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Transition of Persons with Developmental Disabilities from Parental to Sibling Co-Residential Care: Effects on Sibling Caregiver Well-Being and Family Functioning

Richard Steven Glaesser

University of South Florida, rglaesse@mail.usf.edu

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Transition of Persons with Developmental Disabilities from Parental to Sibling Co-Residential Care: Effects on Sibling Caregiver Well-Being and Family Functioning

by

Richard Steven Glaesser

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
School of Social Work
College of Behavioral and Community Sciences
University of South Florida

Co-Major Professor: Nan Sook Park, Ph.D.
Co-Major Professor: Elizabeth Perkins, Ph.D.
Mary Armstrong, Ph.D.
Anne Strozier, Ph.D.

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March 19, 2018

Keywords: intellectual disability, caregiving, co-residential caregiving, family systems

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DEDICATION

This dissertation is dedicated to my father, Hans Glaesser, and mother, Erna Glaesser. Both of my parents worked hard throughout their lives and each was proud of the direction I took to improve the lives of others. For my parents, success was considered an achievement towards a positive objective, and education was held in high regard. While I miss them both tremendously and wished they could have seen this achievement come true, I hope they are looking down with bright smiles for the moment I say, “I did it mom and dad!”

To my brother, Tom, and nieces, Rachel and Natalie, I wish nothing but good fortune and healthy lives. Throughout this study, I learned a great deal about family dynamics and their influence on well-being. I am hopeful they will learn to understand these ideas for their own growth and development. I want you to have great positive experiences in life and become successful, happy individuals.

Lastly, I want to thank Noel. It is serendipitous that you came back my way again, after all these years, at a point when things seemed dark and challenging. Though we do not know where life takes us, I am grateful to have had you by my side at the end of this journey. You were the force I needed to keep me from swaying off the path.
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ABSTRACT

Comprehensive improvements in medical care, technology and residential settings have resulted in persons with developmental disabilities (DD) advancing to older age and outliving parental caregivers (Heller & Arnold, 2010). Typical siblings are expected to become the primary caregiver to their sibling with DD when parents become ill or die and unable to provide care (Burke, Fish, & Lawton, 2015; Heller & Arnold, 2010). This dissertation looks at the wellbeing and family functioning of siblings who become the co-residential caregiver following the transition of a brother or sister with DD from parental to sibling co-residential care.

The family systems framework was the theoretical lens for understanding caregiver wellbeing and overall family functioning. Hermeneutic-narrative inquiry was the approach for interviewing and exploring the stories of 10 sibling caregivers of a brother or sister with DD following their transition from parental to sibling co-residential care. Two analytical approaches were used. Firstly, structural analysis involved a within-case analysis of individual participants’ stories of transition to determine the meaning ascribed to and identified with the caregiving experience. Secondly, thematic narrative analysis included an across-case analysis to identify themes related to caregiver wellbeing, family functioning, reciprocity of mutual support, and anticipating the caregiver role versus actual experience.

Findings from the structural analysis showed that the meaning of the caregiving experience included a duty, obligation, responsibility and commitment to the family. Results from the thematic narrative analysis showed overall lower social and emotional wellbeing among participants, reduced functionality among family members with respect to lower emotional and
social functioning, reduced engagement in recreation/leisure activities, as well as lower economic functionality for sibling caregivers with no spouse or children. Sibling caregivers reported higher overall wellbeing and family functioning due to availability of formal supports (e.g., respite care, day program services), and informal support, such as having support from a spouse, child, or extended family member. Findings regarding reciprocity showed increased instrumental support among sibling caregivers and reduced emotional support. When anticipating the role, caregivers described knowing they would assume the role but were unclear of the shift to assuming a parental rather than sibling role. Other unanticipated discoveries included feeling captive to the role and feelings of helplessness. Caregivers’ actual experiences involved learning to manage new challenges, society’s patronizing view of persons with DD, and an overall sense of pride in caregiving for giving back to their sibling with DD. Grief and future planning were also discussed, including the effect of grief on the sibling caregiver, sibling caregiver’s children and sibling with DD. Future planning looked at the aspects of planning and not having planned for the future of the sibling with DD.

The study concludes with implications for current and future social work practice and research, as well as the study’s strengths and limitations.
CHAPTER 1: INTRODUCTION

The sibling relationship is described as the most important, enduring relationship in a family (Cicirelli, 1995; Doody, Hastings, O’Neill, & Grey, 2010). It is an ascribed association set by circumstance and not by choice (Cicirelli, 1995; Doody et al., 2010). Siblings share family, genetics, historical background, and social class (White, 2001). Traditionally, siblings have a greater attachment and intimacy in childhood and adolescence (Cicirelli, 1995; White, 2001). But, the sibling relationship tends to be less intimate in late adolescence and early to mid-adulthood due to a greater focus on education, career and building a family. However, in late adulthood, the sibling relationship frequently becomes more salient, especially when social and other family support decline (Orsmond & Seltzer, 2007; White, 2001).

For typical siblings of a brother or sister with a developmental disability (DD), the relationship may require greater involvement and commitment throughout the life cycle. A child with DD is likely to have fewer prospects for friendships and peer interactions, and is often more dependent on his or her typical sibling for support (Conger, Stocker, & McGuire, 2009; Gresham & MacMillan, 1998). In addition, the typical-atypical sibling relationship is considered more hierarchical and less egalitarian due to difficulties in building shared life experiences depending on degree of disability (i.e., degree of physical and mental [e.g., cognitive] disability) (Stoneman, 2005). Potential stressors of having a brother or sister with DD are cognitive differences, communication difficulties, non-reciprocated interactions, and problem behaviors (McHale &

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1 Typical refers to having no disability. Atypical refers to having a disability.
2 The typical-atypical sibling relationship/dyad refers to a relationship between siblings where one sibling has a disability.
Harris, 1992). In spite of these challenges, typical siblings mostly form strong bonds with their sibling with DD and continue to play a vital role in their support network particularly in adulthood (Stoneman & Brody, 1993).

**Definition of Key Terms**

See Appendix A for definition of key terms, including quality of life (i.e., overall well-being), caregiving, developmental disabilities, and intellectual disabilities.

**Persons with DD and their Families**

Historically, few community-based services (i.e., formal support) were available to help families provide in-home supports for their member with DD; persons with DD were often institutionalized because it was believed they were incapable of helping themselves (Longmore, 2003; Kersh, 2007; Mackelprang, 2010; Shapiro, 1993). Over time, however, institutions became exposed as places of cruelty and abuse, which led the push towards ‘normalization’ and deinstitutionalization (Shapiro, 1993). There have been extensive relocations of individuals with DD to community housing and integration in the U.S. for last four decades. Furthermore, there has been greater support and encouragement for persons with DD to live in the family home. Currently, approximately 71% of persons with DD reside with a family caregiver (BraddockHemp, Rizzolo, Tanis, Wu, & Haffer., 2017).

**Effects of Increased Longevity and Shift in Caregiver Status**

About 7-8 million Americans have a developmental disability (Morstad, 2012). For persons with DD, Medicaid may be their only funding source since their disability may limit opportunities for private and/or employment-based coverage; many individuals with DD require lifetime supports with activities of daily living (ADLs; The Arc, 2016). Other financial supports, such as social security disability income (SSDI) and supplemental security income (SSI), are
available to persons with DD (The Arc, n.d.). However, many individuals do not meet the strict qualifying standards and it can take months or years to receive benefits. After exhausting appeals, 4 in 10 applicants actually achieve benefits that are considered nothing more than modest. One in 3 persons receiving SSDI are considered at or below the Federal Poverty Level (i.e., in 2015, $11,770 for a person who is single) (The Arc, n.d.).

At present, fewer financial supports, longer waiting lists for residential services and an emphasis on homecare have resulted in burden and stress for family caregivers of a member with DD (The Arc, 2016). Families mostly adapt well to having a son or daughter with a developmental disability (DD), but are at higher risk of poor social, economic, and health outcomes (Heller & Factor, 2008). Challenges of caregiving include lack of health insurance, constrained leisure and social activities, limited social support, lower rates of employment, diminished family savings, and heightened family-work role strain (Blacher & Begum, 2011; Heller & Factor, 2008). Current disability policy is more focused on the individual with DD; less than 1% of total public spending is allocated to DD services (Braddock et al., 2017). Furthermore, 24% of caregivers (typically the mother) are 60 years of age or over (Braddock et al., 2017). In 2015, the median income of U.S. households where at least one person had a disability (aged 21 to 64 years) was $41,600 compared to $65,900 for households with no disability (Erickson, Lee, & von Schrader, 2016).

Over the last century, there has been a substantial increase in the life expectancy of persons with DD due to quality of life improvements, such as progressive changes in institutional and residential settings, advances in medical care and improvements in assistive technology and public health programs (Braddock, Hemp & Rizzolo, 2008; Braddock et al., 2017; Fisher & Kettl, 2005). In recent decades, life expectancy for adults with mild intellectual disability (a
subset of developmental disability) is rapidly approaching similar levels as the general population (Bittles et al., 2002). Even people with moderate or severe intellectual disability, who are more likely to have complex medical conditions, now live into their late 60s and late 50s respectively (Bittles et al., 2002). But older adults with DD encounter a unique set of physiological and psychological conditions such as visual and hearing impairments, poor oral health, thyroid abnormalities, gastrointestinal difficulties, obesity, diabetes, heart disease, cardiovascular disease, osteoporosis, osteoarthritis, dementia and affective disorders (e.g., depression and bipolar disorders) (Fisher & Kettl, 2005; Perkins & Moran, 2010). These additional conditions can present an increased burden for parental caregivers.

Stress associated with caregiving can result in psychological problems (e.g., higher rates of anxiety and depression) that can impact a caregiver’s physical and psychological health and overall well-being (Branscum, 2010; Heller & Factor, 2008; Wolfe, Song, Greenberg, & Mailick, 2014). Aging among parental caregivers can also result in declining physical health, which can affect parents’ overall functioning, quality of life and ability to continue their role (Haley & Perkins, 2004). Considering that persons with DD are now advancing to older age and outliving their parents, typical siblings increasingly are expected to become the primary caregiver to their atypical brother or sister when parents die or become unable to continue caregiving (Burke et al., 2015; Heller & Arnold, 2010).

The Potential Challenges for Typical Siblings

At present, less than 40% of families have made plans for the emotional and financial future of their member with DD partly due to a lack of awareness or reluctance to confront their own mortality (Lauderdale & Huston, 2012). Parents are also frequently overwhelmed and may not directly focus on the future needs of their atypical child since present needs for providing
direct, informal care may seem more important (Lauderdale, Durband, Scott, & Springer, 2010). In addition, parents are frequently indecisive about the future planning of their child with DD because workable solutions are not quickly available due to absent services, excessive costs, or unsuitable residential options (Perkins, 2009).

Among typical siblings, a major concern is parents’ reluctance to include their typical and atypical children in future planning for the time when they are no longer able to provide care (Heller & Caldwell, 2006; Heller & Kramer, 2009). Early research showed 64% of typical siblings were uncertain of future plans (Griffiths & Unger, 1994), and only about 50% of parents made future living arrangements for their child with DD (Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1991). Many parents do not include their typical children in future financial planning but expect them to become a point person to serve as legal guardian, provide financial support, and co-reside with their brother or sister with DD (Bigby, 1997, Freedman et al., 1997; Griffiths & Unger, 1994, Krauss, Seltzer, Gordon, & Friedman, 1996).

Given the decline in government supports alongside the lifelong health needs of individuals with DD (Heller & Kramer, 2009), immediate assistance is rarely available when parents can no longer provide care leaving typical siblings with no option but to assume co-residential caregiving duties for their sibling with DD. This may come at a time when the typical sibling is attempting to balance his or her own needs in the workplace, the needs of children and a spouse, and other possible life pursuits (e.g., finishing college or attending graduate school). Despite concerns over lack of planning among parental caregivers, it remains unclear how many typical sibling caregivers have also not made future plans for their brother or sister with DD in the unforeseen event they cannot carry on caregiving duties. Losing a caregiver can be especially
traumatizing to a person with DD who is often dependent on a caregiver for continuity of care as well as physical, emotional, and financial support (Lauderdale & Huston, 2012).

