that characterize the process of the theory being developed (Creswell, 1998). There are several ways to conduct open coding. The current data was initially analyzed by examining each transcription in full and immediately recording coding notes to answer questions related to the overall theme of the interview. Overarching themes, contextual factors, key stressors, and coping strategies were noted, as well as a summary of the researcher's initial interpretation of the interview. A second phase of open coding took place using line-by-line analysis in order to code for themes within each interview. The researcher closely examined each sentence, phrase-by-phrase, in order to quickly generate categories for future analysis (Strauss & Corbin, 1998). Major concepts and themes were recorded in the margins of each transcription. A third phase of open coding was conducted across participants, coding for rich descriptions and themes across all interviews using line-by-line coding procedures. Initially, three major transitional periods were found to be consistent across all interviews, including the initial receipt of diagnoses, institutionalization, and deinstitutionalization. Once initial categories reached saturation, the coding process transitioned to the second phase of analysis: axial coding.

**Axial coding.** Axial coding is the process of interconnecting the categories and major themes that emerged through open coding in regards to their properties and dimensions (Creswell, 1998; Strauss & Corbin, 1998). During this phase, the researcher examined the relation between each category and their subcategories in order to better understand the central phenomenon

(Strauss & Corbin, 1998). Using the three primary categories found through open coding, the researcher conducted an additional analysis, coding for subcategories within each transitional period. Thirty-four initial subthemes were categorized under the three potential categories of (a) receiving initial diagnosis of ID, (b) institutionalization, and (c) deinstitutionalization.

A second phase of axial coding took place in order to code for the quantity of descriptions of subthemes and overall consistency across all interviews. This process allowed the researcher to take a step back from the data and better understand the processes that were taking place within each interview and across family members. At this phase of analysis, major differences began to emerge between parents and sibling, including differences in emotional responses to different transitions and the timing of such experiences. Using the findings from this phase of analysis, the researcher began to move into selective coding, analyzing the data for process rather than content in hopes of locating a central category across all interviews.

**Selective coding.** The final step of analysis for the study included selective coding. During this phase of analysis, the development of the grounded theory began to emerge. Strauss and Corbin (1998) define this process as “the process of integrating and refining the theory” (p. 143). During this process, the researcher selects a central category that best represents the overall theme of the data (Strauss & Corbin, 1998). The central category of ambiguity was found after extensive and repeated analysis of the data. The researcher kept extensive coding notes of the major themes and categories through each step of analysis, as well as the relation between individual and family processes as they emerged. An additional review of the major themes and their connection with one another allowed the researcher to see the indefinite and unclear experiences that were taking place for both parents and siblings of individuals with ID across time. Thus, the central category of ambiguity best represented the overall findings.

Using the central category, the researcher revisited the data, coding for additional categories and subcategories of ambiguity. Five initial categories emerged: (a) ambiguous futures, (b) ambiguous losses, (c) ambiguous emotions, (d) ambiguous resilience, and (e) ambiguous



roles. Additional subcategories emerged within each major category and between categories. The researcher then developed a theoretical model (i.e., conditional matrix) that visually represented the interrelation of the categories, subcategories, and the central phenomenon that emerged from the data (Creswell, 1998). In order to increase the validity of the findings, an internal auditor continuously reviewed the researcher's interpretations and developing matrix. Discussions about the connectedness between the categories and subcategories confirmed the five major categories and 14 total subthemes across all interviews, respectively.

### **Trustworthiness and Credibility**

In order to increase the trustworthiness of a qualitative study, Creswell (1998) suggests researchers conduct a minimum of two exploring procedures that test the credibility and validity of the study. To increase the credibility of the findings, the current study included a series of procedures including bracketing, rich and thick descriptions, and internal and external audits (Creswell, 1998). To ensure bias is clear, bracketing of all prejudices took place to make certain any predetermined judgments about the data or population from personal experience were set aside in order to obtain a natural understanding of the data (Creswell, 1998). Bracketing procedures were conducted with the addition of the self of the researcher section that acknowledged the researcher's potential biases and theoretical lens from personal and professional experiences with similar populations. Additionally, an extensive literature review of the theoretical lens of ambiguous loss was conducted and discussed in the previous section.

In an attempt to increase the trustworthiness of the study, rich and thick descriptions of the participants and context were provided by the researcher to ensure the findings can be transferred and shared among similar populations (Creswell, 1998; Lincoln & Guba, 1985). In addition to internal audits, external audits were completed by a consultant familiar with the process of qualitative research but unfamiliar to the data and current study (Creswell, 1998; Lincoln & Guba, 1985). During this process, the external consultant assessed for accuracy in the findings and provided objective feedback about the process and findings of the study. External

auditing procedures included a brief overview of the current data and findings, followed by an in-depth analysis of the researcher's analysis procedures, the current theory, and matrix. The researcher then met with the external auditor to review additional findings and suggestions in order to increase the study's credibility. The external auditor confirmed the findings of the current study, including the central category of ambiguity, the five major categories, and the relation between the related subcategories. Additional feedback was provided regarding presentation of the findings and implications for future research and clinical application. The only change that occurred as a result of external auditing included a change in language for the major category of ambiguous resilience. The external auditor suggested using different language that more accurately captured both the adaptive and maladaptive processes that took place within families across time. Thus, the category of ambiguous resilience was replaced by ambiguous *coping*. Overall, external auditing supported the five major categories (e.g., ambiguous loss, ambiguous futures, ambiguous roles, ambiguous emotions, and ambiguous coping) and their relation to the central category.

## CHAPTER IV

### RESULTS

#### **Participants**

The following section introduces each parent and sibling who participated in the study. Each description includes a brief paragraph about each participant, the members of their family, and details regarding their loved one with ID. Additionally, each description will include a brief summary of details about the timing and duration of institutionalization for their son or daughter or sibling with ID. Although each description will focus on the unique details that separate each participant from one another, there are some commonalities shared by all participants. For example, all of the participants had either a sibling or child with a diagnosis of ID who resided in a state institution in Oklahoma for at least 25 years.

#### *Participant 1 – Stella*

Stella is in her early seventies and the mother of two children, an older son and younger daughter. Stella's daughter was diagnosed with Cerebral Palsy when she was one and a half years old and also has a diagnosis of profound ID. Stella's daughter was placed in the state institution at the age of eight and resided there for 41 years until she transitioned to the community in April of 2014. Stella and her husband first learned about opportunities at the state institution through a

mutual friend who served as a state government official at the time. Stella's husband died in 2001. At the time of the interview, Stella and her older son served as co-guardians for her daughter. She remains in daily contact with her daughter now that she has moved to the community.

*Participant 2 – Eva*

Eva is in her mid-eighties and the mother of two children, a son with ID and a daughter who is eight years younger. During her pregnancy with her son, Eva became ill, which doctors warned may cause complications with the birth of her son or could likely lead to some form of disability. This was shocking news for Eva and her family, and she battled with the decision of whether or not to terminate the pregnancy. Her son was later diagnosed with Cerebral Palsy and moderate ID. Eva reported having a son with a disability impacted her decision to go back to school in later adulthood to become a special education teacher. Eva learned about resources available at the state institutions after her son had spent some time at a smaller, specialized school in Oklahoma for children's with ID. Later, Eva's son transitioned to a state institution and resided in the facility for 56 years before moving to the community in April of 2014. At the time of the interview, Eva and her younger daughter served at co-guardians for her son.

*Participant 3 – Anna*

Anna is in her mid-seventies and is the mother of three children, two boys and one girl. Anna's middle child, her daughter, has diagnoses of Cerebral Palsy and profound ID. When pregnant, Anna became ill with the measles, which she contracted from her older son. When her daughter was born with a disability, Anna worried that her older son may have experienced guilt regarding his little sister's diagnosis. Anna's daughter was placed at another state-run institution and spent time at a children's community home before moving to the state institution. Her daughter resided in institutionalized care for 45 years before transitioning to the community around March of 2014.

*Participant 4 – Caroline*

Caroline is in her early sixties and is the mother to one son. When she became pregnant, Caroline reported it was a shocking and devastating experience because she was unmarried and had not planned to become pregnant. Caroline's son had expressed anomalies at birth and was diagnosed with Cornelia de Lange Syndrome at the age of six months. Her son also has a diagnosis of profound ID. Caroline stated that she did not have a supportive husband and that it was very challenging to take care of her growing son on her own. Thus, she made the decision to place her son in a state institution when he was eight years old. Caroline's son lived at the state institution for 36 years before transitioning to the community in November of 2013.

*Participant 5 – Hattie*

Hattie is in her late fifties and the mother of two boys. She reported her sons were always very close, as they were just 11 months apart in age, and that her older son was always very protective of his little brother. Hattie's reported that she believed her pregnancy with her younger son had complications because of the immense amount of stress she experienced during the pregnancy. Her son was diagnosed with Autism and severe ID at a young age. She discussed having a distant and complicated relationship with her husband when her boys were young and that she never felt supported by him through the challenges of having a child with ID or through the institutionalization process. Hattie moved with her two sons to different states and cities in order to find resources for her younger son. After speaking to a doctor in Oklahoma and considering his suggesting to institutionalize her son, Hattie decided to place him in a state institution at the age of nine. Her son resided at the state institution for 33 years before moving to community living in 2014.

*Participant 6 – Olivia*

Olivia is in her early seventies and is the mother of six children: two biological daughters and four adopted sons. Olivia's first adopted son died at a young age and just nine months later, she and her husband adopted their second son at seven weeks old. She reported that her son

showed signs of typical development until around six months of age. At this point, she and her husband began to notice delays in his gross motor skills and took their son to a specialist who confirmed that he had a development delay. He was diagnosed with Cerebral Palsy and later confirmed to have profound ID. Olivia and her husband first placed their son in the care of a children's center in Oklahoma at the age of two. Once he reached seven years of age, they transferred him to the state institution because it was much closer to the family home. Olivia remained very active in advocacy for individuals with ID across Oklahoma and often contacted state officials regarding her son's rights, especially during the deinstitutionalization process. Olivia's son lived in the state institution for 39 years before transitioning to the community during the summer of 2014.