**Transition of Care from Parent to Sibling**

In the literature, early studies looked at the effects on typical adult siblings of having a brother or sister with DD, including psychosocial outcomes of typical adult siblings, and levels of involvement and support from typical adult siblings to parental caregivers. More recent studies have focused on factors regarding typical adult siblings assuming the future caregiving role. However, there are few studies examining the post-transitional effects of a sibling with DD from parental to sibling co-residential care (Coyle, Kramer, & Mutchler, 2014). Thus, there is uncertainty regarding how the typical adult sibling adapts to the caregiving role, including changes to the sibling caregiver’s family functioning and his or her overall well-being. Furthermore, the difference is unclear regarding how a typical sibling adapts to caregiving depending on if the transition is planned or unplanned.

Transitions are considered movements between different life stages or significant life events within life stages resulting in insecurity and a need to adapt (Carter & McGoldrick, 1999; Golan, 1981; Rodgers & White, 1993). But these transitions can be marked by more socially complex life events such as managing a caregiver’s or care recipient’s chronic condition or ill health, former caregiver’s death (e.g., death of parental caregivers), and/or residential change for the individual with DD (Jokinen, Janicki, Hogan, & Force, 2012). Planned transitions can have more positive results because caregivers are aware of stages in change and hence they are prepared for them (e.g., positive overall functioning for typical sibling and his/her family when transition of sibling with DD from parental to sibling co-residential care is planned) (Jokinen et al., 2012). However, unplanned transitions (also referred to as off-time transitions) are
unpredictable with possible adverse results since the transitional change may be abrupt and potentially unexpected (e.g., unplanned relocation of sibling with DD due to parental illness or death) (Jokinen et al., 2012). Though any transition of a sibling with DD from parental to sibling care can greatly impact the typical adult sibling, his or her family, and sibling with DD, both planned and unplanned transitions require a re-adaptation in familial roles and responsibilities for all members involved (Jokinen et al., 2012). Furthermore, how a sibling anticipates the caregiving role may be quite different than when the role is actually assumed.

Reciprocity (level of support provided by sibling with DD to sibling caregiver, and vice-versa [Kramer, Hall & Heller, 2013]) can help to mediate the stressful effects following the transition of a sibling with DD from parental to sibling care. Reciprocity considers that when you receive something from others, you are required to provide something in return (Bubolz, 2001). Implicit in this assumption is that typical-typical\(^3\) sibling relationships are generally considered equivalent in level of support received and given between each member of the sibling dyad (Kramer, et al., 2013). In the context of the typical-atypical sibling dyad, the relationship is often considered asymmetrical due to the inequality of shared financial, emotional and practical/physical resources (Stoneman & Berman, 1993).

**Problem Statement/Purpose of Study**

This study explores the life stories of 10 adult sibling caregivers within five years following the planned or unplanned transition of a brother or sister with DD from parental to sibling co-residential care. It is expected that the post-transition period (from zero to five years) ensures that guardianship and permanency of co-residential placement are firmly established. Few studies have looked at the effects of this transitional event on typical sibling caregivers of a

\(^3\) Sibling relationship where there is no disability.
sibling with DD (Coyle et al., 2014). Findings can elucidate the meaning sibling caregivers ascribe to this unique caregiving experience, how sibling caregivers self-identify with their role, overall well-being of sibling caregivers, how sibling caregivers’ families function post-transition, post-transitional effect on sibling caregiver’s life trajectories (e.g., family and career), reciprocal support as related to caregiver stress and family functioning, as well as differential effects on whether the transition is planned or unplanned.

**Implications for Social Work Practice**

The findings of this study can help social work practitioners better understand the treatment and support needs of families as they manage the post-transitional effects (planned or unplanned) of a sibling with DD from parental to sibling co-residential care. This knowledge of the support needs of adult sibling caregivers will strengthen interventions that support the fluid transition of a sibling with DD to a new family unit. Family interventions can help with family interaction (resulting in positive family functioning), including restructuring roles among family members, helping sibling caregivers and their families readapt to unfamiliar changes and cope with new stressors, and creating open communication tools to reduce conflict between members in the family. Policy interventions may involve the development and funding for formal service supports, including funding for respite, financial aid to caregivers, volunteer care provision, and job protection (e.g., protections through the Family and Medical Leave Act) to help sibling caregivers mediate the effects following the transition. Prior study has shown that the negative impact from family caregiving can be reduced through informal as well as formal supports (Ekwall & Hallberg, 2007).
Research Questions

1. How do typical adult siblings make meaning of their experience and identity as a caregiver following the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care?

2. What is the effect on typical adult siblings’ well-being after assuming the caregiving role following the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care?

3. How does the planned/unplanned transition of a sibling with DD from parental to sibling co-residential affect sibling caregivers’ family functioning?

4. Does level of reciprocity between adult sibling caregivers and their siblings with DD mediate a more fluid transition from parent to sibling co-residential care?

5. Is there a difference between how typical siblings anticipate the co-residential caregiving role prior to the transition of their brother or sister with DD from parental to sibling care and the actual experience of the role following the transition?
CHAPTER 2: LITERATURE REVIEW

The literature review covers how typical siblings in childhood and adolescence experience growing up with a sibling with DD and how their relationships change in adulthood with a focus on static (i.e., fixed) and dynamic features of the typical-atypical sibling relationship. Early studies on childhood and adolescence suggested that typical siblings of a brother or sister with DD experienced increased distress, heightened demands, and greater pessimism when compared to typical siblings (Griffiths & Unger, 1994; Seligman & Darling, 2007). More recent studies, however, have shifted these earlier notions and generally featured the typical-atypical sibling relationship as positive and associated with higher well-being (Doody et al., 2010; Heller & Arnold, 2010; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2000). In adulthood, typical siblings of a brother or sister with DD report lower depression levels, better health and feeling more rewarded for their sibling relationship (Hodapp & Urbano, 2007). This chapter examines the following sections: family systems framework, parental caregivers and persons with DD, adult siblings and their brothers and sister with DD, and summary and direction of the dissertation.

Family Systems Framework

For this study, the family systems framework is used as a guiding theoretical model to understand the functioning of and effects on typical adult siblings and their family members following the transition of their sibling with DD from parental to sibling co-residential care (Turnbull, Turnbull, Erwin, & Soodak, 2006). The family is defined as two or more persons who see themselves as a family and perform functions that typical families do (Turnbull et al., 2006).
The family is viewed as a social system and group, which has tremendous influence on human behavior (Ashford & LeCroy, 2010). Families are goal-directed, self-correcting entities and regarded as interconnected, dynamic systems that influence and are influenced by their environment (Seligman & Darling, 2007). Hence, what affects one family member may influence the whole family (Samuel, Rillotta, & Brown, 2012). This perspective assumes that family members influence each other individually and holistically (Minuchin, 1985). In this regard, family members are viewed as independent and inter-related parts of the family system (Fingerman & Bermann, 2000). Family systems as a framework assumes that: 1) each family is distinctive for its individual characteristics, largely influenced by its ideology and cultural style, 2) parts of the family system mutually interact, and contain continually shifting boundaries and varying levels of opposition to change, 3) families engage in different functions, collectively and individually, that stimulate growth and development among family members and the family as a whole, and 4) families pass through developmental and non-developmental shifts that create different levels of stress affecting its members (Turnbull et al., 2006).

Turnbull et al. (2006) developed the family systems framework in the context of families of a child with a disability. Accordingly, the family systems framework is made up of four components: 1) family characteristics (inputs into the family system), 2) family interaction (processes of interaction among individual family members, family subsystems [marital, parent-child, sibling, and extended family subsystems], whole family and its environment, including members’ levels of cohesion and adaptability to manage change), 3) family function (outputs or tasks within the family to meet the individual and collective needs of its members), and 4) family life cycle (stages and transitions experienced by a family along the continuum of its life path). In summary, inputs into the family system are considered the family’s characteristics that are
processed by the family system (interactions between family members, family subsystems, and the whole family with its outside environment) that result in its output (how the family functions).

**Family Characteristics**

Family characteristics are viewed as inputs into the family system and consider how a family defines itself based on size (number of members) and form (e.g., number of parents [single or two parent]; biological, adoptive or foster parents; and, number of children) (Turnbull et al., 2006). It also looks at the cultural background (beliefs and values that shape the way family members interpret, perceive and behave in their family and community), which includes cultural and microcultural features. Cultural features involve race and ethnicity (individual’s religion, race and national origin), and microcultural features refer to how an individual constructs his or her identity such as religion (customs, beliefs and rituals that may influence how families celebrate events), language (communication in families [if families speak English, level of literacy]), gender (beliefs about roles of family members), race (potential influence for racism/discrimination), ethnicity (beliefs about how families associate/belong to their community), age (related to experience of family members), geography (influence of location [e.g., rural versus urban]), and income/socioeconomic status (resources available for families to cover their needs). Family characteristics also considers life management skills, which are techniques family members use to solve problems (i.e., coping strategies). Life management skills involve: reframing (how a member changes his or her view about a situation to encourage a positive over negative outcome [Hastings & Taunt, 2002]), passive appraisal (not allowing worries to become consuming), spiritual support (attaining guidance and comfort through spiritual beliefs [Poston & Turnbull, 2004]), social support (obtaining emotional and practical
support from family members and friends [Brown, Anand, Fung, Isaacs, & Baum, 2003]), and professional support (receiving help from agencies and professionals [Zoints, Zoints, Harrison, & Bellinger, 2003]).

**Family Interaction**

Family interaction uses family systems theory to understand the dynamic processes of interaction among individual family members, family subsystems and the whole family, as well as factors that influence those processes and the family’s development (Turnbull et al., 2006). Factors influencing family processes include: roles (e.g., who manages the money, which member makes what decisions, and who takes on different household tasks), rules (influenced by family culture, including how members are supposed to feel, behave, and think, how decisions are made, and how problems are solved), power distribution (how each member has a certain amount of power to preserve his/her personal interest, influence decisions, resolve conflicts, and ensure the well-being of other members and the family as a whole), and communication (based on the premise that all behavior, including silence, is considered communicative) (Allen, 1982; Turnbull et al., 2006).

Each system in the family unit has a boundary, which is related to the level of communication and information exchange between family members, and the family as a whole and its environment (Turnbull et al., 2006). In family systems theory, a family’s boundaries can be open or closed. Open systems suggest more positive functioning and greater levels of communication/information exchanged within and outside the family (Friedman & Allen, 1997). An open system may show greater functionality and ability to manage conflict. Closed systems imply potential dysfunction, lower levels of communication/information, and greater difficulties coping with stressful situations (Friedman & Allen, 1997).
Cohesion and adaptability are two elements that influence family interaction. Boundaries also help to define family cohesion and refer to emotional bonding between members and level of independence members feel within the family as a whole (Olson, Russel, & Sprenkle, 1980). Cohesion follows a continuum where high disengagement (little cohesion among family members) is at one end of the continuum and high enmeshment (inappropriately high level of cohesion among family members) sits at the other. The family’s cultural background and values can affect the range of cohesion where, for example, highly cohesive (enmeshed) families have blurred or weak boundaries among subsystems (Minuchin & Fishman, 2009). When cohesion is balanced, there is positive growth, strong communication, positive daily living skills and good social skills in children (Gavidia-Payne & Stoneman, 1997; Hauser-Cram et al., 1999).

Adaptability considers the family’s ability to adapt to developmental and situational stress (Olson et al., 1980). Adaptability within a family is also affected by the family’s cultural background and values and follows a continuum where families unable/unwilling to adapt to stress sit at one end and those in continual flux (resulting in confusion and poor adaptability) sit at the other. High levels of structure and control within the family’s power hierarchy may indicate rule-driven interactions, heightened rigidity, and low adaptability for managing stress (Turnbull et al., 2006). Low levels of structure and control can indicate fewer and rarely enforced rules (e.g., promises and commitments are not kept, lower ability of family members to depend on each other, and no true family leader where roles are uncertain and ever-changing). In well-functioning families, there is stability and balance between high and low adaptability (Olson et al., 1980).
**Family Function**

Family function is the output of the family systems framework, which looks at the tasks performed by the family (processes of interaction among individual members and the whole family with its environment) to meet its members’ individual and collective needs (Turnbull et al., 2006). Family functions contain eight categories: 1) affection (degree to which members exchange physical/verbal affection and unconditional love [O’Byrne, Haddock & Poston, 2002; Summers, 1987]), 2) self-esteem (feelings of self-worth and strength among family members, and family as a whole [Turnbull et al., 2006]), 3) spirituality (beliefs about spirituality and religion related to how individual members perceive of the connection to themselves, other persons, and the universe, and find meaning in their lives [Canda, 1999; Gaventa, 2001]), 4) economics (source of income [Turnbull et al., 2006]), 5) daily care (meeting members’ health and physical needs through activities of daily living [ADLs], for example, available health care, transportation, cleaning, laundry and cooking), 6) socialization (joys and disappointments through friendships), 7) recreation (seeking leisure time, recreation and play that enhances self-esteem and socialization, and reduces stress), and 8) education (family’s emphasis on educational pursuits to enhance quality-of-life through greater employment opportunities and increased financial gain) (Turnbull et al., 2006).