*Participant 7 – Scarlett*

Scarlett is in her early seventies and is the mother of four children: two biological daughters and adopted twin brothers. Scarlett's younger daughter has a diagnosis of severe ID, but did not show any signs of development delay until the age of two, when she started to having difficulty walking and talking. Scarlett's pregnancy with her younger daughter was planned and included no complications. At the time of her daughter's birth, Scarlett's husband was away on military deployment and did not meet their younger daughter until she was about seven months old. Scarlett first learned about a children's home for individuals with ID through family friends who also had a child with ID who was residing at the center. After living at the children's home for a few years, Scarlett moved her daughter to the state institution, where she resided for 36 years before moving to community living in March of 2014. Scarlett reported that she lost touch with her daughter while she was living at the state institution after she and her husband moved to Mexico. After her husband passed away and learning about the closing of the state institutions, Scarlett moved back to Oklahoma to play an active role in her daughter's transition.

*Participants 8 & 9 – Charlotte & Owen*

Charlotte and Owen, who are in their late seventies and early eighties, are the parents of

two daughters. Their older daughter first showed signs of delays and seizures at the age of four and half months. At the age of two, she was diagnosed with cerebral palsy and profound ID. When she was just a little over five years old, Charlotte and Owen moved their older daughter to a children's hospital where she resided for less than a year before transitioning to a state institution at the age of six. Charlotte and Owen discussed the challenges with having a daughter at the state institution, while still caring for another daughter living at home. Both Charlotte and Owen were active in the Parent-Guardian Association while their daughter was living at the institution. Their daughter resided there for 44 years before moving to the community in January of 2014. At the time of the interview, Charlotte and Owen's younger daughter was going through the process of becoming a co-guardian for her sister.

*Participants 10 & 11 – Polly & William*

Polly and William, both in their early sixties, are parents to two daughters. Their younger daughter was diagnosed with profound ID after a brain scan confirmed brain abnormalities when she was a child. After receiving advice from their doctor, Polly and William chose not to have another child after learning of their younger daughter's diagnosis because of an increased risk of having another child with ID. After placing their daughter in the state institution, she resided there for 27 years before transitioning to the community in 2013.

*Participants 12 & 13 – Beth & Elliot*

Beth and Elliot, who are in their late sixties and early seventies, are the parents of three children: two older daughters and one son. Their son, youngest of the three siblings, experienced extreme seizures since he was an infant. However, it wasn't until the family was in a serious car accident that his symptoms seemed to exacerbate. After living in two prior children's facilities as a young child, Beth and Elliot moved their son to the state institution at the age of five. He remained there for 32 years before transitioning to community living in June of 2014. Beth and Elliot reported the careers of their older daughters were impacted by having a sibling with ID, as they both went on to professions in the health field.

*Participant 14 – Charlie*

Charlie is in his late fifties and is one of four siblings. Charlie's older brother has a primary diagnosis of profound ID and was placed in a state institution when Charlie was five years old. Charlie reported that he was too young at the time to remember much about his brother's diagnosis or the initial transition to the state institution. However, he did report that his step-father was primarily the one who made the decision to place his older brother in the care of the state. Charlie stated that his mother suffered from severe mental illness and was not able to take adequate care of his brother. Even so, Charlie reported that he strongly disagreed with his parents' decision to place him in the institution. At the time of the interview, Charlie reported that he was unsure of the status of his brother's guardianship and did not believe that he was his legal guardian. Charlie reported that he was unsure exactly when his brother transitioned to the community because of a lack of involvement in his brother's life. State records indicate his brother resided in institutionalized care for 52 years.

*Participant 15 – Jackson*

Jackson is in his early sixties and is the second oldest of five brothers. Jackson's younger brother, the third of five siblings, has a diagnosis of severe ID; however, Jackson reported limited experience and knowledge of his brother's diagnosis and its impact on the family system. His parents made the decision to place his younger brother in a state institution when his brother was nine years old after receiving recommendations from their doctor. His brother remained at the state institution for 47 years. Over the years, Jackson has remained an active advocate for his brother and others with ID in Oklahoma, including serving in many leadership positions at the state-level and as a volunteer advocate for two other individuals with ID. To date, Jackson and another brother serve as co-guardians for his brother with ID.

*Participant 16 – Chloe*

Chloe is the youngest of three siblings, all of whom were adopted by the same family.



Her exact age is unknown. Her sister, the second oldest of the three siblings, was diagnosed with Cerebral Palsy at a young age. However, Chloe's adoptive parents were not aware of her sister's disability until after she was adopted. After having a negative experience at a children's facility, Chloe's parents started a small special education school in Oklahoma in order to provide the type of care her sister required. However, shortly after, her mother became ill and was unable to provide for her sister so her parents decided to place her sister in a state institution. Her sister remained in the institution for 58 years before moving to the community. At the time of the interview, Chloe was serving as her sister's legal guardian.

*Participant 17 – Aubrey*

Aubrey is in her mid-fifties and has three siblings. Aubrey is the third of the four children in her family. Her older brother, who is the second oldest of the four siblings, has a diagnosis of Down syndrome and severe ID. Because she was younger than her brother, she was unable to discuss details regarding his initial diagnosis, but she reported being angry with her parents' decision to place her brother in a state institution. Her older brother lived in the institution for 50 years before transitioning to the community in September of 2013. Aubrey remained active in her brother's transition and wrote letters in an attempt to show opposition of the state's decision to close the institutions. At the time of the interview, Aubrey served as her brother's legal guardian.

*Participant 18 – Hannah*

Hannah is in her mid-fifties and is the only girl of five children in her family. She is the third child of five. Hannah's younger brother had damage to his frontal lobe from birth and was diagnosed with Cerebral Palsy and profound ID at a young age. As the only girl, Hannah took on many responsibilities around her home growing up and was the primary care provider for her younger brother with ID. Hannah reported that she was forced to grow up very quickly because of her parents' decision to designate her as her brother's caretaker. Once her brother got older, Hannah and her parents made the decision to place her brother in a state institution. After only a few years, Hannah and her parents brought her brother back home after a physical incident.

However, because Hannah was getting married and starting her own family, she and her parents decided it was best to take her brother back to the institution. He resided at the state institution for a total of 40 years until moving to the community in December of 2013.

*Participant 19 – Zoe*

Zoe is in her mid-sixties and is the oldest of three siblings. Zoe's siblings were five years younger than her and twins. Just after birth, the female of Zoe's twin siblings died. This was not the first time Zoe's mother had experienced loss, as she had two previous miscarriages before Zoe was born. At birth, Zoe's parents were informed of her younger brother's disability, and he was later diagnosed with Cerebral Palsy and profound ID. After receiving recommendations from their doctor, Zoe's parents made the decision to place her younger brother in an institution because they believed it would be the best care for him. He lived in the state institution for 51 years before transitioning to the community in July of 2013. After her mother's death, Zoe became the legal guardian of her brother.

*Participant 20 – Melanie*

Melanie is in her mid-fifties and has six siblings. She is the sixth of seven children and serves as the legal guardian for her older sister, second oldest of all seven children. During her interview, Melanie was unexpectedly joined by her brother and sister-in-law. However, because of their limited responses, their participation was excluded from data analysis. When Melanie's sister was about three years old, she accidentally fell into a water well and hit her head. Her fall led to severe brain damage, and she was later diagnosed with severe ID. Her sister remained at home until adolescence, when she began to exhibit severe behavioral issues. Her parents sought help from a psychiatrist who suggested placing Melanie's sister in an institution. Her sister remained at the state institution for 50 years before moving into community housing in September of 2013. Melanie reported that she was not happy with her sister's care in the institution, but was also not in support of deinstitutionalization.

### *Participant 21 – Ethan*

Ethan is in his early fifties and is the youngest of three siblings. Ethan's second oldest brother is deceased. At the age of three, Ethan's family first noticed his oldest brother showing signs of developmental delay. His brother was later diagnosed with Autism, Schizophrenia, and severe ID. At the age of 13, his family took Ethan's older brother to a children's facility in Oklahoma. Ethan remembered being shocked and horrified by the structure and overall facilities of that specific location. After only living there for a short time, his brother transitioned to the state institution where he resided for 47 years before transitioning to the community during the summer of 2014.

### *Participants 22 & 23 – Autumn & Sean*

Autumn is in her early sixties and is married to Sean, who is in his mid-fifties. Autumn is the second oldest of four children in her family. Her older brother has diagnoses of Cerebral Palsy and profound ID. Because she was younger, Autumn's knowledge about her brother's initial diagnosis is limited. Autumn reported that her older brother was first placed in a specialized care facility for individuals with cerebral palsy before moving to the state institution at the age of 16. He resided at the institution for 48 years. Autumn and Sean serve as her brother's legal guardians and described their current relationship as more of a parental role rather than a legal or sibling role to Autumn's brother.

## **Central Category**

### **Ambiguity**

The purpose of the central category in grounded theory methodology is to narrow the findings from each phase of analysis into a key concept in order to connect the major categories and subsequent subthemes which help to describe the overarching theory of the current study. When interviewing participants about their experiences of having a child or sibling with intellectual disability, as well as their experiences with making decisions for their loved ones' care across the life course, all participants described feelings of uncertainty and indefinite

emotional experiences.

Parents and siblings provided abstract responses that hinted at a lack of clarity and feelings of ambiguity related to the many aspects of each transition and the meaning it had for their families. Participants seemed to respond matter-of-factly, with common responses and phrases such as “We do what we have to do. You know, it’s just that simple.” When asked to expand on the emotions or processes behind their experiences, participants struggled to provide language or clarity regarding their intra or interpersonal processes.

Other times, ambiguity appeared within parent and sibling responses that were incongruent with the emotionality of the topic of discussion. For example, some parents and siblings would laugh when using words like “trauma” or “shocking” to describe what it was like to receive their loved one’s initial diagnosis or how dramatically impacted their families were once their loved one with ID moved out of the family home. Additionally, it was not uncommon for participants to respond to questions or requests for elaboration with “I don’t know” and long pauses, indicating hesitancy and uncertainty as to the right words to use to describe their intra and interpersonal processes. At times, participants seemed as if they were stopping themselves from saying the wrong things or redirecting the conversation away from vulnerable topics and difficult emotions by using humorous comments to describe their loved one, such as “But she’s just so cute.”

The qualitative interviews were analyzed first, within each participant, then, separately within parents and within siblings, and finally, across all siblings and parents. As a result of this ongoing analysis, the continuous reports of uncertainty and vagueness regarding individual and family emotional processes across the life course from all participants emerged leading to the central theme of “ambiguity”. The following theoretical model was developed in order to provide a visual representation of the major categories and subcategories in relation to the central theme of ambiguity for families of individuals with ID (see Figure 1).

Although the manner and feelings in which family members described their experiences

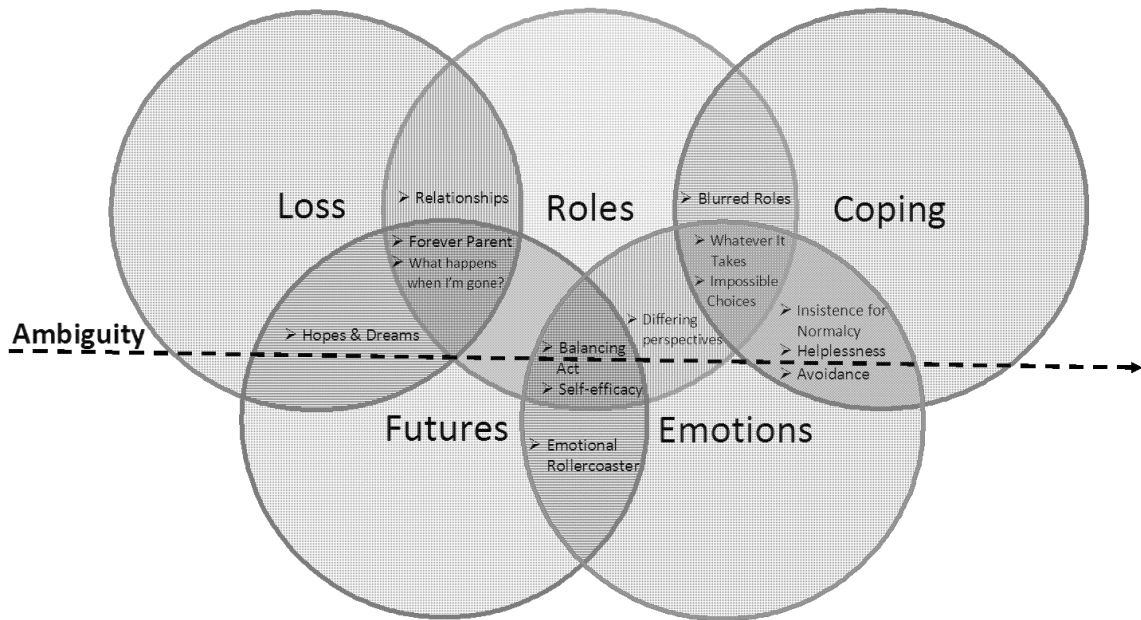
with having a loved one with ID and the family processes that occurred over time differed based on individual experiences, across all interviews, five major categories were consistent. The five major categories across the 19 interviews included (a) ambiguous loss, (b) ambiguous futures, (c) ambiguous roles, (d) ambiguous emotions, and (e) ambiguous coping. The following section first introduces and describes the major categories. These descriptions are focused on the similarities shared across interviews with parents and siblings. Descriptions of the major categories will then be followed by further explorations of the relationships between and across the various categories and subcategories. While it is important to highlight the major categories and how themes emerged across participants, the process of how such categories and subcategories relate to one another over time helps to describe the overall experiences of families of individuals with ID in greater depth. The matrix, shown in Figure 1, represents the relations between all categories and subcategories, as well as the central category of ambiguity. The relations between categories are represented by overlapping circles, highlighting how each category is impacted by the others. The overlapping of subcategories provides additional support for the central theme of ambiguity, in that families of individuals with ID often experience numerous family and individual processes simultaneously, creating even more intense experiences of instability and ambiguity. The following section will highlight the integration of individual and family processes across all interviews and present the relation between the major categories and their various subcategories.

## **Major Categories**

### **Category 1 – Ambiguous Loss**

Although the experiences of each participant and family varied across the lifespan, many parents and siblings described experiences of loss and grief at different points across their loved one's development. When asked about experiences of receiving the initial diagnosis of ID for their child or sibling, themes of an ambiguous form of loss emerged. Additionally, themes of loss re-emerged as participants described the process of first placing their loved one in a state-run institution, suggesting family members often experience varying forms of unclear and ambiguous

**Figure 1.**



losses simultaneously. When asked about her opinion of her parents’ decision to place her brother with ID in an institution when she was a young girl, Aubrey compared her experience to a “divorce” and as an unwanted “separation.” Aubrey reported:

When you love them and you're used to being with them, and you do everything with them, and they can no longer live in your house, that's just, that just shouldn't happen. It was like a divorce I guess in a way, but I didn't want that divorce. I didn't want that separation. Somebody said I had to have that separation.

Participants experienced varying types of loss with different transitions, including a unique form of psychological loss of their loved one with ID that accompanied family stressors, while others described the physical loss but psychological and emotional presence of their loved one during other transitional points.

Ambiguous loss theory (Boss, 2006) describes one of the two forms of ambiguous loss as a psychological loss or absence of an individual or desired experience while still having the

physical or tangible presence of that specific individual or construct. Parents experienced a unique form of psychological loss upon the initial receipt of their child's disability while still having the physical presence of their loved one in their lives. Olivia described the psychological loss she experienced after learning of her son's diagnosis of ID, "It's like having a child who was alive but dead. You know, everything is gone, but the shell."

Because many siblings were either yet to be born at the time or too young to recall their experiences of learning about their sibling's diagnosis, sibling reports of experiences regarding the receipt of diagnosis were limited. However, when discussing the experience of first placing their child or sibling in an institution, parents and siblings described an unclear and unique form of physical loss.

Narratives from parents and siblings were consistent with Charlotte's description of placing her daughter in an institution as a form of physical loss while still having the emotional presence of her daughter, "It was like losing a child." Olivia, whose first child died at a young age, described her experience of institutionalization as a type of trauma and compared it the prior loss her family endured, "Oh, taking him [to the institution], that was pretty traumatic. That was harder than burying my first child." She continued describing how it felt to have a child living away from the family, "He was alive, but I had to leave him. It's like a living death."

## **Category 2 – Ambiguous Futures**

From the moment parents first received their child's diagnosis of ID, many parents experienced immediate overwhelming fears as they faced an uncertain and ambiguous future for not only their child with ID, but for their family as a whole. Struggling with letting go of their original hopes and wishes for their loved ones and families, family members experienced many intense emotions of sadness, fear, and worry for extended periods of time and during different transitions. Caroline described being flooded with concerns about how her son would fit in with others his age within moments of learning of his diagnosis, "I'm thinking, 'he's not going to be able to do things normal kids do.'"

### **Category 3 – Ambiguous Roles**

In addition to experiencing unique forms of loss and feelings of uncertainty about what the future would hold for their loved ones, family members continuously described feeling unclear about the role they currently played and would play in their loved ones' lives over time. This uncertainty in roles often led family members to question their own worth as parents and caregivers. While family members expressed knowledge that placing their child with ID in the institution was in the best interest of their children's well-being, narratives highlighted the continuous battle over their decision many family members faced over time. Parents were often hard on themselves for the decision they made to institutionalize their loved ones and continuously wrestled with their own justifications for their decision. Olivia discussed the difficulty with accepting that she could no longer provide quality physical care for her son,

I wouldn't have been able to take care of him. That's probably one of the hardest things as a mother that I had to face and that is that someone else could care for my child better than I could.

### **Category 4 – Ambiguous Emotions**

Family members expressed a range of emotional experiences across the lifespan, including sadness, guilt, anger, grief, and acceptance. The breadth of emotions experienced by parents and siblings were present at various points across the lifespan and during various transition periods. While many different types of extreme emotions were highlighted by all participants, there was a lack of consistency regarding the type and duration of such emotions across interviews. Additionally, context causing such emotional experiences and how participants responded to such individual and family emotional processes was limited. While no specific emotions were saturated across all interviews, the ambiguity and variation in emotional processes and responses to different experiences across almost all parent and sibling emerged as a fourth category supported by ambiguity.

When discussing their emotional response when making the decision to place their child



in an institution, parents provided equivocal, yet powerful descriptions of the difficulty of making such a decision. Caroline, who placed her son in an institution at age eight reported, "It was like pulling my heart out." Polly and William described a similar experience after dropping their son off at the institution for the first time. They added, "We cried all the way home. We both said, as soon as we pulled out of the drive, that it was just like someone reaches in, grabs your heart, and pulls it out."

### **Category 5 – Ambiguous Coping**

A final category in which ambiguity was present throughout parent and sibling narratives was coping. When discussing how family members coped with the experiences of receiving initial diagnoses of ID of their child or sibling and the numerous stressors and transitions their families underwent over time, many families suggested they did their best to be a "normal family" or they "just adjusted to it." However, participants provided little information regarding how or why they desired such normalcy or what adjustment looked like for their families. When asked follow-up questions regarding what coping looked like or how their families bounced back and adjusted to the stressful transitions, parents and siblings were unsure of exactly what those processes looked like and were unable to provide details into their families' adaptive processes.

Family members suggested a "go with the flow" mentality in order to cope with the challenges they often accompanied with having a loved one with a disability, and suggested that resilience means, "you just cope." Other family members discussed that many of the stressors and challenges they faced were out of their control and suggested that over time, feelings of helplessness left family members no choice but to accept a new way of life. Charlotte and Owen described, "We just took what came. At some point you've just done everything you can do." They vaguely added, "We adjusted to it. Sometimes there's nothing more you can do."