**Family Life Cycle**

The family life cycle describes how families change across time (Carter & McGoldrick, 1999; Rodgers & White, 1993). This component of the family systems framework proposes that families experience predictable, developmental stages (Turnbull et al., 2006), including 1) leaving home as a single young adult, 2) marriage and becoming a new couple, 3) families with young children, 4) families with adolescents, 5) launching children, and 6) families in later life.
Culture also plays a role regarding how families vary in their experience at different life stages (Turnbull et al., 2006). As a family moves from one stage to another, they move into an interim phase called a transition. Transitions are points between stages when a family adjusts its roles and interactions to get ready for the next developmental stage (Carter & McGoldrick, 1999; Rodgers & White, 1993). Changes during points of transition affect changes in family characteristics (inputs), interactions (processes), and functioning (outputs) (Turnbull et al., 2006). After the transition has completed, the family has reached its next developmental stage and readjusted the interactions and tasks appropriate for that stage. Off-time (unplanned) transitions (e.g., transition of member with DD from parental to sibling co-residential care) can involve conflict and confusion and comprise periods of increased stress (Carter & McGoldrick, 1999; Olson et al., 1980).

**System Balance, Transitions, and the Family Systems Framework**

All members in a family interact to maintain stability, balance, and create a properly functioning whole (Hutchison, 2010). Balance is described as attaining homeostasis (variable balance requiring frequent adjustments to small, ongoing internal/external influences) and equilibrium (sense of being in balance; overall balance of the whole system) (Friedman & Allen, 1997). When working properly, the whole family and its individual members have achieved a collective, dynamic balance within its environment. However, problems (internal/external) can occur, which cause imbalance and shifts within the family system (Robbins, Chatterjee, & Canda., 2006; Suppes & Wells, 2012). These shifts can result in transitions, where individual members and the family itself must readapt itself until a new level of equilibrium (overall balance) and developmental stage is achieved.
Figure 1 represents the family systems framework in equilibrium. However, the transition of a person with DD from parental to sibling co-residential care (whether planned or unplanned), will result in shifts in the family’s characteristics, interactions and functioning. These transitions can significantly disrupt the balance within the family system.

Changes in the family’s characteristics can include increasing the size of the family, changes in microcultural features (how families re-identify themselves and manage potential changes [e.g., declining income from one member taking on caregiving role]), and changes in

Figure 1. Family Systems Framework (Turnbull, Summers, & Brotherson, 1984).
life management skills (i.e., how members manage the stress of changing characteristics). Transitions also directly influence factors affecting family interactions, including changes in members’ roles, rules, power distribution, ability to communicate, and boundaries (communication/information exchange) to adjust to the new member (person with DD) that likely has additional, specific needs. As interactions within the family shift, family functioning also changes influencing, for example, how members demonstrate affection, level of self-esteem within the family and among individual members, family finances (economics), socialization, recreation, and potential for educational pursuits. Depending on where the family sits within the life cycle (e.g., a family with young children, or parents nearing retirement), also contributes to these shifts.

Open communication (i.e., more permeable boundaries) can result in positive family interaction and greater cohesion and adaptability. However, closed communication can lead to greater conflict (due, in part, to undefined boundaries), lower ability to manage stress, and difficulties adapting to the new changes. Positive interaction can result in greater family functioning but negative interaction through increased conflict may create greater dysfunction. Any change to the family system (planned or unplanned) will require individual family members to change and readapt to achieve equilibrium.

No matter whether the transition of a sibling with DD from parental to sibling co-residential care is planned or unplanned, the transition may occur in crisis as the result of a parent’s illness or death. In this regard, family members may have little opportunity to prepare for the transition. The transition of a member with DD to the new family unit immediately affects the family’s characteristics (i.e., inputs), including increasing the family size and form, as well as potentially impacting the family’s income and ability to cope with the new changes.
Interaction among family members will also change as members must assume new roles (e.g., sibling taking on the primary caregiving role) and rules. Power will likely also shift to the sibling as the household lead that can potentially affect the family’s marital and parental subsystems. In addition, children may take on additional responsibilities to manage the new changes. Open communication among family members can result in greater cohesion among family members, including more appropriate boundaries and ability to adapt to (i.e., manage) the new changes. Closed communications can result in greater difficulties for families to adapt due to poor cohesion and delineation of boundaries (e.g., enmeshment or disengagement among family members). Open communication and positive boundaries typically result in positive family functioning. However, closed communication and poor interaction among family members can result in negative functioning. For example, increased responsibilities for the sibling caregiver may include limited opportunities for socializing, recreation and educational pursuits. The increased demands can also affect the sibling caregiver’s level of affection directly influencing functioning within the marital and parental subsystems. Furthermore, the overall influence on the sibling caregiver’s self-esteem is an inability to complete tasks due to the increased demands associated with the new caregiving role. Transitions at different stages of the family life cycle can affect whether the sibling is able to take on the co-residential caregiving role. For instance, siblings in later life may lack the physical ability to assume the new role.

**Parental Caregivers and Persons with DD**

Seventy-one percent of persons with DD live with a family member, and at this point, parents provide the bulk of care to their child with DD (Braddock et al., 2017). These parental caregivers face similar obstacles as those within the general caregiving population but form a distinct subgroup due to the extensive length of the caregiving role. The average duration of the
caregiving role in the general population is four years (National Alliance for Caregiving & AARP, 2015). But providing care to a person with DD is a lifelong experience that can last upwards of 60 years (Haley & Perkins, 2004). Although older adults with DD encounter similar health conditions to those in the general population, they experience a higher predisposition to age-related and pre-existing health risks (as described in Chapter One: Introduction) (Haverman et al., 2010; Krahn, Hammond, & Turner, 2006; World Health Organization [WHO], 2000). The cumulative long-term impact of providing care to a person with DD, especially for those who co-reside with their child with DD, can result in continued social isolation and diminishing physical and psychological ability to perform caregiving duties at a point when the aging care recipient may be increasingly more dependent (Perkins, 2009; Seltzer, Floyd, Song, Greenberg, & Hong, 2011).

Providing care to a child with a disability can often negatively affect a family’s finances and many parental caregivers do not attempt to seek outside services for their aging child with DD until they can no longer provide care (Ansello & Janicki, 2000). Jarbrink, Fombonne, and Knapp (2003) reported that caring for a child with a disability was approximately three times the cost of caring for a typical child. This is quite a different encounter when comparing young adults with DD to typical young adults. While typical young adults transition from parental dependence towards employment, marriage and establishing one’s own household (Aquilino, 1996), adults with DD have limited self-supporting opportunities, emphasizing the continuous pattern of dependency on parents and related stress (Seltzer, Greenberg, Krauss, Gordon & Judge 1997). Parish, Rose, and Swaine (2010) found that a high proportion of parental caregivers studied (N = 753) had limited assets that could be used to offset a financial crisis in the face of health problems, job loss, or other dilemma (Parish et al., 2010). At this point, federal and state
funding sources and service supports do not adequately meet parental caregivers’ additional financial needs. Thus, continual financial strain and concerns over the future residence of their child with DD can overburden many caregivers and result in delaying plans for retirement (Perkins, 2009). It is concerning that more than 300,000 persons with DD nationwide are awaiting services and the wait time throughout the U.S. can be as much as 10 years (The Arc, 2016). Most adults with DD continue to live with a family member, and a growing percentage of caregivers is over 60 years of age (Coyle et al., 2014; Fujiura, 2003). Thus, many persons with DD will continue to depend on family caregivers and typical siblings (who are aging themselves) are considered the likely choice to provide care (Coyle et al., 2014). It is assumed, however, that becoming a primary co-residential caregiver to a brother or sister with DD can affect the typical sibling’s physical, psychological and financial overall well-being (quality of life), as well as functioning of the typical sibling’s family.

**Adult Siblings and their Brothers and Sisters with DD**

Studies over the past two decades on the typical-atypical sibling dyad in childhood and adolescence are largely influenced by static (i.e., fixed) and dynamic (i.e., changing) factors that can affect the typical sibling’s psychosocial outcomes, as well as closeness, involvement and types of support (i.e., emotional or instrumental) for their sibling with DD in adulthood (Bigby, 1997; Seltzer, Begun, Seltzer, & Krauss., 1991; Turnbull et al., 2006). More recent studies consider these factors and their association with taking on future caregiving when parents are no longer able. One problematic trend is the high number of adult siblings of persons with intellectual and developmental disabilities (IDD) still receiving care from parents who are usually not involved in discussions around future planning (Heller & Kramer, 2009). This limited involvement in planning heightens the risk of crises during periods of transition
(Freedman et al., 1997). Often, persons with DD who have always lived with parents may have limited community support, such as state funding for residential services. In the event a parent can no longer provide care and services have not been arranged, the atypical sibling will likely transition to the typical sibling’s residence at a time when the typical sibling has his or her own family. Furthermore, there is limited information on sibling caregivers of a brother/sister with DD in the context of co-residence.

**Contact, Closeness/Involvement and Support**

**Static and Dynamic Factors**

Research suggests that sisters are more involved than brothers in the life of their sibling with DD (Bigby, 1997; Greenberg, Seltzer, Orsmond & Krauss., 1999; Orsmond & Seltzer, 2000; Pruchno, Patrick, & Burant, 1996; Seltzer et al., 1991; Zetlin, 1986). Typical adult sisters have shown to provide higher levels of emotional support and companionship than brothers (Orsmond & Seltzer, 2000). This lends to the female principle and gendered characteristic of caregiving where women fulfill the role of caregiving more often than men (Moen & Wethington, 1999). It is also more probable that sisters will co-reside with their siblings with DD when parents are no longer able (Burke Taylor, Urbano & Hodapp, 2012; Seltzer et al. 2005). In some cases, sisters of individuals with DD will delay marriage and may be less inclined to have children (Hodapp, Urbano, & Burke, 2010).

Typical brothers are likely to have stronger relationships with a brother than with a sister with DD (Orsmond & Seltzer, 2000). Regarding birth order, siblings (usually sisters) older than their sibling with DD reportedly provide greater support and involvement (Pruchno et al., 1996; Seltzer et al., 1991). Siblings who live closer to their sibling with DD are found to have greater contact and involvement (Doody et al., 2010; Rimmerman, & Raif 2001; Seltzer et al., 1991;
However, degree of disability has shown varied results where greater involvement was related to greater independence in the atypical sibling (Rimmerman & Raif, 2001) but greater support was also observed when the brother or sister with DD was less capable (Pruchno et al., 1996; Zetlin, 1986). Type of disability can affect contact and involvement. Seltzer et al., (1997) examined closeness and well-being among typical adult siblings of adults with an intellectual disability (aged 21-63 years; \( n = 369 \)) and adults with severe mental illness (aged 26-60 years; \( n = 61 \)). The authors found that siblings of persons with an intellectual disability were mostly positive about their relationship whereas siblings of persons with mental illness were mostly negative. Seltzer et al., (1997) proposed that since having an intellectual disability is a lifelong condition, the typical sibling had learned to adapt and cope whereas typical siblings of a brother or sister with a mental illness were required to quickly adapt to changes, often due to an acute crisis. Hodapp and Urbano (2007) compared adult siblings (aged 18 to 85 years; \( N = 284 \)) of adults with Down syndrome and autism. The authors found higher levels of emotional closeness and future optimism among typical siblings for their sibling with Down syndrome than for siblings with autism. Findings were attributed to social impairment and repetitive/unusual behaviors observed in persons with autism resulting in the potential for greater future challenges when assuming the caregiving role (Hodapp & Urbano, 2007).