While some family members described a desire or insistence to move on with their lives as "normal" as possible, a few parents and siblings indicated that they directly faced the

challenges and changes to their families. However, they did not provide detail of what that process looked like or how they were able to reach such a place of acceptance. Family members' vagueness may suggest family members attempted to protect themselves from the more challenging experiences of having a loved one with ID by minimizing their true feelings, or family members felt they had no other choice but to overcome the associated risks, and therefore, accepted the new normal in order to survive as a family. When asked about how her family responded to learning about their loved one's disability, Olivia stated, "I think they had just accepted this is the way things are. This is our life."

### **Relation between Categories and Subcategories**

Presented below are the relations found between and across the major categories and their subsequent subcategories. The purpose of this section is to integrate individual and family processes across all interviews. While the central theme of ambiguity creates a challenge for identifying specific experiences among all participants, it also adds to the findings by explaining the unique and unclear experiences families of individuals with ID experience across the lifespan. The connectedness between categories highlights that families are not faced with a single challenge or decision at any point across their loved one's development, but instead are faced with numerous stressors simultaneously and often for extended periods of time.

### **Loss and Futures**

When describing their experience with having a loved one with ID, twelve family members discussed feelings of loss at different periods across time. However, the losses described were not limited to the physical losses of having their loved ones living outside of the family home or the psychological loss many parents described when referring to their child's diagnosis. A relation between the major categories of loss and futures emerged as family members described a loss of the hopes and dreams they had imagined for their child before learning of their diagnosis of ID.

*Loss of hopes and dreams.* When asked about family members' initial responses to the gained knowledge of their child's diagnosis, eight family members described experiences of loss regarding what they had always imaged for their loved one's future. After first learning of her daughter's disability, Scarlett discussed feelings of disappointment that her daughter would never live up to the expectations she had originally set for her. She remembered thinking once she received the initial diagnosis, "She wasn't going to be what we expected her to be."

One parent described how the physical characteristics of their child's disability also served as a visual reminder of the future hurdles their loved one would face over time. Olivia reported,

I think just every time I would see him, it was just a reminder to me that my hopes and dreams for him were crushed. And it was hard me for to understand just why this happened. However, when you reach that point where you accept them for what they are and stop wishing for what you wish they were, then it makes it pretty easy to love them the way they are.

### **Loss and Roles**

Family members also experienced feelings of loss regarding their past, present, and future roles in their loved ones lives.

*Loss of current, future, and past relationships.* When loved ones were placed in the state institutions, it created a unique shift in family dynamics that impacted the way parents and siblings viewed their roles in their loved ones' lives and in their family systems at the time. Family members described that when their loved one with ID left the family home, relationships were dramatically altered and that some relationships were completely lost as a result of institutionalization.

When asking about what current relationships looked like for family members, Jackson reported, "My relationship with [my brother] ended when I was about six years old." Jackson was referring to the age when his mother made the decision to move his older brother to a state

institution. This shift in the relationship between brothers continued into adulthood as Jackson went on to describe his role in his adult brother's life while living in the community as "a stranger." Siblings also described feeling deprived of the opportunity to have close relationships with their siblings as children while they were away from the family home. Hannah, whose brother lived in the institution for 40 years, stated, "Years I went without [my brother]; years [my brother] went without me! And I have been so deprived from being with him..."

Many parents were aware of lost relationships between siblings that took place after their loved ones with ID were placed in the institutions; however, parents felt as if there was not much they could do to help nurture these detached relationships. When describing her youngest son's relationship to his sister with ID, Anna stated, "[My son] didn't have a relationship with [my daughter]." She went on to say, "Long gone and out and away. She was just a myth to him."

Scarlett discussed that after she placed her son in the institution, her daughter's relationship with her sibling ended. Referring to how her youngest daughter responded to her brother moving away from the family home, Scarlett reported, "And all of a sudden [my daughter] was the only child."

After experiencing such a unique and unclear form of loss through institutionalization, siblings' ability and willingness to form close bonds with other siblings and family members was dramatically altered. Olivia discussed how the loss experienced when she institutionalized her son with ID led her oldest daughter to be hesitant to form close relationships with her younger siblings: "[My daughter] was the one that was really, really devastated and after having just lost her brother not that long before. I personally think that when we adopted the last two brothers, she never did become close to them."

One participant discussed that the stepparent roles within his family were challenged with having a sibling with ID. When faced with the emotional and physical challenges of having a child with a disability, Jackson described that his step-father provided his mother with an ultimatum of either placing Jackson's brother in an institution or his step-father would leave the

family. Jackson stated, "I don't know if that's the reason our dad left or not, but having [my brother] around was sort of hampering [the family]." He added, "I just remember listening to [my step-father] complain about how [my brother] was holding him back"

While this "forced" loss of relationship between family members was limited across interviews, Charlie's experience described above represents the constant challenges of maintaining positive relationships with loved ones with ID and others when families were faced with extreme stress.

Family members also described experiences of loss for their loved one with ID when discussing their opinions of deinstitutionalization. Parents and siblings discussed concern regarding the loss of close relationships their loved ones had formed over time while living in the institutions. Chloe, whose sister had lived at the institution for 58 years, shared how difficult it was for her to witness the loss of long-term companionship her sister experienced as a result of transitioning to the community: "When they took [my sister's friend] away from [my sister], it was like taking away her mate." She added, "It's like, you know, taking away their family from them. It's like these people are dying."

### **Futures and Roles**

Subcategories emerged across interviews that connected the categories of futures and roles. Many family members described constant concern for the next phase of life regarding their role in their loved one's lives over time.

***Forever parents.*** Many parents discussed an immediate concern for their future role as caregiver after learning more about their son or daughter's disability. Parents described seeing no end to their role as caregiver, compared to most parents whose major caretaking responsibilities diminish once their child reaches adulthood. Eva stated, "It looked like I was going to be a forever mother of a little boy."

In contrast, other parents described a desire to outlive their loved ones with ID in hopes of maintaining an ongoing caregiver role until the end of their adult child's life. When asked

about hopes for her future relationship with her son, Oliva reported,

I would like to be the one to put him to rest forever. That's my hope for him. For now, whatever will be will be, but I hope before I go, he does so I can finish my last bit of care. My prayer is that [my son] would die before I do so that I can finish taking care of him. That's something I want to do.

*What happens when I'm gone?* While some family members questioned what their role would be across their loved one's development, almost all participants expressed concerns about what future care for their loved one would look like once they were no longer living. Parents and siblings, alike, questioned what would happen to their loved one once they were no longer able or available to oversee their care. Ethan stated, "I do worry about what would happen to [brother] if something were to happen to me AND my wife." Hattie reported, "If I die first then I don't know what he's going to do without ME, and I don't know what I'm going to do with HIM."

Narratives from both parents and siblings included the ongoing questions and uncertainty regarding future care for their loved ones and what role they would play across their loved ones' lives. Parents and siblings expressed constant uncertainty and concern as to who would be responsible for their loved one once they were gone. Eva's initial response to her son's diagnosis included immediate questions about his future. She recalled asking herself, "How is he going to live his life?" Eva expressed that her uncertainty and questions regarding her son's wellbeing continue today, some 60 years later, as she worries about who will care for him after she is no longer living, "How does this all work out after I'm gone?" She continued, "What's going to happen to him when I'm gone?"

Similar fears and questions regarding the future of their loved ones' care were present for family members during the institutionalization process. When discussing what it was like to make the decision to place her daughter in an institution, Scarlett described an ongoing worry about her wellbeing, "You worry about where she's going to be, and who's going to take care of her. Your primary concern is who is going to be taking care of her. You know, is she going to be okay?"

## **Futures and Emotions**

*Emotional rollercoaster.* Family members highlighted numerous examples of extreme emotional experiences at different transition periods across the life course. One transition period that evoked the most extreme, yet ambiguous emotional responses from parents and siblings appeared following the institutionalization of their loved one. The breadth of emotions experienced by parents and siblings varied from grief to resentment and often occurred at various transitions and in conjunction with numerous emotions at different points across time.

Aubrey described the emotional toll of re-experiencing feelings of grief and loss each time her family left her brother after their weekly visits to the institution:

It was so difficult for us to leave him and so was it difficult for him to see us go. That was an emotional trauma for us EVERY WEEK. I think really, that was probably the most dangerous thing that happened in our family was when the officials at the institution requested for us to stop coming. We began to not really communicate well as a family anymore. Bitterness really, I think, set in for everybody.

## **Roles and Emotions**

When discussing the emotional experiences of having a loved one with ID, parents and siblings shared many commonalities while also expressing very different themes depending on their specific family role (i.e., parent versus sibling). While parents and siblings expressed similar emotional experiences across the lifespan, the timing of such emotional responses differed significantly. Parents typically experienced negative emotions earlier than siblings because of their experiences with receiving their children's' initial diagnoses. The emotions parents described included fear, sadness, loss, shock, and anger. Siblings, however, provided fewer examples of their initial responses to receiving their siblings' diagnoses due to the fact that many were too young to remember or were yet to be born at the time. While the timing of siblings'

negative emotional experiences came much later compared to parents and was related more to the institutionalization process, siblings described experiencing similar emotions across the life course.

*Differing perspectives.* The decision to place loved ones with ID in institutionalized care created tension between many family members over time. Siblings described feeling resentful towards their parents for making such decisions for their family and expressed present feelings of anger toward their parents for their decisions, regardless of whether they were able to acknowledge the difficulty of making such a decision. When discussing how he felt about his mother's decision to place his brother in an institution, Charlie stated, "In my opinion, it's the rudest thing a family can do. It's not your fault how you're born. I don't believe in that."

Because most families were encouraged by medical professionals to place their children in out-of-home care, parents felt as if they had no other choice but to place their children in the institutions. Parents' decisions were fueled by their desire to do the best thing for their children. In contrast, siblings described difficulty with understanding their parents' perspectives at the time of institutionalization. Additionally, siblings reported currently having residual feelings of resentment toward their parents even into adulthood. When discussing how she felt about her parent's decisions to place her brother in an institution, Aubrey reported, "Obviously I'm bitter. I wish the decision [to institutionalize him] hadn't have been made. [My siblings and I] begged them not to take him."

### **Futures, Roles, and Emotions**

As mentioned previously, parents often felt a lack of control over the decisions they were making regarding the future care of their children with ID. Parents often experienced extreme emotions, including guilt, sadness, and hopelessness, as a result of the difficult decisions they encountered. At the same, parents discussed feeling that they made the decisions that were best for their families.



**Balancing act.** After receiving initial diagnoses, family members were faced with difficult decisions regarding the future care of their loved ones with ID. Parents discussed having the pressure of outside perspectives of what was best for the future of their child with ID and their other children. Many families were given professional advice to place their loved ones in institutions. Yet, parents still struggled with deciding what was best for the family as a whole. This balancing act of deciding what was best for their child with ID and the rest of their family led family members to feel an array of emotions simultaneously. On one hand, parents felt sad and guilty about their decision to place their daughter or son in an institution while also feeling relieved for the rest of their family. Beth and Elliot, parents of three children including their son with ID, reported, "One of the dilemmas you run into with this kind of situations is, you have to build a balance between your other kids, your handicap kid, and your family."

Parents also described reaching a point in their son or daughter's development when they had to face the fact that they could no longer provide the adequate care their child with ID required. When asking how she came to the decision to place her daughter in the institution, Scarlett discussed how she avoided thinking about how she was not able to provide the care her daughter needed in order to make an objective decision, "You don't think about that, you know, you can't. We had to do something because we weren't helping her. The main thing is we wanted what was best for her, and what was best for us too."

Even after placing their loved one in the institution, the difficult decisions did not end for family members. When discussing visitations to the state institutions, almost all family members described that their families continued to experience difficult emotions and repeated experiences of "trauma" and grief after each visit. Parents were faced with difficult decisions regarding what was best for the overall wellbeing of the family. When discussing her personal struggle with remaining emotionally available for her other children at home after visiting her son at the institution, Olivia stated,

I would always come home so depressed. I mean, every time I was shocked for

about four or five days after I'd go visit because it was just so depressing. So eventually I just thought, 'You know what, he doesn't know me, and I'm doing nothing but shorting myself and my family that I have at home.

She continued,

I wanted to go see him, but I could see [my daughter] was just falling apart over [my son's absence]. I had the whole family at home that I needed to take care of and hold together. It really hurt to leave him there and not to go see him a lot, but I knew it was the right thing to do.

Other parents described a similar experience of balancing being involved in their child's life while they resided in the institution while still being emotionally available for their other children and spouses. When discussing how her role in her family was altered by constant visitations to the institution, Olivia reported, "I began to notice that, emotionally, I was a wreck for several days. I just really could basically get nothing accomplished, and I knew my kids were going to suffer from it. I just needed to take care of my family."

While siblings struggled with understanding their parents' perspectives as young children, they experienced similar processes once they became the legal guardians of their adult siblings. Siblings expressed a constant back-and-forth battle of balancing their new role as guardian with care for their own families and individual wellbeing. Zoe stated,

Yeah, being a guardian is emotionally draining to me. It's something I can't...I have a job to take care of. I have a husband. I have other things. But now I'm having that guilt feeling of I can't be there every two or three days. You know, who's going to keep an eye on this if I don't?

She continued to describe the balance of being her brother's guardian and moving forward with her own life,

Well, I mean my husband and I are getting ready to retire in a year and we would

like to think about moving. I'm not going to be able to do that. Even if I thought I could be some place where I thought I'd be able to get back [to my brother] frequently, I'm not willing to not have some contact into what's going on. I'm not comfortable leaving.

Siblings also struggled with balancing their role as guardian with their role as sibling into adulthood. When discussing their present role in their adult sibling's lives, siblings described a desire to make up for lost time and to form new and close relationships with their siblings. Because it was a common response for siblings to feel cheated out of a close relationship with their brothers or sisters with ID as children, siblings often over-functioned in their current relationships with their adult siblings, which often impacted their relationships with their current families. When discussing how her role as guardian affected her current family, Hannah stated, "It's not about my time, but about jealousy. My warning to my husband and children was that when [brother] arrives at our home, the very day he arrives, they can go float their own boat."

*Self-efficacy.* The emotional difficulty of placing their child in someone else's care seemed to create questions of self-efficacy for caregivers across the life course. Parents and siblings alike questioned the quality of their previous and current roles in their loved ones' lives. Parents described a struggle with the incongruence between their anticipated role or expectations of themselves as parents and the reality of their inability to meet the overwhelming needs of their child.

Caroline described the difficult journey towards acceptance over the fact that she had not been the one to provide care for her son for most of his life. She reported,

I feel like that God presented me with this child and the number one thing I can do for this child is love him. And just like all the other changes, the transitions that he's gone through, it hasn't been me that has taken care of him.

Reflecting on the day her parents first took her brother to the institution, Zoe described the double bind families of individuals with ID often face: "I remember that day that they came home after

dropping [my brother] off. How hard it must be for you to turn your child over to the care of strangers, but my mother would've been dead."

Zoe went on to describe what she believed it was like for her mother to make the decision to institutionalize her brother. She described the constant emotional battle with feeling inadequate that she felt her mother must have endured regarding her role in both her brother and Zoe's lives: "Somebody else was doing the job that maybe [my mother] should've been doing. And she felt inadequate that she could not do that."

Olivia described the constant battle with insecurity many parents and siblings experience as caregivers across their loved one's development. Describing her perspective of how her father felt about her brother moving into the community after the closing of the state institutions, Olivia stated, "I think he feels guilty because he's not got him in the home taking care of him."

Similar to the experiences of parents, siblings also struggled with questioning their own self-efficacy as guardians and siblings. Much like the difference in timing of emotional responses to institutionalization, siblings also questioned the effectiveness of their role as caregivers much later in their sibling's development compared to parents. The biggest questions about self-efficacy with sibling roles was present during later adulthood, after siblings had taken over legal guardianship of their brother or sister with ID. Ethan, who is the legal guardian of his brother, stated,

I love my brother. That's one thing I WILL say is that you know, I'm never going to turn my back on him completely. I often feel like I'm not doing ENOUGH. I feel I ought to be there [with him] every day. But at the same time, you've got to make a living; you have to do things that you have to do for your own children. But I'm not ready to just dust him off. Hell, he's 54 not 84.

These questions of worth and self-efficacy as guardians was most evident during their loved ones' transition to community living. When asked about how she viewed her current role in her sister's life, Melanie was overcome with emotion as observed by her inability to hold back

tears as she reflected on the balance of being a sister and a legal guardian:

Well, I see her as both [a sibling and my child], but I'm her voice. And I worry sometimes, 'Did I make the right decisions?' I look at her and I say to her, 'Am I doing what you need done?'

### **Roles and Coping**

When discussing the roles family members played in their loved ones' lives across the life course, many family members noted their roles adapted over time in order to meet the needs of the family. Siblings often took on more adult roles as children in order to help their parents with the care of their sibling with ID. The magnitude of responsibility that came with providing care for their growing sibling led many siblings to feelings of resentment toward their parents. Hannah reported,

I had a resentment against my mother for taking my childhood away from me. [My brother] was my total, I mean it, was my total responsibility. I was almost a momma role. I was thrown into that role for a long time. [My brother] did see me as mom.

**Blurred roles.** Many family members described that their role of parent, sibling, and guardian merged overtime in response to what was needed for the family at any given point. After their loved ones with ID had transitioned into the community, many family members discussed the roles they established when their loved ones were younger had shifted. When asked whether family members felt more like parents and siblings or guardians to their loved ones after their transition to the community, "both" was a common response.

Some family members described feeling as if they took on completely different roles when their loved one reached adulthood. Autumn, older sister and current legal guardian for her brother, discussed how her role as sibling shifted once her brother reached adulthood because of the different responsibilities required from her as a legal guardian. When asked how she viewed their current role in her brother's life, Autumn stated, "I think more as a parent, anymore.

Because he's just like a little kid, you know." She added, "[My husband]'s kind of like the daddy, and I'm the momma." Scarlett discussed how parents also experienced a shift in roles over time. She viewed her current role in her adult son's life as "more as a guardian."

One parent described her current role as more distant now that their adult child was in the care of community staff. When describing how she viewed her present role in her daughter's life now that she was living in the community, Anna stated she felt more "like an aunt or a distant relative."

### **Coping and Emotions**

When discussing how families responded to the many challenges they faced over time, additional subcategories emerged that connected the emotional and coping experiences that took place for many families.

***Insistence for normalcy.*** Family members suggested a desire to move on with their lives as normally as possible, despite the significant, life-altering transitions they faced after receiving an initial diagnosis and after they moved their loved ones to the institutions. The desire to be viewed as "normal" compared to families who do not have family members with ID created a trend for family members of minimizing how they truly felt about having a loved one with ID and their perspectives on the associated challenges.

Six family members described that it was difficult at first for their families, including extended family members, to accept that their loved one had a diagnosis of ID. Eva stated, "No one wanted to accept that he was handicapped. They wanted him to be normal." She added, "We did as much for him as we could do to be like a normal child."

One parent discussed that their desire for normalcy was fueled by their concerns of how their other children would be affected by having a sibling with a disability. When discussing how their other children were impacted by having a brother with ID, Beth and Elliot stated, "We tried to keep it absolutely normal for the girls even though you know it wasn't normal to have him."

Other family members suggested that over time, families with individuals with ID reach a

point of acceptance by acknowledging what the new “normal” looks like for their families.

Jackson, when describing how his family adjusted to having a brother and son with a disability and what it was like for him to have his brother move into the institution, reported, “It was just natural stuff. Just natural.” He continued, “You know, when anybody moves away, you miss them being around. Pretty soon, having my brother out of the family home was just a normal deal.”

**Helplessness.** Many family members noted feeling a lack of control over the many transitions that took place for their family across time. These feelings of helplessness left many families with no choice but to accept their current circumstances. When discussing how their family was able to remain resilient with the many risks they had faced, Charlotte and Owen stated, “Sometimes there's nothing more you can do.”