**Psychosocial Outcomes.**

Heller and Arnold (2010) reviewed the literature to understand the psychosocial outcomes of having a sibling with DD. Psychosocial outcomes are conceptualized as the typical sibling’s well-being and perceived effect on his/her life and family life of having a sibling with DD. The authors found that siblings of persons with DD expected to assume a greater future supportive role to their atypical siblings and were influenced towards a career choice in special
education as well as starting a family. However, typical siblings of persons with autism showed lower rates of involvement and higher levels of depression. The authors also reported that research on adult siblings was limited due to poor representative samples. Studies in the United States involved individuals with a European heritage and higher socioeconomic level than compared to the general population (Heller & Arnold, 2010).

Hodapp and Urbano (2007) found that most typical siblings reported a positive relationship, including good health, positive functioning, lower levels of depression, and feeling rewarded for the experience. Seltzer et al. (1997) found higher well-being when the relationship was considered emotionally close. When compared to having a sibling with Down syndrome or autism, typical siblings of a sibling with Down syndrome reported better health and lower depressive symptoms (Hodapp & Urbano, 2007).

Physical disabilities, such as cerebral palsy (a subset of developmental disability), can influence level of involvement between typical siblings and sibling with a disability. Persons with cerebral palsy (CP) often require substantial supports with activities of daily living (ADLs) and personal care due to motor disorders affecting the atypical sibling’s health (e.g., osteoporosis, eating and swallowing disorders, and depression) and communication (e.g., complex communications needs and severe communication disorders) (Dew, Llewellyn, & Balandin, 2013). As persons with CP age, their support needs increase due to heightened intensity of physical care, such as lifting, transferring and positioning the individual during the day and at night, and personal care assistance with showering, toileting, and preparing meals. This could potentially be emotionally and physically challenging for a sibling co-residential caregiver who may already have family and career responsibilities, and unaccustomed to providing instrumental supports.
Dew et al. (2013) explored the relationships of typical adult siblings \((n = 16)\) and their sibling with moderate to severe CP \((n = 12)\). The authors found that for typical siblings and siblings with CP who lived together in childhood, typical adult siblings strongly understood the needs of their sibling with CP regarding physical supports, personal attributes, and communication style. Among those separated in childhood, they knew less of one another and had less contact as adults. Thus, level of mutual support and contact in adulthood reflected the level of cohesion in childhood (Connidis, 2009). The study also reported that typical adult siblings described having to readjust the relationship with their sibling with CP when parents were no longer able and felt obligated toward their brother or sister with CP regardless of their connection in childhood (Dew et al., 2013).

A more recent study looked at the psychosocial outcomes and relationship quality of typical siblings of individuals with autism spectrum disorder (ASD) \((\text{aged } 18-62 \text{ years}; n=45)\) and individuals with intellectual disability (ID) without ASD \((\text{aged } 19-61 \text{ years}; n=37)\) (Tomeny, Ellis, Rankin, & Barry, 2017). Findings indicated that attitudes towards the sibling relationship had greater significance than demographic predictors (i.e., age, gender, birth order, race, education, and income) of aid/support, life satisfaction, depressive symptoms, and stress. As a result, siblings of persons with ID showed more positive attitudes that are related to greater levels of support/aid and life satisfaction, and reduced levels of stress and depressive symptoms. Alternatively, siblings of persons with ASD showed less positive attitudes indicating lower levels of support/aid and life satisfaction, and higher levels of stress and depressive symptoms. The study emphasized the importance of attitudes when considering the psychosocial outcomes of TD siblings (Tomeny et al., 2017).
**Types of Support.**

Support from typical adult siblings can involve emotional and/or instrumental support (Seltzer et al., 1991). Emotional support is the exchange of emotion and companionship, and instrumental support is the provision of direct and physical aid (Orsmond & Seltzer, 2000). Typical adults frequently carry multiple roles in midlife with respect to marriage, parenthood and career, but also provide instrumental and emotional support (often peripheral) when there is a brother or sister with DD (Seltzer et al., 1991).

Early findings showed that typical siblings generally provided greater emotional support but engaged in instrumental support when necessary (when parents were not able) (Grant, 1989; Krauss & Erickson, 1988; Krauss, Seltzer, & Goodman, 1992). Sisters more so than brothers were found to take on higher levels of instrumental support (Orsmond & Seltzer, 2000). Seltzer et al. (2005) found greater emotional support from sisters than brothers. But typical siblings with minor children were less inclined to provide instrumental support, and younger, less-settled siblings provided lower levels of overall support compared to middle-aged siblings who were more settled and reliable (Greenberg et al., 1999). Tasks more commonly performed by typical siblings included decision-making, mediation, financial management (more often when parents were deceased), companionship, social interaction through recreational activities and social contact, and advocacy (Bigby, 1998; Dew Llewellyn & Balandi., 2004). Reasons why siblings do not assume supportive roles are health status and age, other family members’ demands, and geographic proximity (where geographic closeness is associated with and may predict greater involvement and support) (Bigby, 1998; Doody et al., 2010).
Factors Related to Future Caregiving and Co-Residence

As parents become older and can no longer provide care due to illness or death, typical siblings are expected to become the primary caregiver (Heller & Arnold, 2010). Reportedly, 60% of siblings expect to take on the future primary caregiving role (Heller & Arnold, 2010). Bulmer (1987) defined the provision of primary care as providing direct personal assistance and/or care and supervision over tasks related to ADLs. A descriptive study by Mass Mutual and Easter Seals (2012) on current and anticipating sibling caregivers of a sibling with DD (n = 351) found that close to approximately 33% of typical sibling respondents stated they expected to take on future caregiving, and around 80% stated they were comfortable with this role. However, anticipating sibling caregivers reported feeling more comfortable providing emotional than financial support (60% vs. 33%) (Mass Mutual & Easter Seals, 2012). Sixty percent of typical siblings described difficulties maintaining long term financial goals, and 40% currently face financial stress (Mass Mutual & Easter Seals, 2012). Furthermore, families with a member with DD have 27% less savings than their general counterpart (Parish, Seltzer, Greenberg & Floyd, 2004), and more mothers earned less and worked part-time than mothers of a typical child (Stabile & Allin, 2012). Though anticipating sibling caregivers (67%) expected to receive emotional, physical and financial support in the long term, little more than half of current sibling caregivers (58%) stated they actually received this support (Mass Mutual & Easter Seals, 2012).

Factors Related to Future Caregiving

While typical siblings anticipate future caregiving for their sibling with DD, the type of caregiving may be different from what they expected (Burke et al., 2015). Generally, factors related to taking on future caregiving include being a sister, lone siblings, siblings who report having a close relationship with their sibling with DD, siblings that live close to their sibling
with DD, as well as life stage and circumstances (e.g., familial demands, willingness of partner/spouse, and impact of disability on the family) (Burke, Taylor, Urbano & Hodapp, 2012; Davys, Mitchell, & Haigh, 2016).

Parents play a strong role in the decision of typical siblings to assume future caregiving (Heller & Kramer, 2009). Evidence shows that typical siblings will likely provide support to their brother or sister with DD when parents expect it (Jewell & Stein, 2002). Parents who provide extensive, quality care to their child with DD expect the same involvement from their typical adult child (Davys, Mitchell & Haigh, 2011). However, some aging parents feel it unfair to burden their typical adult child with caregiving for their sibling with a disability (even when the typical sibling is willing to take on the role) (Lefley, 1987). In families where parents were reported as having a poor ability to provide care (though not clearly defined), typical siblings expected to provide care in one or two of five areas only (i.e., residential, companionship, legal, financial, or interaction) depending on whether caregiving is provided independently or shared (Burke et al., 2012). For parents who encourage greater independence of their child with DD, the typical sibling’s role usually involves managing the affairs of their brother or sister with DD (Davys et al., 2011). When siblings are uninvolved, parents expect more formal supports (Davys et al., 2011).

Burke et al. (2015) suggest that actual caregiving duties may differ from what is anticipated. Using focus groups, the authors compared the perspectives of current sibling caregivers (i.e., current caregivers [M age = 45.48; 84% female; n = 25]) with those who anticipated caregiving in the future (i.e., anticipating caregivers [M age = 31.76; 82.4% female; n = 17]). Findings showed that current caregivers engaged in recreational activities and ADLs, and anticipating caregivers expected to engage in social outings, provide emotional support, and
assist with sourcing information for parents. Regarding rewards, current caregivers reported enjoyment in seeing their sibling with DD become more independent whereas anticipating caregivers felt increased reward for providing respite to parents. Current caregivers discussed frustrations attaining and retaining disability services and feeling alone in their experience. Anticipating caregivers discussed uncertainty about the future, and not understanding the adult service system. Both groups agreed on caregiving challenges related to managing problem behaviors, as well as agreement that paid caregiving was acceptable. However, current caregivers felt more positively about paid caregiving whereas some anticipating caregivers were adamantly against or ambivalent about paid caregiving (Burke et al., 2015).

Saxena (2015) reviewed the available data and proposed factors that may encourage or impede caregiving activities among typical siblings. Regarding age and life stage of development, the author found that having a lifetime experience with a sibling with DD can create a curiosity among adolescent siblings resulting in a career choice in special education, and may influence the decision to take on the caregiving role (Burton & Parks, 1994; Marks, Matson, & Barraza, 2005). In early adulthood (i.e., ages 30 to late 40s), typical siblings are managing their own life issues, including employment, relationships/marriage, and having children, but feel a “growing sense of filial responsibilities and obligations” (Saxena, 2015, p. 212) that stimulates increased contact and provision of support (Shifren, 2009). In middle-age, individuals may experience a decrease in emotional and physical well-being, and increased stress and interpersonal conflict that can impede a desire to engage in caregiving activities (Saxena, 2015). But having a network of friends and family for social and emotional support can reverse this trend. Caregivers in later adulthood (i.e., 60 years and above) can experience cognitive and physical changes hampering their ability to perform caregiving tasks (Patrick & Goedereis,
This study also highlighted an uncertainty about whether employment and geographic proximity affected whether siblings assumed caregiving duties. When considering social support, and physical and mental health, it was noted that lower perceived social supports can negatively affect physical and mental health resulting in increased stress, higher burden, and symptoms of depression that can diminish a proclivity for accepting the caregiving role.

Motivating factors towards future caregiving include returning to the sibling with DD a perceived debt since the sibling with a disability may not have had (what is believed) a ‘normal’ life (Scelles, 2002). Other siblings believe that future caregiving is a chance to attain greater purpose and meaning in life, and an aspiration to do better than their parents for their sibling with a disability (Scelles, 2002).

Factors Related to Expectations of Co-Residential Care

Studies that have described typical sibling caregivers who co-reside with their adult sibling with DD are scarce. Earlier data mostly explored presumptive factors associated with expectations among typical siblings for taking on future caregiving and providing co-residence. Seltzer et al. (2005) found that factors related to expectations of future co-residence between typical and atypical siblings included parental desire/expectations, parents’ poor health status, gender and atypical sibling’s level of functioning. Sisters are more socialized to assume the caregiving role and expect future co-residence more so than brothers (Bigby, 1997; Seltzer et al., 2005). Greater shared activities and contact in childhood and adulthood may lead to a self-imposed responsibility for future caregiving and co-residence (Bigby, 1996; 1997; Griffiths & Unger, 1994). In addition, typical siblings who are geographically close and share more frequent activities with their sibling with DD expect co-residence (Seltzer et al., 2005). Higher degrees of intellectual disability (mild or moderate) (Krauss et al., 1996; Seltzer et al., 2005) and fewer
problem behaviors (Greenburg, Seltzer, Krauss, & Kim, 1997) in siblings with DD are likely factors related to expectations of co-residential caregiving due to lesser demands and burden on the caregiver (Dew et al., 2004). But factors associated with typical siblings’ lower emotional support and not assuming future co-residence are lower degrees of intellectual disability (severe and profound) often related to the atypical sibling’s higher physical needs, communication challenges and behavior difficulties (Greenberg et al., 1999; Griffiths & Unger, 1994; Krauss et al., 1996). Though many typical siblings anticipate co-residence with their adult sibling with DD (Krauss et al., 1996), Freedman et al. (1997) found that within a three-year period following transition only about 10% of atypical siblings remained in the typical sibling’s home. Krauss et al. (1996) found that while typical siblings expected to co-reside with their sibling with DD, some families still sought formal residential services. In addition, future co-residence was likely more common among typical siblings who had already established their lives in adulthood (Krauss et al., 1996).

**Future Planning and Service/Support Needs of Future and Current Caregivers**

A number of studies have looked at future planning, and the service/support needs of future and current sibling caregivers. Traditionally, families have reported a high degree of unmet service needs in housing information, legal and financial planning, respite, and case coordination (Heller, Caldwell, & Factor, 2007). There is limited understanding of how well the disability service system is supporting sibling caregivers (Holl & Morano, 2014). Typical siblings who anticipate future caregiving often feel neglected in discussions regarding the support needs of their sibling with DD (Hewitt, Agosta, Heller, Cameron Williams, & Reinke, 2013). Reportedly, service providers of persons with DD are more familiar with working with
parents when discussing supports and making decisions, but unaccustomed to working with typical siblings (Arnold, Heller & Kramer 2012, 2012; Heller & Kramer, 2009).

Studies have found that siblings who anticipate future caregiving desire information on in-person and online support groups, caregiving instruction, organizing finances, and guidance on future planning (Arnold et al., 2012; Heller & Kramer, 2009). Arnold et al. (2012) found that typical siblings desired greater inclusion in the planning process of their siblings with DD, as well as learning to develop a stronger voice in policy decisions to address their own support needs.

Holl and Morano (2014) looked at the service/support needs of sibling caregivers and the service system’s ability to meet those needs. Their research results revealed the following eight themes: 1) services, such as future planning guidance, psychotherapy, or siblings support groups for typical siblings and siblings with DD, were a necessary means for siblings caregivers’ overall well-being, 2) greater knowledge was needed regarding availability and access to services, 3) barriers to services and difficulties navigating the service system continue to exist, including service providers’ lack of outreach to siblings, unclear eligibility requirements and funding procedures, confusing enrollment measures, and challenges sourcing individualized services, 4) barriers to services continued due to parents’ unwillingness to share important information, 5) a need existed for understanding future planning needs, 6) more information was desired regarding residential options, 7) more services and supports were needed to help sibling caregivers take better care of themselves, and 8) more informational services were requested to help connect with other sibling caregivers (Holl & Morano, 2014).

The results of Holl and Morano (2014) are consistent with findings from other similar studies. However, findings from the Mass Mutual & Easter Seals (2012) study showed that 64%
of current sibling caregivers were aware of specialized service supports but 29% did not take advantage of the services due to the challenges of balancing their own needs with the needs of their immediate families (Mass Mutual & Easter Seals, 2012). Taylor and Hodapp (2012) report that a sibling caregiver’s health is negatively affected when the sibling with DD does not participate in daytime activities. This finding suggests that the provision of formal services for persons with DD are likely related to the emotional and physical well-being of sibling caregivers.

Sonik, Parish, Ghosh and Igdalsky. (2016) compared sibling caregivers of persons with DD $n=78$ years) and general working age adults to determine caregivers’ sociodemographic features and prevalence of material hardship. The study found that compared to the general group, sibling caregivers were older, and tended to be women, Black more so than White, less well educated, and more men than women were less likely to be married. Regarding health status, caregivers self-rated as having less excellent, very good, or good health. For material hardship (i.e., income, economic hardship, and participation in government programs), caregivers tended to have income between 200 and 300% below the poverty level, reside in households with some food insecurity, as well as reside in households that received benefits of Supplemental Security Income or SNAP (Sonik et al., 2016). The authors acknowledged that findings were consistent with current data regarding gender but differed on race, education level, and socioeconomic status.

**Transitioning from Parental to Sibling Co-Residential Care**

As baby boomers approach middle age, their caregiving duties may increase due to responsibilities for providing care to aging and/or ill parents. But for typical siblings of a sibling with DD, caregiving duties can significantly expand to primary care and co-residence when parents are no longer able. The Mass Mutual and Easter Seals (2012) study found that among
typical siblings surveyed, 14% of respondents co-resided with their sibling with DD and 23% self-reported as the current primary caregiver. For current sibling caregivers, 75% of typical siblings reported that caregiving was a full-time job, 80% percent of typical siblings believed their sibling with DD positively enhanced their life, and 63% reported a positive impact on quality of life (though this concept was not clearly defined) (Mass Mutual & Easter Seals, 2012).

**Effects of Transition on Typical Sibling**

Coyle et al. (2014) found that there are many challenges for typical siblings who transition to the caregiving role, including caring for their sibling with DD and mediating the impact of these new responsibilities on other aspects of the caregiver’s life. The planned or unplanned transition of a brother or sister with DD from parental to sibling co-residential care may occur at a time when the typical sibling is juggling other demands, such as caring for ill parents, dealing with the death of their parent(s), dealing with the death or ill-health of a spouse, rearing their own children, managing emotional aspects of children leaving home, and/or looking forward to the enjoyment of a grandchild’s birth (Dew, Balandin, & Llewellyn, 2008). This suggests that the post-transitional effect of providing care and co-residence to a sibling with DD can significantly impact the sibling caregiver’s life trajectories, especially family.

Data from the Mass Mutual and Easter Seals’ study (2012) found that about 75% of typical sibling caregivers reported that the relationship with their sibling with DD put a strain on family life and 20% stated that having a sibling with DD negatively impacted the cohesiveness of their family, relationship with parents, and interactions with extended family. Seventy-four percent reported difficulty balancing their own needs, those of their family, and those of their sibling with DD. Forty-five percent reported financial strain from caregiving, and 30% reported receiving no emotional, physical or financial support from family and friends. These findings are
similar to earlier studies which found that co-residence was significantly related to a reduction in caregiver well-being in mental health, financial resources, and social participation (George & Gwyther, 1986).

Yet, scholarly research offers limited information regarding the post-transitional effects of co-residence on sibling caregivers of a brother/sister with DD (Coyle et al., 2014). Furthermore, there are few models and data available that provide a comprehensive understanding of this phenomenon. Taylor and Hodapp (2012) found that an atypical sibling’s lack of participation in daytime activities (i.e., through formal supports) could result in increased negative health outcomes for a typical sibling. This finding implies the possibility of a direct negative effect on the material and social well-being of the sibling caregiver. For instance, depending on the individual’s needs, most persons with DD are not able to fully function independently without some supervision. Without the support of formal services, it is unlikely many sibling caregivers have the financial means to remain at home alone, provide constant direct care, and have no general income through employment. Furthermore, full-time caregiving can result in isolation and impede opportunities for social engagement.

Coyle et al. (2014) looked at the perspectives of adult sibling caregivers (\(M\) age = 57; female 93%; \(N = 15\)) regarding the intergenerational transition (i.e., transition of sibling with DD from parental to sibling care) of care and support. The authors noted that few models existed to help typical siblings anticipate what to expect when taking on the new caregiving role. Findings revealed three key themes. The first theme referred to managing the pervasiveness of age-related changes in the sibling with DD from dementia or ill-health, the caregiver’s own aging process, and ill-health/death of parents or other relatives. In this context, the sibling caregiver must juggle multiple duties to ensure the well-being of their sibling with DD and ability of the caregiver’s
family to respond to their needs. The second theme referred to the lack of and need for proper planning to become better prepared for taking on the caregiving role. The authors noted that in many cases, participants expected to become the caregiver but there were inadequate plans made by parents for how or when the transition would ensue, or parental expectations were assumed but not verbalized. The final theme reflected the need for improved informal and formal supports from family and service providers, respectively. These supports were suggested to help buffer the difficulty of managing the age-related changes in their sibling with DD. Though this study highlighted the potential challenges related to transitional adjustment and support, it was unclear regarding the timeframe from the point of transition to the time of interview. As proposed in this dissertation, a post-transition period from zero to five years can ensure guardianship and permanency of co-residential placement are firmly established. Having this knowledge can provide a more thorough comprehension of factors related to the sibling caregiver’s experience and available support. Furthermore, only 40% of typical siblings in this study resided with their sibling with DD. As a result, there is uncertainty with respect to the types of informal and formal supports proposed within the context of co- and non-co-residence. Further study can include looking at the post-transitional experiences of sibling caregivers within the context of co-residence.

Effects of Transition on Other Family Members

Whether the transition of a sibling with DD from parental to sibling co-residential care is planned or unplanned, the transition itself will likely occur as a crisis due to the death or ill-health of a parental caregiver (Vanhoutrteghem, Hove, D’haene & Soyez, 2014). Vanhoutrteghem et al. (2014) explored the narratives of siblings-in-law ($N = 14$) regarding their involvement in the decision process to provide co-residential care to their spouse’s family member with a
learning disability. The authors noted that while typical siblings are the expected caregivers of their sibling with a learning disability, their spouses and children are also involved in providing support. Interviews revealed that siblings-in-law believed household members were relatively unprepared for the transition. Siblings-in-law discussed feeling isolated and not being asked about their opinion or included in the family process and solution. Siblings-in-law talked about their belief that the birth family made the decision (implicitly or explicitly) without regard to their feelings and thoughts, but they had no alternative other than to go along with the decision. In addition, responses revealed how siblings-in-law felt “pushed around” and that the transition impacted different aspects of their lives (i.e., conflicts between sharing family time with their children and the new member with a disability, reduction in shared time as a couple, and significant loss of personal freedom). Despite these challenges, some siblings-in-law noted positive changes from living with their sibling-in-law with a learning disability, most notably a stronger connection to their spouse.

**Effects of Transition on Atypical Sibling**

The incapacity or death of a parent who has provided support over a lifetime, combined with the loss of surrounding networks and home, can be devastating to a person with a disability (Llewellyn, Gething, Kendig & Cant, 2004). People with DD rarely marry or have children, and do not likely have traditional family members who provide support as they age (Dew et al., 2008). Hence, a dilemma ensues regarding who will provide support when parents become unavailable. Siblings are likely the closest relatives to persons with DD when parents become deceased. Like many individuals, persons with DD are accustomed to a familiar environment.

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4 Learning disability is a broad term often used in European countries to describe persons with language and speech problems, emotional and/or behavioral problems, hearing impairments, and learning difficulties (LeRoy, Evans, & Deluca, 2000).
Thus, the immediate transition to a new familial milieu can create great anxiety even when the individual with DD knows his or her other family members. For the sibling caregiver, there is little data on how these post-transitional effects on the atypical sibling will affect the typical sibling’s well-being and family functioning.

**Reciprocity**

There is growing evidence on reciprocity and its beneficial effects on caregiver well-being. In social relationships, reciprocity is considered an unconditional, mutual exchange of emotional support (e.g., showing displays of affection, providing companionship) and/or tangible support (e.g., providing assistance with household duties) that benefits both parties, and fosters and maintains social ties (Levi-Straus, 1963). Reciprocal exchanges, in the context of family caregiving (reciprocal relationship between caregiver [e.g., parental or sibling] and care recipient), are not ordinarily unconditional due to physical and mental differences in the caregiver and care recipient. Caregivers may initially feel a sense of beneficence, personal benefit and greater life purpose and reward for providing assistance to their family member in need. However, the lack of reciprocal support from the care recipient can, over time, outweigh the beneficence associated with the caregiving function. In other words, increased stress and coping challenges related to managing the care recipient’s activities of daily living, care recipient’s age-related health issues and behavioral difficulties, and the caregiver’s own physical decline without receiving support can heighten caregiver burden and affect overall well-being.

It is noted that providing support to another person has greater benefits for well-being than receiving support (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Thomas, 2010). Furthermore, reciprocity was found to significantly predict a reduction in stress (Jung, 1990). Emotional reciprocity is related to an increased sense of well-being, and reduced stress and burden result
when the care recipient provides even minor tangible support in return (Dwyer, Lee, & Jankowski, 1994; Dwyer & Miller, 1990). It is suggested that the simple effort of attempting to help is perceived favorably by caregivers and may reduce negative feelings associated with care recipients’ dependency level (Perkins & Haley, 2013).

Perkins and Haley (2013) examined parental caregivers ($M$ age = 60.8 years, $N$ = 91) of adult children with an intellectual disability (ID) to assess caregivers’ perceptions of emotional/tangible reciprocity within the caregiver/care recipient relationship, association between emotional/tangible reciprocity and caregiver’s quality of life, desire for seeking alternative residence for their son/daughter with ID, and the utility of emotional/tangible reciprocity. Results showed that caregivers acknowledged reciprocity in the relationship but reported giving more emotional/tangible support than received. Higher disadvantage in tangible reciprocity (providing greater physical supports than received) was associated with increases in depressive symptoms and poor global mental health. This finding suggests reduced quality of life for the caregiver, and diminished mutual support due to the care recipient’s significant support needs and limited ability to give support in return. There was no significant correlation observed between emotional reciprocity and caregiver well-being or desire to find alternative residence for recipient with ID. However, the disadvantage of tangible reciprocity was associated with a reduced desire to find alternative living arrangements for the son/daughter with ID (Perkins & Haley, 2013).