When deciding the best option for the care of their children with ID, most parents highlighted a lack of available resources in Oklahoma and that there were no other options but to place their children in the institutions. Zoe, while reflecting on her parents’ decision to institutionalize her brother, reported,

But I think a lot of it had to do with the financial ability and resources. If my parents had been wealthy or well off they probably could’ve paid somebody to be there all the time but they didn’t. There was just nothing. There was NOTHING to give [my brother] any kind of quality of life.

Other family members noted how the professional advice their families were given regarding care for their children with ID, impacted parents’ feelings of helplessness. Melanie stated, “I think momma did the best she could because you don’t know and you’re listening to the doctor, and you’re thinking they’re telling you what needs to be done that’s best for her.”

Jackson, reflecting on his parents’ decision to institutionalize his brother, added, “Well, I don't think they had a choice. [The professionals] said that's where you need to put them.”

**Avoidance.** In addition to feeling helpless during transitional periods across the life course, avoidance was another popular emotional process used by parents in an attempt to

protect their other children and family members from adversity during different points of transition. Family members described a lack of communication within the family about their loved one's transition, as well as a lack of communication regarding how each member felt after their loved one being taken out of the family home. When discussing what family communication looked like regarding their loved one's disability and the institutionalization process, parents and siblings suggested little information was shared between family members. When asked how about how Scarlett's younger daughter responded to the institutionalization of her older sister, Scarlett stated, "I never really discussed how she felt with her, and I probably should ask her."

Family members also suggested they suppressed their true feelings after placing their loved ones in the institutions in order to protect their other children and family members. When discussing how she coped after placing her child in an institution, Beth described how she attempted to shield her other family members with a positive persona when interacting with her other children and spouse, but would succumb to the more negative emotions when alone. Beth reported,

For about a month after [institutionalization], [my husband] didn't know this at the time, but I'd get the girls up and out [to school] and then I would go back to bed. And I'd stay there until I heard the school bus come back, and then I'd get up, make the bed, and act like I'd been up all day.

### **Roles, Coping, and Emotions**

Expanding on the primary themes already discussed, family members discussed that in order to survive as a family, many of the family dynamics had no option but to shift over time. This process often presented family members with difficult choices regarding care for their loved ones with ID, while again, balancing the family system as a whole. Thus, subcategories of "whatever it takes" and "impossible choices" emerged, connecting the major categories of ambiguous roles, coping, and emotions for family members over time.



***Whatever it takes.*** When faced with stressors, family members were left with no choice but to adapt to the challenges they were faced with. This often resulted in the relocation of families in order to be closer to resources for their child with ID or a larger support system for the family. Zoe noted that her family moved in order to have better care for her sister, "The reason we moved back to Oklahoma was because [my parents] needed to be close to my mom's family where she had some support system."

Other family members noted the sacrifices they made for their families during times of stress, including changes to careers and social systems. Hattie stated, "It was a terrible experience I had with [my son]. It made me cry easily. I had to quit my job for a while because I had to take care of him."

***Impossible choices.*** Family members discussed being faced with numerous decisions over time that felt almost impossible. These difficult choices often placed family members in double binds, leaving them in what felt like no-win situations. For example, parents struggled with making choices that would benefit their sons or daughters with ID without negatively impacting their other children or their relationships with others. Eva's response suggested parents often faced these difficult decisions upon the initial receipt of their child's diagnosis, specifically when that information was gained while their child was still in utero. She reported, "I didn't want to end [the pregnancy], but yet I didn't want him to be born in such a condition."

Across parent and sibling narratives, it seemed that the most challenging of decisions was the family's initial decision to place their loved one with ID in an institution. Advice from outside parties, including extended family and medical professionals, only exacerbated the difficulty with making such decisions. Aubrey stated, "Everyone said, doctors and professionals, said at that time that [institutionalization] was what you needed to do for you and your family." She continued to discuss how she came to terms with the difficult decisions she had to make, "That seemed to be the common thread in both of the conversations regarding whether or not to institutionalize, that I remember thinking, this is for the family."

Anna added, “People would say, 'You can't keep her at home. You must do something else with her because she's going to get big.’”

Reflecting on their experience of receiving advice from their doctor when their son was first diagnosed with ID, Beth and Elliot reported,

That was the advice we were given: ‘You need to put him away, forget about him, and go about your business.’ And there are people who do that. The professional advice we were given early on is that you just need to put him away and forget about him.

## CHAPTER V

### DISCUSSION

In order to develop a theory that is grounded in the literature and current data, it is important to link the emerging theory to the existing literature and to provide hypotheses for better understanding the current population based on the findings. Comparing the results to the existing literature is the final step in confirming the results of a study using grounded theory methodology (Creswell, 1998; Strauss & Corbin, 1998). Participants' discussions of their experiences of having a loved one with ID suggest that family members often experience various intra and interpersonal processes simultaneously and at numerous transition points across time. Additionally, these experiences are often indeterminate and unique in nature, creating even more intense feelings of ambiguity in numerous aspects of the family across the life course.

#### **Major Findings**

Giving birth to a child is often a very emotional yet joyful experience for most families (Bondas & Eriksson, 2001). After learning about their pregnancy or soon after the recent birth of a child, family members typically begin to make future plans for their child and begin to picture what life will look like for their family over time (Hugger, 2009). They often develop hopes and expectations for their child's future. However, when things don't go as planned, hopes and

dreams are impacted and expectations for family members are forced to change (Hugger, 2009). These are the experiences described by the parents and siblings of the current study. From the moment they learned of their child or sibling's diagnosis of ID, the expectations and hopes for their loved ones, themselves, and their families shifted. The initial receipt of their loved ones' diagnoses that seemed to be the gateway to chronic, on-going ambiguity that impacted individual and family functioning and set family members on a new and unfamiliar path throughout the lifespan.

Participant responses suggest the primary intra and interpersonal processes across the lifespan and during difficult transition points include experiences of ambiguous loss, ambiguous roles, ambiguous futures, ambiguous emotions, and ambiguous coping. Adding to the ambiguity of each transition period for families, including the initial reception of diagnoses and the processes of institutionalization and deinstitutionalization, parents and siblings suggest these unique stressors are not easily predictable and have no clear indication for the duration or frequency of each process. Participants' descriptions of their experiences across the lifespan suggest that from the moment they learned of their loved one's disability, family members began feeling isolated from others families facing "typical" transitions. Family members, parents in particular, were immediately faced with questions regarding the care of their loved one and the wellbeing of their family – questions for which family members never felt there were clear options or answers. Unlike the experiences of families who do not have a loved one with ID, family members' narratives described that expectations for the next phase of life were non-existent and expectations for their loved one with ID were minimal. Each major transition point created more intense feelings of ambivalence that decreased family members' sense of control.

In addition to the unpredictability of each experience, family members' narratives suggested unique relations among the five major categories. Rather than occurring progressively with one process following another, the categories of family experiences seem to have a circular and multidirectional relationship, suggesting that all major categories and experiences of family

members of individuals with ID are interconnected and mutually influenced by one another. Family members of individuals with ID seemed to describe feeling set apart and isolated from others, even other families with individuals with ID, and yet, as illustrated within the current findings, family members of individuals with ID do share common experiences. Family members in the current study shared many similar narratives, highlighting the need for more opportunities for family members to have their voices heard and to hear the voices of other family members who are experiencing similar life phase events. Additionally, the current findings suggest that more effort is needed to consolidate the stories of family members in an attempt to provide a roadmap for families impacted by ID and the ambiguity associated with such experiences.

**Ambiguous roles and futures.** Participants' responses suggest family members of individuals with ID often experience questions regarding the past, present, and future roles for themselves and other family members in the lives of their loved ones with ID. Not only do parents and siblings of individuals with ID often question the future of their personal role in their loved ones' lives, the findings suggest family members are also experiencing concern about the future of their child or sibling with ID, including worries about their loved ones' overall wellbeing and health, future care, and safety, especially when living outside of the family home.

**Ambiguous coping and emotions.** Throughout the process of acceptance and along the road of ambiguity, many family members described how their personal perspectives of family values were challenged, and they were often faced with many difficult decisions for their loved one with ID and their families at different transition points. Continuous questions of what was best for their families as a whole and for their loved ones with ID created a paradox for many family members. Participants reported continuously facing difficult decisions and a sense of lack of control regarding their loved ones' care, which resulted in a sense of stuckness as there was never an answer that seemed appropriate and pleasing for all. Similar to previous findings, each of these experiences was accompanied by intense emotional experiences for both parents and siblings, which only exacerbated the challenges associated with each transition and the impact of

such stressors on family functioning (Goff et al., 2013; Roper & Jackson, 2007).

**Ambiguous loss.** An emotional experience highlighted by almost all participants when describing their experiences of having a loved one with ID included the phenomenon of ambiguous loss (Boss, 2006; Boss, 2010; Goff et al., 2013). An ambiguous loss is a unique form of loss that is often externally caused and traumatic in nature, yet because of the nebulous and indefinite nature of the loss is often nearly impossible to resolve (Boss, 2006; O'Brien, 2007). This study supports previous findings (i.e., Goff et al., 2013; Roper & Jackson, 2007) that found family members of individuals with ID, specifically parents, often experience feelings of ambiguous loss at different times of transition. Parents reported feelings of ambiguous loss upon the initial receipt of diagnosis for their child, marked by the psychological and emotional absence of their son or daughter while still having them physically present within the family (Boss, 2006). Parents also described similar feelings of ambiguous loss for the future of their son or daughter and subsequent feelings for the loss their personal hopes and desires for their child. The initial shock of learning of their child's diagnosis created prolonged challenges of acceptance for many family members, specifically fathers. Previous literature supports the findings of how emotional distressing initially receiving a diagnosis of ID can be for parents and that suggests mothers often experience increased levels of depressive symptoms and distress compared to mothers who do not have children with ID (O'Brien, 2007); However, little is known about the experiences of fathers, and therefore, should be explored in the future studies in order to bridge the gap in experiences for both mothers and fathers who have children with diagnoses of ID.