Relationships between typical siblings and their sibling with DD are not considered symmetrical since typical siblings are believed to give more support than received (Kramer et al., 2013). The transition of a sibling with DD from parental to sibling co-residential can be highly stressful, given the likelihood for greater inequality of shared financial, emotional and tangible
supports (Stoneman & Berman, 1993). Heightened stress can result in increased burden for sibling caregivers and reduced overall well-being. However, findings from the Perkins and Haley (2013) study may indicate that greater tangible supports from care recipients can offset increases in stress related to caregiving. Reduced stress can enhance caregiver well-being and quality of life.

**Summary and Direction of the Dissertation**

Studies over the past two decades have found that certain static factors among typical adult siblings are related to greater closeness, involvement and emotional/instrumental support between the typical sibling and sibling with DD, as well as predict future caregiving and co-residence. These factors include being a sister, higher degree of intellectual disability (i.e., mild and moderate intellectual disability that reportedly exhibit fewer problem behaviors), type of disability (e.g., greater involvement, closeness and support towards siblings with Down syndrome than autism [due to social impairment/unusual behaviors] and cerebral palsy [due to higher physical needs]), and geographic proximity (Doody et al., 2010; Orsmond & Seltzer, 2000, Rimmerman & Raif, 2001). In addition, although most adult siblings of a brother or sister with DD demonstrate a positive psychosocial outcome, including lower levels of depression, positive functioning, good health, and feelings of reward for having the experience, type of intellectual/cognitive and physical disability can also affect involvement and future caregiving/co-residence (Dew et al., 2013; Hodapp & Urbano, 2007). Hodapp and Urbano (2007) found that adult siblings of a brother of sister with Down syndrome were closer and more involved compared to adult siblings of a sibling with autism (reportedly due to more challenging behaviors in sibling with autism). Dew et al. (2013) reported that the increasing physical needs of persons with cerebral palsy who are aging require greater instrumental supports, which can
strongly affect the involvement and future care/co-residence of a typical adult sibling who is aging him- or herself and unable to provide a high level of care.

It is widely reported that typical adult siblings are expected to take over future caregiving when parents are no longer able (Burke et al., 2015). However, there is only scant data on the post-transitional effects on typical adult siblings who have already taken on caregiving and co-reside with their sibling with DD. Thus, little is fully understood about the caregiver’s well-being, functioning of the caregiver’s family, effect on caregiver’s life trajectories in career and family, and differences between planned and unplanned caregiving. Results show that current sibling caregivers felt rewarded in their role but alone in their experience and frustrated sourcing disability services (Burke et al., 2015). Reported post-transitional effects on typical sibling caregivers were challenges managing age-related changes in their sibling with DD and caregiver’s own aging process, lack of future planning to prepare for taking over caregiving role and balancing family’s needs, and desire for informal and formal supports (Coyle et al., 2014). Siblings-in-law described feeling isolated from and forced into the decision to provide co-residence to their sibling-in-law with DD (Vanhouotteghem et al., 2014).

The transition of care from parent to sibling often occurs at a crisis point when parents can no longer provide support (Vanhouotteghem et al., 2014). But when formal supports are not available, siblings will likely provide residence to their sibling with DD. Whether planned or unplanned, it is difficult to anticipate the timing of a transition. However, the outcome of any transition that results in co-residence can have a significant effect on the sibling caregiver’s well-being and functioning of his or her family members. Thus, what a sibling anticipates for the caregiving role can be much different than what he or she actually experiences. When applied to the family systems framework, the planned/unplanned transition of a sibling with DD to the
sibling’s co-residential care can result in changing family characteristics and family interactions (i.e., changes in members’ roles, rules, power distribution and boundaries) that influence family functioning. In addition, where the family sits on the lifecycle continuum can affect the adjustment of all family members. More data is needed that explores the effect on the wellbeing and family functioning of typical sibling caregivers following the transition of a brother or sister with DD from parental to sibling co-residential care.
CHAPTER 3: METHODOLOGY

This study explored the narratives (i.e., life stories) of adult sibling caregivers following the transition of their sibling with DD from parental to sibling co-residential care. Interviews were conducted with 10 adult sibling caregivers. Narrative methodology was used to analyze their stories, and hermeneutics was the process for analyzing narratives. This process involved analyzing narratives as a whole and their different parts for themes relating back to this study’s research questions.

The purpose of this study was to understand the effects of parental to sibling caregiving transition on the meaning caregivers ascribe to their experience, caregivers’ well-being, functioning of caregivers’ families, reciprocity within the typical-atypical sibling dyad, and assumptions made about caregiving pre- and post-transition.

Narrative Methodology

Narrative methodology has great importance for social work research and practice (Riessman & Quinney, 2005). Narratives provide an account of individuals’ stories and histories. The significance of listening to individuals’ narratives is that they provide an understanding of important aspects related to a phenomenon (Larsson & Sjöblom, 2010). In narrative methodology, narratives are described as containing both phenomenon and method, where the phenomenon is considered the story and inquiry is the method (Connelly & Clandinin, 1990). The following section defines the term narrative and provides an overview of narrative inquiry.
What is a Narrative?

The term narrative can have many meanings depending on its use among different disciplines (Larsson & Sjoblom, 2010; Riessman, 2008). Narratives can be oral stories (e.g., interviews), written texts, field observations or visual materials (Riessman, 2008). Narratives typically have structure, including a beginning, middle and end, and suggest something about the narrator’s inner world (i.e., subjective experience) (Gergen & Gergen, 1988; Larsson & Sjoblom, 2010). They can also contain an element of drama involving actors, settings, plot, conflict, and resolution (Gergen & Gergen, 1988; Mishler, 1986). Narratives reveal the meaning ascribed to a lived experience, in the realm of one’s reality, by exploring past events that provide an explanation of the present (Gergen & Gergen, 1988; Mishler, 1986; Riessman, 1993).

For this study, the narrative was the narrator’s oral story revealed within each single interview. The story involved a first-person, oral telling drawn from the narrator’s memory to explain his or her life, family, personal history, and social experience that accounted for an event or action, or sequence of events or action, connected chronologically and meaningfully (Czarniawska, 2004; Larsson & Sjoblom, 2010).

Narrative Inquiry

The principal tenet of narrative inquiry is that “humans are storytelling organisms who, individually and socially, lead storied lives” (Connelly & Clandinin, 1990, p. 2). Narrative inquiry seeks to understand a narrator’s experiences and views about his or her daily life, and what he or she perceives as important (Roberts, 2002).

In narrative inquiry, analysis generally begins with the narrative interview and involves a process of inductive reasoning (Lincoln & Guba, 1995). The goal of narrative analysis is to explore how the individual’s experience is being described and interpreted (by both narrator and
researcher) to produce one accurate story that depicts the primary meaning made by the narrator (Andrews, Sclater, Squire & Treacher, 2002; Edvardsson, Rasmussen, & Riessman, 2003; Phoenix & Sparkes, 2008; Riessman, 1993). Exploring the stories people tell reveal the meaning given to their lived experiences (Creswell, Hanson, Plano Clark, & Morales, 2007). Meaning, however, is not created only by the narrator but co-constructed between narrator and researcher through multiple stories (Riessman, 1993). Hence, the researcher and narrator form an important, collaborative relationship where the researcher and narrator work together to build the story’s meaning during and following the interview (Creswell, 2009). In this context, the researcher looks at both personal experience and meaning-making systematically through a process of restorying (Giovannoli, 2000). This process involves gathering and transcribing stories, reading and re-reading transcriptions, analyzing textual parts for themes, reorganizing stories into a framework for analysis (e.g., time, plot, and characters), and reconstructing stories to understand its idea (Ollerenshaw & Creswell, 2000). Since the sequence of the narrator’s story can often be missing or not developed logically, restorying is a tool for rewriting and reorganizing narratives creating a causal link among different ideas.

**Hermeneutics**

“Hermeneutics is the science of correct understanding and interpretation” (Polkinghorne, 1983, p. 218). Modern hermeneutics examines the issue of human understanding where self-understanding and world understanding are interconnected (Polkinghorne, 1988). Drawing from the German philosopher Max Weber, Polkinghorne (1998) wrote, “the human realm is primarily the realm of meaning, and meaning fills human experience” (p. 215). In this context, the interpreter achieves understanding by acquiring “the meanings carried by the linguistic articulation of the text” (Polkinghorne, p. 226). The interpreter (e.g., researcher), however, may
be influenced by life-world expectations and preconceived ideas (based on subjective practices, beliefs, values and concepts) about what he or she will find in the text. From this vantage, interpretation is a construction of or mediation between the language of the text and interpreter’s own language (Polkinghorne, 1988). Alveson and Skoldberg (2000) used the following example to describe how human understanding develops. A child is observed attaining the meaning of an experience in one setting. The child builds on the knowledge of what he or she has learned and applies that to another setting. The child continues to transform the understanding of that meaning, tests it still again and again, and continues to develop the knowledge learned from that initial experience.

**Hermeneutic-Narrative Inquiry**

In hermeneutically focused narrative studies, narratives are the focus of hermeneutic practice, the practice of meaning-making, to help interpret our notions of self and identity (Brockmeier & Meretoja, 2014). Contemporary hermeneutics considers that human understanding is mediated through signs (e.g., language), sociocultural conditions, and history. Related to this idea is the interpretive imperative—the theory that the interpretive nature of human understanding is mediated by its social, historical, cultural and linguistic features. In this regard, past experiences, cultural traditions, and aspects of life that influence our identity shape how we encounter our present moment.

**The Hermeneutic Circle**

The hermeneutic circle is a methodological tool of co-construction involving the narrator’s perspectives revealed through dialectical discourse between researcher and narrator, researcher’s examination of the transcribed interview, and narrator’s agreement of the researcher’s interpretation of the story (Rodwell, 1998). It is a process to protect against
misunderstanding and chance that requires the researcher and narrator to shape “a new, more sophisticated construction or understanding of the fullness of the reality under investigation” (Rodwell, 1998, p. 28).

The hermeneutic circle begins by examining the narrator’s life story (linguistic text or transcribed interview) as a whole to attain an initial understanding of his or her lived experience and overall meaning (Polkinghorne, 1988, Rodwell, 1998). However, there is a shift in understanding the whole textual meaning after analyzing its different parts for themes (Polkinghorne, 1988). The process continues as a constant circular movement from whole to part to whole, where ongoing examination of the parts and the whole builds the strength of understanding to the point where a shared meaning/understanding of the story between narrator and researcher is achieved (Polkinghorne, 1988; Rodwell, 1998).

In this study, hermeneutic-narrative inquiry was used to explore the meaning typical sibling caregivers ascribed to their experiences (attained through life story interviews) following the planned/unplanned transition of a brother or sister with DD from parental to sibling co-residential care. Constituent parts of the whole text were also examined to identify themes related to categories addressed in the research questions. These categories are defined in Table 3.1.
Table 3.1. Categories Related to Research Questions.

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning of caregiving experience</td>
<td>Meaning is operationalized according to the shared values and specific beliefs an individual ascribes to the caregiving experience (van Eechoud, Grypdonck, Leman, Van Den Noortgate, Deveugele, &amp; Verhaeghe, 2015)</td>
</tr>
<tr>
<td>Well-being</td>
<td>Well-being is operationalized according to three domains (or themes), each organized around five subdomains (or subthemes) (see Appendix A for more developed description)</td>
</tr>
<tr>
<td>Subdomains</td>
<td></td>
</tr>
<tr>
<td>1) objective life conditions</td>
<td>1) physical well-being</td>
</tr>
<tr>
<td>(objective measure of the five subdomains)</td>
<td>2) emotional well-being</td>
</tr>
<tr>
<td>2) subjective feeling of well-being</td>
<td>3) social well-being</td>
</tr>
<tr>
<td>(subjective measure of the five subdomains)</td>
<td>4) material well-being</td>
</tr>
<tr>
<td>3) personal values and aspirations</td>
<td>5) development and activity (Felce &amp; Perry, 1995)</td>
</tr>
<tr>
<td>(measure of the importance of satisfaction with</td>
<td></td>
</tr>
<tr>
<td>five subdomains)</td>
<td>(Felce &amp; Perry, 1995)</td>
</tr>
<tr>
<td>Overall family functioning</td>
<td>The family systems framework (as described in Chapter 2: Literature Review) includes four domains that indicate overall family functioning.</td>
</tr>
<tr>
<td>Domains</td>
<td>1) Family characteristics (input into family system)</td>
</tr>
<tr>
<td>2) Family interaction (family system that shows</td>
<td>2) interactional processes between members and whole family with outside environment)</td>
</tr>
<tr>
<td>interactional processes between members and</td>
<td>3) Family function (output of family system)</td>
</tr>
<tr>
<td>whole family with outside environment)</td>
<td>4) Family life cycle (family’s life stage that can influence other three domains)</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>Reciprocity is the mutual exchange of emotional and tangible support given and received between the caregiver and sibling with DD.</td>
</tr>
<tr>
<td>Understanding sibling caregiving pre and post-transition</td>
<td>The pre-transition understanding of caregiving considers an abstract view that reflects empathy for the role but no direct experience for having fulfilled the role (Burke, Fish &amp; Lawton, 2015). The post-transition understanding of caregiving focuses on the actual details and logistics related to the caregiving experience (Liberman &amp; Trope, 2008; Trope &amp; Liberman, 2003).</td>
</tr>
</tbody>
</table>
Sampling Methodology, Participant Selection, and Ethical Considerations

Sampling methodology.

Eleven participants (sibling caregivers) were recruited for this study. However, one asked to withdraw, leaving 10 participants in total.

The sampling methodology involved a mix of non-probability sampling strategies, including convenience sampling (sourcing participants based on the most available population), criterion sampling (generating participants based on meeting the inclusion criteria), opportunistic sampling (gaining new participants as the research develops), and snowball sampling (finding participants from sampling elements who know one another) (Hays & Singh, 2012).

Recruitment began with sending email requests to local and national stakeholder groups (i.e., Sunrise Community [Florida service provider], Family Care Council [advocacy and educational group representing persons with disabilities], each state’s Developmental Disability Council (through Facebook), Epilepsy Foundation, United Cerebral Palsy, SibShop [national sibling support group], The ARC [national advocacy group for persons with developmental disabilities], and the Sibling Leadership Network [national advocacy and support group for siblings of persons with developmental disabilities]) to distribute to an advertisement (constructed by the researcher) to its base outlining the study’s purpose, need for volunteer study participants, and email for interested persons (See Appendix B for Email and Advertiser-Flier scripts). Sunrise Community, SibShop, and The Arc each distributed the advertisement to its membership. The Sibling Leadership Network provided access to its Facebook page. Regarding the state Developmental Disability Councils (DDC), some states allowed free access to their Facebook pages where others required permission. With this in mind, an advertisement was posted on all DDC Facebook pages with free access. However, requests were made to some
DDCs requesting access to its users. In total, 124 messages were sent using Instant Messenger. Once permission was granted, the advertisement was posted to the Facebook page.

At the outset, the goal was to find a sampling unit of twelve participants. However, despite the broad sampling approach, it was difficult to find a study sample of 12 participants who met the inclusion criteria. In this regard, this study includes only two male participants. In addition, both male participants were former co-residential caregivers having transitioned their siblings with DD to alternative residential facilities, each three years prior to interview. Furthermore, one male participant was 69 years of age. Regarding the unequal proportion of participants according to gender, this outcome was representative of the caregiving trend where more women than men are caregivers (Moen & Wethington, 1999).

**Participant selection and inclusion criteria.**

The inclusion criteria for persons to participate in this study were: 1) typical adult siblings who self-reported as the primary caregiver of and who co-resided with a brother or sister with DD, 2) typical adult sibling co-residential caregivers who held the primary caregiving role from zero to five years’ post-transition, 3) 30 to 60 years of age (as this reflected the date range of siblings who could take over for parents aging out of the caregiving role), and 4) English-speaking.

**Ethical Considerations**

Prior to participant recruitment, approval for the study of human subjects was obtained from the Institutional Review Board of the University of South Florida (see Appendix C). Once approval from the Institutional Review Board was received, the researcher began the sampling process. After a sample participant was identified, the researcher set up a phone interview time of the prospective participant’s choosing. Ahead of each interview, the researcher emailed to the
participant a copy of the informed consent (see Appendix D), for his or her review, requiring a recorded verbal consent to participate in the study. The consent letter clearly stated that participation was voluntary, and free to end the interview at any time or withdraw without reprisal from the study. Participants were assured that identifying information and content were kept confidential.

For this study, the primary sources of data were the recorded phone interviews and the researcher’s field notes. Essentially, field notes were the researcher’s reflexive notes of observations made of participants’ emotional expression during interviews and researcher’s own understanding of ideas during the narration (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). For all interviews, the participant chose the interview time and all efforts were made to de-identify stories and researcher’s field notes making sure no identifying information was revealed. Thus, participants and their family members were given pseudonyms. Furthermore, transcriptions and field notes were stored in the researcher’s laptop, and were password protected to ensure confidentiality. No hard copies were made containing participants’ information.

Data Collection

Procedure of Data Collection

After a potential participant was identified, the researcher contacted the individual initially by email to ask identifying questions and confirm the potential participant met the inclusion criteria. In the email, the researcher explained his background, the study’s purpose, and described what was involved in participating (i.e., one interview [and a second, if needed] as well as verifying the researcher’s final analysis). If the participant met the inclusion criteria and there was agreement on moving forward with the interview, a phone interview time of the participant’s choosing was determined.
Prior to each interview, the researcher sent to each participant the informed consent for review, including all details related to study, and permission to end interview or withdraw from study without reprisal. At the start of each interview, the researcher reviewed the informed consent with the participant and recorded the participant’s consent agreeing to participate in the study. Following this step, the researcher began asking questions using the Interview Guide (see Appendix E). Towards the end of each interview, the researcher asked demographic questions, including caregiver age, age of sibling with DD, race/ethnicity, and religion. In most cases, demographics appeared during the course of each interview. Once it was agreed between the researcher and participant that all questions were answered, and no more information was needed, the interview ended.

**Interviews**

Interviews lasted approximately two hours each, and were recorded using a secure phone app, TapeACall. No second interviews were required. During the interview, the researcher listened attentively and limited his involvement to encourage participants to tell their story in their own way (Wells, 2011; Riessman, 1993). Stories surrounding events were encouraged to draw out memories revealing the meaning behind participants’ experiences (Lieblich Tuval-Masiach & Zilber., 1998). Early memories were considered a vehicle for understanding an individual and his or her life view (Wells, 2011). Follow up questions were presented at the end of interviews to attain demographic information, and general conversation ensued that resulted in participants revealing further information related to study findings.

Though the researcher mostly engaged in active listening, he used probing questions at appropriate moments in the interview to clear up any confusion or give the participant a chance to expand and deepen his or her story. This approach followed a collaborative format where the
researcher and narrator co-constructed the narrative and together developed the meaning underlying the story (Polkinghorne, 1988; Riessman, 1993; Riessman, 2008; Squire, 2008). The researcher also drafted reflexive observations, as already described.

Transcribed interviews are integral to narrative research because they embody the story’s truest representation (Giovanalli, 2003). Once an interview was completed, it was transcribed within a month. The researcher transcribed two interviews. Eight interviews were transcribed using a professional transcriptionist. The transcription service provided a mutual confidential disclosure agreement (see Appendix F) guaranteeing the confidentiality of all information. Furthermore, the service automatically deleted all transcriptions 30 days after the time of order completed.

Data Analysis

In narrative inquiry, the narrative is the narrator’s oral story that develops within a single interview (Riessman, 2008). The goal of narrative analysis is “to provide an interpretation of the data [narrative] by telling or retelling a story” (Lichtman, 2013, p. 249). Narrative analysis focuses on the structure, content and context of the story (Esin, 2011). Though the researcher can look at just one of these components, in this study narrative analysis looked at all aspects to understand how the meaning of the experience was constructed as a whole (Esin, 2011). How events are connected in a story can reveal how persons give meaning to their lives (Riemann, 2003).

Analytical Process

There are different perspectives on how data are analyzed and interpreted within narrative inquiry. In this study, data analysis involved a pluralistic analytical model using two approaches: 1) structural analysis and 2) thematic narrative analysis. The hermeneutic circle was the iterative
process of analysis. This process required moving back and forth between analyzing the narrative and its constituent parts to build knowledge and develop a deeper understanding of the data (Riessman, 2008; Tesch, 1990). Hermeneutics also considered stories for the sociocultural, political, and historical context in which they were told.

**Structural analysis.** Structural analysis focuses the structural components of stories for their narrative form (how stories are told) (Riessman, 2008). It is a type of within-case analysis focusing on the actual narrative (i.e., story) to understand its meaning. In structural analysis, the narrator persuades the listener to believe his or her explanation of events (Riessman, 2008).

This study used structural analysis to answer the first research question regarding how sibling caregivers made meaning of their lived experience and identified with the caregiving role. The unit of analysis was the participant’s story about the transition of their sibling with DD from parental to sibling co-residential care. Once the transition story was identified, the researcher used the process of re-telling the transition stories for clarity and temporal order, and applied a table of analysis (constructed by the researcher) to identify certain elements, which follows.

**Structural analytical template.** A structural analytical template (see Table 3.2) used for analyzing each story’s elements was constructed using the model of Labov (1982), table of Robichaux (2003), and further expanded to include elements drawn from the ideas and discussions of Mishler (1986), Robichaux (2003), Riessman (2008), and Wells (2011). Labov’s model defined a narrative as a story that describes one’s individual experience of a past specific event. Labov’s approach assumes that: a) stories (i.e., narratives) have a temporal order (i.e., beginning, middle, and end), b) stories reference events believed to be true, and c) stories are told to those that have not heard it before but will understand it (Georgakopoulou, 2006). The
transition stories in this study can be viewed as hypothetical narratives since they referred to possible circumstances or events but lent to their overall meaning (Riessman, 1990).

Table 3.2: Structural Analytical Template

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Story Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Characters</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Place</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Time</td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td></td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>What does narrative mean?</td>
<td></td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is the causal relationship (change in one factor causes change in another)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td></td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3.2 shows the template applied to and used for analyzing the stories of transition. According to Labov, complete narratives comprise six main elements. To analyze these elements, Labov proposed a question method that requires asking a series of questions related to each element. These elements and related questions are: 1) Abstract (What is the story about?), 2) Orientation (Who is involved, when, and where?), 3) Complicating Action (Then, what happened?), 4) Evaluation (What is the point?), 5) Resolution (What finally happened?), and 6) Coda (Returning story to the present). The table was further expanded to include praise and blame among the story’s characters, causal relationships indicating how a change in one factor causes change in another, contextual considerations, and story’s overall meaning (Robichaux, 2003, Riessman, 2008, and Wells, 2011). Sentence clauses within each story were analyzed for their structural element and/or sub-element, and summary interpretation included in the table to determine the story’s meaning.

**Thematic narrative analysis** Thematic narrative analysis focused on the thematic meanings of narratives rather than their form (Riessman, 2008). Similar to structural analysis, there are many different approaches to thematic analysis in narrative inquiry (Langellier, 1989; Mishler, 1986; Riessman, 2008). In this study, thematic narrative analysis drew from the ideas of Ewick and Sibley (2003) that loosely followed the category-centered method in grounded theory (Riessman, 2008). This analytical approach involved the researcher identifying stories that met specific criteria, contextualizing excerpts, and organizing excerpts into categories subcategories (related to the research questions), and themes. This approach included seeking out a similarly shared meaning across narratives (Riessman, 2008).

**Coding.** A basic goal of thematic narrative analysis was to sift through and re-read transcribed interview data to identify themes and underlying assumptions (Lichtman, 2013). In
this regard, the researcher identified stories related to a specific event, organized story excerpts according to categories and subcategories related to the research questions, and source emergent themes (as represented by story excerpts) related to the categories and subcategories. NVivo software (Version XX) was used to organize story excerpts into the categories and subcategories. Considering the small study sample, participants had many similar ideas. These ideas, however, were not always identical. With this in mind, themes represent a grouping of similarly related ideas.