Moreover, parents and siblings discussed additional experiences of ambiguous loss during the process of institutionalization, marked by the physical loss of their child or sibling after removal from the family home while still maintaining an emotional presence of memories and relationships (Boss 2006). Both experiences of ambiguous loss created unique challenges for family members; however, neither was necessarily described as more difficult. However, with additional transitions over time, the feelings and challenges associated with such losses were

retriggered during times of family stress. These themes fit with the current literature that families of individuals with disabilities often experience ambiguous loss at different points across the lifespan (Goff et al., 2013; Roper & Jackson, 2007). However, the study expands on previous findings of ambiguous loss (i.e., Betz & Thorngren, 2006; Boss, 2006; Boss, 2010; O'Brien, 2007) to include the phenomenon of experiencing both the psychological and physical loss of loved ones with ID simultaneously over time.

Most notable within the findings was the timing of such emotional experiences between parents and siblings. While parents described simultaneously experiencing feelings of loss, grief, anger, and sadness upon the initial receipt of their loved one's diagnosis, sibling reports suggested their first experience with such emotions regarding their siblings with ID did not occur until their parents made the decision to institutionalize their loved one. The institutionalization process evokes an array of emotions for all family members, and parents are forced to make difficult decisions for not only their loved one with ID but also their other children at home (Butterfield, 1977; Tabatabainia, 2003). While parents felt they had no choice but to place their child with ID in the state's care and that their decision was best for their loved one with ID and the larger family system, siblings describe feeling resentment towards their parents, questioning their parents' perspectives of what was best for the family. It wasn't until siblings gained legal guardianship of their adult siblings many years later that they described being able to take on the perspective of their parents and better understand the associated challenges and stress that accompanied decision-making processes for their sibling with ID. Siblings described being faced with similar decisions of those their parents faced early in their loved one's life when they had to make choices about their siblings' care in the community following deinstitutionalization. Similar to the experiences of their parents, siblings described an emotional and physical balancing act between their role in their adult siblings' lives and within their own families.

While previous literature has primarily focused on specific transition periods for families of individuals with ID (i.e., initial diagnosis and institutionalization; Butterfield, 1977; Makela et

al., 2009; Tabatabainia, 2003; Goff et al., 2013; ) and has more so looked at specific diagnoses, such as Down Syndrome (i.e., Dyke, Bourke, Llewellyn, & Leonard, 2013; Goff et al., 2013; McGrath, Stransky, Cooley, & Moeschler, 2011; Povee, Roberts, Bourke, & Leonard, 2012; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008) and Autism Spectrum Disorder (American Psychiatric Association, 2013; McStay, Trembath, & Dissanayake, 2014; Navot, Jorgenson, Vander Stoep, Toth, & Webb, 2016; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011), the current study aimed to focus more broadly on the overarching experiences of families of individuals with ID across the life course. The current theory provides a visual representation of the interconnection between the major themes in intra and interpersonal processes for parents and siblings of individuals with ID across the lifespan. The model highlights the overlap between individual and family experiences along with the continuous role of ambiguity within family processes. This theory suggests parents and siblings often experience numerous indistinct and ambiguous emotional experiences and stressors simultaneously and that each process is interrelated with one another. Additionally, family members often experience such processes at different transitional points in their loved one's life across time.

As described in the Family Resilience Model (Henry et al., 2015), family adaptation to stressors is often impacted by broader factors. Additionally, a family's ability to make meaning of their experiences and their protective factors influence the family's ability to bounce back when faced with adversity (Henry et al., 2015). The current study supports the role of outside resources and broader influences in family resilience processes. Family members suggest their experiences of family stress were often elevated with the inclusion of outside of opinions (i.e., medical professional, extended family members, community members, etc.), as well as the exclusion or lack of external resources and community supports for their loved ones with ID early in development and into adulthood. Additionally, the model suggests family resilience is influenced by each family member's perception of the risk and their level of vulnerability (Henry et al.,



2015).

Parent and sibling narratives suggest their perceptions of the presented risk, whether the receipt of a diagnosis, institutionalization, or the transition to the community, was heavily impacted by the availability of resources and the family's preparation for such stressors. For most families, they experienced shock and feelings of loss as different transitions because of the lack of control they felt over the loved ones' lives. Further, these stressors were heightened by the lack of resources and preparation they felt at each transition, making them more vulnerable for risk and stress with each new transition (Butterfield, 1977; Tabatabainia, 2003). What was not confirmed from this study was the role of meaning-making in the adaptation process (Henry et al., 2015). As evidenced by the vague and ambiguous responses when discussing risk and resilience, it was not clear how or when family members reached a point of acceptance or adaptation after each transition. Many participants responded with themes of "I don't know" or "we just adapted" when asking about their family's process of adjustment, leaving a gap in the current data for the role of meaning making and family adaptive systems presented in the Family Resilience Model (Henry et al., 2015). Future studies should focus on the role of such meaning-making and adaptive processes within families of individuals with ID in order to better understand family processes of adaptation and resiliency over time.

### **Strengths and Limitations**

Among the strengths of this study were the methodology features and extensive analysis processes that took place throughout the formation of the current theory. Grounded theory methodology provides an in-depth analysis of the current data in order to discover new ideas and patterns that are not necessarily found in previous literature (Strauss & Corbin, 1998). This process includes a continuous, multi-step analysis of the data, using the participants' own words and perspectives to conceptualize specific phenomena in hopes of forming a substantive theory for similar populations (Hylander, 2003; Strauss & Corbin, 1998). Through this process, the principal investigator used continuous internal auditing procedures to increase the trustworthiness

of the study. The internal auditor of the current study was one of two principal investigators of Phase 1 of data collection and analysis, and therefore very familiar with the current data and qualitative methodology. Continuous debriefing of the findings and investigator's interpretations increased the internal validity of the study by providing objective insight into the themes and emerging theory while keeping the primary investigator honest and aware of their personal biases (Creswell, 1998).

In an attempt to further increase the transferability and credibility of the study, external auditing was conducted by a qualitative researcher who was familiar with grounded theory methodology but not associated with the original study or data collection processes (Creswell, 1998; Strauss & Corbin, 1998). External auditing included examining both the process of theory development and the final product in order to assess for accuracy and validity of the findings (Creswell, 1998). The external auditor blindly examined the interpretations and findings in order to determine whether it is supported by the data (Creswell, 1998).

Despite the strengths, the study included limitations worth noting. The first limitation was the small, homogenous sample size of 23 participants. While data analysis reached a point of theoretical saturation across interviews, future studies should attempt to recruit larger and more diverse samples to validate the findings. A second limitation of the study was related to data collection processes. In-person interviews were conducted by one of three graduate students. While researchers were provided with a guided list of open-ended questions, the quality and quantity of follow-up questions to participants' responses varied across interviews. In addition to variance in follow-up questions during data collection, some interviews needed further questioning in order to better understand family adaptive processes. Many participants reported being unsure of how or when their families were able to cope with stressors across the lifespan, and while some interviews included follow-up questions about these processes, many did not. Therefore, in order to better understand how families cope over time, future research is needed to further explore what, specifically, family adaptive and meaning-making processes look like for

families of individuals with ID over time.

A third limitation of the study included the theory's focus on negative and more stressful experiences associated with having a loved one with a diagnosis of ID. While these findings were not consistent across all participants, Polly and William reported that their experiences with having a child with a disability positively impacted their relationship, increasing their ability to communicate with one another and bringing them closer as a couple. While this was not a saturated theme across interviews, it is worth noting because of its consistency with previous literature that highlights the positive contributions for families and parents of individuals with ID (i.e., Blacher, Begum, Marcoulides, and Baker, 2013; Hastings, Beck, & Hill, 2005; King, Zwaigenbaum, Baxter, Rosenbaum, & Bates, 2006). Previous literature highlights that families often express a positive shift in perspectives and beliefs about disabilities and society as a whole, as well as increased empathy for others after raising a child with a disability (Blacher et al., 2013; King et al., 2006). Additionally, parents often express appreciation for their child with ID and the things they have taught them about their personal strengths and abilities (King et al., 2006).

A final limitation that should be noted is that all analyses and the development of the current theory were conducted by the primary investigator. The generalizability and overall creativity of the theory may be limited by using only one investigator. Because of the principal investigator's theoretical lens of trauma and loss, theoretical sensitivity may have been impacted by personal biases and interpretations. As mentioned previously, steps were taken to ensure the trustworthiness and confirmation of the emerging theory through internal and external auditing procedures. However, future studies should consider the inclusion of additional researchers for data analysis in order to bring unique perspectives and depth to the theory. Additionally, the inclusion of member checking procedures should be considered in future studies for confirmation of the emerging theory (Creswell, 1998). Member checking is the process of eliciting participants' views of the findings and interpretations and is often considered by qualitative researchers to be the most crucial step for increasing validity (Creswell, 1998).

## **Clinical Implications**

Although the study included a unique cohort of families who experienced difficult transitions since the 1950s, including institutionalization and deinstitutionalization, the results span across all families of individuals with ID facing unique decisions, challenges, and stressors across the lifespan. Clinicians and professionals have a unique opportunity to serve in various roles for families of individuals with ID. The current theory can assist families today facing unique transitions, including changes in employment, school and graduation, shifts in legal guardianship, and community living.

Families of individuals with ID often struggle to find adequate services and support because of lack of availability or barriers to access, including lack of awareness and knowledge, financial issues, waiting lists, and physical location (Hewitt et al., 2013). However, the support families do often receive is typically state or federally funded, making them primarily dependent on policies set in place by government officials (Hewitt et al., 2013). While families may no longer be facing decisions about institutionalization, they continue to be influenced by others (i.e., extended family, healthy professionals, and state employees) regarding decision-making processes for community inclusion and services for their loved ones with ID. With each new decision and transition they face, families are continuously turning to others for support and answers. Therefore, it is necessary for clinicians to be educated about policy that impacts families and individuals with ID when working with this population. Previous literature suggests family members value competitive employment, independent living, and social relationships for their loved ones with ID when transitioning into adulthood (Henninger & Taylor, 2014). These desires are the types of decisions and difficult transitions clinicians may come to know when working with families of individuals with ID. Knowing what is important to these families during transitions can help clinicians better understand the challenges and needs of such families. Additionally, clinicians can serve as a voice for these family when working in a collaborative care setting.

Additionally, the theory can assist clinicians when working with families and discussing more difficult topics that may evoke unclear and unfamiliar emotional processes with each transition, including conversations around marriage, sexuality, and procreation. Historically, sexuality, intimacy, and romantic relationships among individuals with ID have been topics to avoid by many parents and caregivers. In fact, before being banned in the 1970s, parents and other caregivers favored the sterilization of their children and loved ones with ID (Aunos & Feldman, 2002). However, more recent studies have found that while parents are still hesitant regarding procreation and childrearing by their adult child with ID, they are more open to the formation of intimate relationships (Aunos & Feldman, 2002). In addition, more recent support for sexual education courses for individuals with ID have been found among caregivers, educators, and staff of individuals with ID (Aunos & Feldman, 2002; Swango-Wilson, 2010). While things have changes in recent years, and it seems that family members are more open to topics of sex and marriage, there is still no clear model for how to have such conversations or to assist families with making difficult life phase decisions. Clinicians must be prepared to facilitate conversations with parents and other family members about the legal rights and desires of their loved ones with ID and the family rules about such topics.

Further, the theory provides understanding for clinicians about the challenges many families with a member who has a diagnosis of ID often face over time. Clinicians should acknowledge the interconnectedness of family emotional processes and the ambiguity associated with such experiences for families of individuals with ID. Family members described emotional processes such as grief and loss at numerous transitions over time; therefore, trauma-informed services and interventions may be appropriate for working with such individuals or family members. Previous studies have found the most common and effective psychotherapeutic treatments for individuals and families who have experienced trauma and loss to be Cognitive Behavioral Therapy (CBT; Kira, Ashby, Omidy, & Lewandowski, 2015); Trauma-Focused Cognitive Behavioral Therapy (TF-CBT; Cohen & Mannarino, 2015; Konarnur, Muller,

Cinamon, Thornback, & Zorzella, 2015; Thornback & Muller, 2015) for children and adolescents, and Cognitive Behavioral Therapy-Rational-emotion behavior therapy (CBT-REBT; Malkinson, 2010). These treatment models and interventions primarily focus on the influence of cognitions and beliefs on individual behaviors and family interactions, as well as include extensive psychoeducation about trauma, grief, and loss for all members of the family (Kira et al., 2015; Cohen & Mannarino, 2015; Konarnur et al., 2015; Malkinson, 2010; Thornback & Muller 2015). However, clinicians should be cautioned with using trauma language when working with such families who may not view their experiences as traumatic. Previous literature has also found therapeutic models that allow clients to be the experts of their experiences while focusing on solutions rather than problems, such as solution-focused brief therapy, to be beneficial when working with families of individuals with ID (Lloyd & Dallos, 2008).

Boss (2010) suggests that closure and healing from experiences of ambiguous loss are unattainable. Because of the unclear and vagueness of ambiguous losses, grief is often complicated and is different than the experiences of other form of loss (i.e., death losses) because of the lack of resolution (Boss, 2010). The process of bereavement is inhibited by external factors beyond the control of the one experiencing such grief and loss (Boss, 2010). Research suggests that in order to reach a place of resilience after experiences of complicated loss, clinicians and professionals should work to guide individuals and families through the bereavement process by making meaning of the loss and beliefs about such losses and by tempering mastering in order to counteract feelings of helpless and hopelessness (Boss, 2010). These processes allow individuals to regain a sense of control during a period of transition.

Additional time may need to be spent making sense of such experiences and creating insight into family members' experiences and what having a loved one with ID means for their families and individual senses of self. Narrative therapy and interventions using externalization (i.e., letter writing) have also been found to be helpful for working with individuals and families who have experienced unique forms of loss, combat trauma, and ambiguous loss (Betz &

Thorngren, 2006; Keenan, Lumley, & Schneider, 2014). Narrative therapy allows individuals and families to recreate their stories while considering the impact of social contexts in order to gain a sense of control (White & Epston, 1990). Further, acknowledgement of the difference yet connectedness between intra and interpersonal processes and the roles of individuals and within family systems is necessary. Therefore, assumptions about traditional or typical individual experiences, emotional processes, and family roles should be avoided. For example, family members described feeling torn between their own wants and desires and what they felt their other family members needed.

Research also suggests working to restructure one's identity of having a loved one with ID or after experiences of ambiguous loss is important. Roles within such family systems often shifted over time. Siblings of individuals with ID often take on more caregiving responsibilities for their loved one early on in childhood and adolescence and continue in such roles well into later adulthood (Ouellette-Kuntz et al., 2014), which can result in siblings experiencing their own form of ambiguous loss for their personal childhood. At the same time, many siblings discussed that once their sibling with ID reached adulthood, their role as sibling transitioned. Sibling roles shifted to either more of a legal relationship following guardianship, separating them from the emotional relationship with their sibling with ID, or into more of a parental role where loyalties between their roles as "pseudo-parent" for their sibling and parent for their own children often conflicted one another.

The theory also introduces family therapists to the unique and unclear experiences of coping for family members of individuals with ID. While many family members describe feeling seemingly resilient over time, their processes of reaching such resiliency are quite ambiguous. Clinicians should assist families in discussing individual family members' descriptions of resilience and the role of adaptive and maladaptive coping mechanisms that have taken place for families over time. Many participants described emotionally cutting off from their intrapersonal feelings of hurt or loss and expressed a desire to exude normalcy for their families and to others.

However, some clinicians would argue the descriptions of emotional disengagement suggest a form of maladaptive coping and that family members need to learn to express their needs and feelings while managing their own anxiety (Bowen, 1985). Therefore, when working from a Bowen Family Systems Theory lens, clinicians may work to make meaning of family experiences by increasing individual family members' levels of differentiation and reorganizing senses of self and family (Bowen, 1985). Normalization of the ambivalence and conflicted experiences of individuals and families of individuals with ID can be an important part of the bereavement process (Boss, 2010). Clinicians can provide safety for families to discuss their negative feelings by providing a nonjudgmental setting (Boss, 2010).

Research suggests the final steps of working to resolve complicated grief from ambiguous losses is through the healing of attachment injuries and rediscovery of hope (Boss, 2010). While the relationship between parents and child and siblings may not be reciprocal with the presence of severe or profound levels of intellectual disability or as a result of institutionalization, it may be necessary for family members to revise the attachment relationship rather than avoiding the ambiguity (Boss, 2010). Clinicians can also work to help individuals and families to discover newfound hope in various ways by providing resources and by offering their own sense of hope for families when working through difficult circumstances.

The central theme of ambiguity provides evidence of the unclear and unique challenges clinicians may experience when working with family members of individuals with ID, and therefore, can provide a guide for exploring such ambiguous experiences for each member of the family system.

## **Conclusion**

Previous literature has explored the impact of specific experiences of receiving initial diagnoses of ID and institutionalization for families of individuals with ID. However, little is known about the overall experiences and emotional processes that take place for family members across time. The current study aimed to take a first step toward developing a transferable model



of family risk and resilience for parents and siblings of individuals with ID across the lifespan. The study provided a framework for exploring the in-depth emotional experiences of family members when faced with difficult transitions for their loved ones and their families as a whole. Findings suggest a relation between five major categories (i.e., ambiguous loss, ambiguous futures, ambiguous roles, ambiguous emotions, and ambiguous coping) that often take place for such families across their loved ones' development. While further research is needed to confirm and expand the current findings, this study provides important implications for clinicians and researchers interested in better understanding the unique and often ambiguous intra and interpersonal processes that take place for family members of individuals with ID across the lifespan.

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## APPENDIX

Appendix A

Oklahoma State University Institutional Review Board

Date: Wednesday, February 17, 2016 Protocol Expires: 3/27/2017

IRB Application No: HE-1419

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

Reviewed and Processed as: Exempt Modification

Status Recommended by Reviewer(s) Approved

Principal

Investigator(s):

Natalie Richardson Jennifer L. Jones Kami L. (Schwerdtfeger) Gallus
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Stillwater, OK 74075 Stillwater, OK 74078 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.

PI 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 1) change project title to "Families and Intellectual and Developmental Disability: Understanding Risk and Resilience Across the Lifespan" from "NORCE and SORC Family Member Survey", 2) add Natalie Richardson as the PI and 3) move Jennifer Jones to Co-PI with Kami Gallus as the advisor

Signature :

[Handwritten Signature]
Hugh Crethar, Chair, Institutional Review Board

Wednesday, February 17, 2016
Date

VITA

Natalie M. Richardson

Candidate for the Degree of

Master of Science

Thesis: A LIFETIME OF AMBIGUITY: UNDERSTANDING THE EXPERIENCES  
OF FAMILIES IMPACTED BY INTELLECTUAL DISABILITY

Major Field: Human Development and Family Science

Biographical:

Education:

Completed the requirements for the Master of Science in Human Development and Family Science with a Specialization in Marriage and Family Therapy at Oklahoma State University, Stillwater, Oklahoma in December, 2016.

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

Experience:

Graduate Teaching Assistant for the College of Human Sciences at Oklahoma State University, Stillwater, Oklahoma from August, 2016 to December, 2016.

Marriage and Family Therapy Clinical Intern at the Center for Family Services, Stillwater, Oklahoma from August, 2014 to November, 2016.

Graduate Research Assistant for the Dept. of Human Development and Family Science at Oklahoma State University, Stillwater, Oklahoma from August, 2014 to August, 2016.

Marriage and Family Therapy Clinical Intern at the Warren-Alexander Group, Stillwater, Oklahoma from August, 2015 to July, 2016.

Professional Memberships:

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Oklahoma Association of Marriage and Family Therapy (OKAMFT)