**Analytical Framework**

The following six steps were followed as a framework for analyzing narratives (Steinwedel, 2013):

**Step 1—Transcribing the interview.** The first step of data analysis involved transcribing participants’ interviews. The researcher transcribed two interviews and used a confidential transcription service to transcribe the remaining eight interviews. Interview transcriptions were de-identified of any confidential information.

**Step 2—Ensuring accuracy of transcription.** In the second step, hard copy transcriptions were reviewed for clarity and matched against audio recordings to ensure their accuracy. This step involved becoming more immersed in the data to more deeply understand whole narratives, their stories, and underlying meanings.

**Step 3—Memoing.** The third step included reading through transcripts again without the audio, and memoing. Memoing was a means of reflecting again on what was learned in interviews, and identifying ideas about the data, including stories, story excerpts, potential themes and their relative categories and sub-categories. Transcriptions were also uploaded into
the NVivo software, and categories and sub-categories were created as nodes for future organization as a tool for thematic narrative analysis.

**Step 4—Structural analysis.** In the fourth step, the researcher began the process of structural analysis where he identified each participant’s story of transition, re-storied the stories for clarity and temporal order, analyzed story clauses for their relative structural elements (using the structural analytical table), and posted the interpretation of clauses in the appropriate sections. Once completed, the researcher explored all interpretations to determine a meaning of each story and drafted his findings. As part of this step, the researcher also included his reflexive thoughts.

**Step 5—Thematic narrative analysis.** The fifth step involved thematic narrative analysis using the NVivo software package. Each singular interview was examined using the NVivo software package, and story excerpts identified and organized within their respective categories and sub-categories (referred to as nodes). The hard-copied transcripts with memos were also reviewed to ensure any other information was not missed. After story excerpts were organized within the categories and subcategories, they were cleaned up for clarity and continuity. Following this step, the process of theming began. Once excerpts were themed within the respective categories and sub-categories, the process of writing the final analysis continued.

**Step 6.** As a final step and opportunity to validate the data, the researcher sent the drafted findings of the structural analysis to all participants for verification. In addition, the researcher sent a part of the transcript to a dissertation committee member for coding and theming. The researcher compared results from the participants and coders to validate the
information and ensure the correct methods were used. After this process was completed, the researcher completed the analysis and drafted the final discussion.

Validity and Trustworthiness

Validation is an integral piece of all qualitative research. It is important to determine if the data presented in a study is not only accurate but trustworthy (Milinko, 1999). One threat to validity is research bias that can result from selective recording and observation of data, and letting personal perspectives and views influence the data’s interpretation.

Validity of the Structural Analysis

Three strategies were used to validate the findings of the structural analysis: researcher reflexivity, member checking/participant feedback, and theoretical validity. Researcher reflexivity highlighted the researcher’s ideas and biases that developed from interviews and could influence findings. Reflexivity is noted as Interviewer’s Reflexive Thoughts and followed at the end of each participant’s structural review. The researcher also engaged in member checking/participant feedback where findings were shared with all participants giving an opportunity for feedback and to clear up any errors or confusion. While all participants were contacted regarding the researcher’s findings, only seven out of 10 participants responded. Subsequently, changes to the final analysis were made to incorporate participants’ feedback. Theoretical validity considered the extent to which a proposed explanation that emerged from the data was credible and defensible. With this in mind, the meaning of each participant’s story of transition was viewed as a proposed construct to conceptualize the actual meaning participants ascribed to and identified with their experience as a co-residential caregiver. For further explanation, see the Summary of Structural Analysis at the end of section B in Chapter 4.
Validity of Thematic Narrative Analysis

The strategies for establishing the validity of data obtained through the thematic narrative analysis, included: triangulation, peer debriefing, and natural generalization. Triangulation involved the use of different sources of data and methods to create an understanding of the study phenomenon (i.e., siblings who become the co-residential caregiver following the transition of their siblings with DD from parental to sibling co-residential care) and identify themes (Cresswell & Miller, 2000; Patton, 1999). Data triangulation involved the analysis of multiple sources of data (i.e., participants’ interviews). Referred to as an across-case analysis, this study’s researcher explored the interviews of 10 participants to identify common themes. Investigator triangulation was another approach involving the researcher and a member of the researcher’s dissertation committee who cross-checked the researcher’s observations. Validity, in this regard, was achieved once a consensus of observations was achieved between the dissertation committee member and the researcher.

Finally, while generalizing this study’s findings was not achievable, naturalistic generalization was achieved since there was an agreement of ideas among participants due to participants’ similarities and experiences regarding the phenomenon.
CHAPTER 4: RESULTS

This study used hermeneutic-narrative methodology to understand the well-being and family functioning of typical adult sibling caregivers following the planned or unplanned transition of a brother or sister with a developmental disability from parental to sibling co-residential care. As part of the narrative tradition, narrative data (i.e., the complete interview transcript from each study participant [sibling caregiver]) was the unit of measure used for analysis. Data analysis involved a pluralistic approach that included two components: 1) structural analysis (within-case analysis), and 2) thematic narrative analysis (across-case analysis). The structural analysis responded to this dissertation’s research question 1: how sibling caregivers make meaning of their experience and identify with the caregiving role. This approach explored each participant’s singular, episodic story regarding the transition of their brother or sister with DD from parental to sibling co-residential care. The thematic narrative analysis involved an across-case analysis as a response to this dissertation’s remaining research (questions 2 through 5) exploring the post-transitional effect of co-residence on the sibling caregiver’s well-being, family functioning, reciprocity between sibling caregiver and atypical sibling, and how sibling caregivers anticipated their experience pre-transition and actual experience post-transition. Hermeneutics was the iterative process that looked at the whole narrative, its essential parts, and where appropriate, relative context (i.e., political, sociocultural and historical features) to more thoroughly understand the circumstances in which stories were told.
This chapter has three sections: Demographics of Study Sample (see Table 4.1), Structural Analysis, and Thematic Analysis.

Demographics of Study Sample

Table 4.1. Demographics of Study Sample.

<table>
<thead>
<tr>
<th>Main Category</th>
<th>Secondary Category</th>
<th>N=10</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (Caregiver)</td>
<td>Female</td>
<td>8 (MFC; DFC)</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>2 (MM; SM)</td>
<td>20</td>
</tr>
<tr>
<td>Participants who Self-Reported as Primary Co-Residential Caregiver</td>
<td>Yes</td>
<td>8 (MFC; DFC)</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2 (MM; SM)</td>
<td>20</td>
</tr>
<tr>
<td>Age (Caregiver)</td>
<td>30-39</td>
<td>2 (35 [male]; 37 [female])</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>3 (44 [female]; 45 [female]; 45 [female])</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>50-59</td>
<td>3 (51 [female]; 52 [female]; 54 [female])</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>60-69</td>
<td>2 (60 [female]; 69 [male])</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M = 49.2; SD=10.30</td>
<td></td>
</tr>
<tr>
<td>Birth Order</td>
<td>Oldest</td>
<td>7 (MFC)</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Lone</td>
<td>3 (DFC; MM; SM)</td>
<td>30</td>
</tr>
<tr>
<td>Months in Co-Residential Caregiving Role</td>
<td>&lt;12 months</td>
<td>2 (MFC)</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>12-23</td>
<td>1 (MFC)</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>24-35</td>
<td>6 (MFC; DFC; SF; MM; SM)</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>36-47</td>
<td>3 (MFC)</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M = 26 months</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>Single</td>
<td>2 (SF; SM)</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>7 (MFC; MM)</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>1 (DFC)</td>
<td>10</td>
</tr>
</tbody>
</table>

* MFC=married female with children; DFC=divorced female with children; SF=single female; MM=married male; SM=single male
Table 4.1. Continued.

<table>
<thead>
<tr>
<th>Main Category</th>
<th>Secondary Category</th>
<th>N=10</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td># of children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
<td>3 (SF; MM; SM)</td>
<td>30</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>3 (1 MFC has a daughter; 2 MFCs each have a son)</td>
<td>30</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>4 (3 MFCs each have 1 son and 1 daughter; 1 MFC has 2 sons)</td>
<td>40</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td></td>
<td>9</td>
<td>90</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma</td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Some college</td>
<td></td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>Associate Degree</td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Undergraduate</td>
<td></td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Graduate</td>
<td></td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not employed</td>
<td></td>
<td>2 (1 SF; 1 MFC—receives state-issued stipend)</td>
<td>10</td>
</tr>
<tr>
<td>Employed part-time</td>
<td></td>
<td>2 (2 MFCs; 1 MFC reduced hours; 1 MFC reduced hours and received state-issued stipend)</td>
<td>20</td>
</tr>
<tr>
<td>Full-time employed</td>
<td></td>
<td>4 (2 MFCs; 1 DF; 1 MM)</td>
<td>40</td>
</tr>
<tr>
<td>Full-time + extra</td>
<td></td>
<td>1 (1 MFC—has extra job)</td>
<td>10</td>
</tr>
<tr>
<td>Retired</td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Transition Type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planned-Fluid</td>
<td></td>
<td>1 (1 MFC)</td>
<td>10</td>
</tr>
<tr>
<td>Planned-Non Fluid</td>
<td></td>
<td>6 (4 MFC; 1 MM; 1 SM)</td>
<td>60</td>
</tr>
<tr>
<td>Unplanned-Fluid</td>
<td></td>
<td>1 (1 SF)</td>
<td>10</td>
</tr>
<tr>
<td>Unplanned-Non Fluid</td>
<td></td>
<td>2 (1 MFC; 1 DFC)</td>
<td>20</td>
</tr>
</tbody>
</table>

* MFC=married female with children; DFC=divorced female with children; SF=single female; MM=married male; SM=single male
Table 4.1 represents the demographic features of the study sample. These demographic categories were organized around this study’s inclusion criteria, interview questions, and static and dynamic factors outlined in this dissertation’s literature review. The figures outlined in Table 4.1 are estimates achieved after sifting through participants’ stories and calculating dates and times. Though the potential inaccuracy of this information puts into question its validity, efforts were also made while collecting the data (i.e., during the interview process) not to impede the flow in which participants explained their stories.

In total, 10 individuals participated in this study, including 8 female caregivers and 2 male caregivers. All female participants self-reported as the primary co-residential caregiver of their brother/sister with DD. The male participants self-reported as the primary caregiver, and formerly co-resided with their siblings with DD between 2 to 3 years prior to sourcing alternative residence for their siblings. All but one participant fell within the age range of 30 to 60 years; however, one male participant was over age 60 years. The mean participants’ age was 49.2 (SD = 10.30). The majority of participants had undertaken the co-residential caregiving role for a span of between 24 and 35 months, 2 female participants held the role less than 11 months, 1 female participant held the role between 12 and 23 months, and 1 female participant between 36 and 47 months. The average duration within the co-residential caregiving role was approximately 26 months. Following co-residence with their siblings with DD for over two years, both male participants sourced alternative residences for their siblings with DD three years prior to interview. With respect to birth order, 7 participants were the oldest siblings in their families, and 3 participants identified as the lone sibling of their sibling with DD. Regarding marital status, 2 participants were single, 7 participants were married, and 1 participant was divorced. For participants with children, 3 participants had no children, 3 participants each had 1 child, and 4
Participants each had 2 children. With respect to race/ethnicity, the majority of participants identified as Caucasian (n = 9) and 1 participant reported as African American. With respect to education, 1 participant reported having a high school diploma, 2 participants reported having some college, 1 participant stated having an associate degree, 3 participants reported having an undergraduate degree, and 2 participants stated they had a graduate degree.

Since this study explored the post-transitional effect on adult sibling co-residential caregivers, type of transition (i.e., transition type) was deemed an integral factor when considering participants’ demographics. In this regard, transition type was added as a demographic feature, but viewed according to whether the planned or unplanned transition was fluid or non-fluid. The delineation of fluid and non-fluid emerged from participants’ narratives but was also considered within the literature (see Vanhoutteghem et al., 2014). Fluid transitions could occur when the adult sibling caregiver had time to prepare, adjust, and plan ahead for the co-residential transition of their sibling with DD whether the transition was planned or not. In non-fluid transitions, transitions could occur following a crisis involving a parent’s death or illness requiring the immediate co-residential transition of their sibling with DD. In this case, there was little time for any family member to prepare for this event.

Among most participants (n = 7), the transition was planned. However, only one participant described the transition as fluid. This result indicates that although participants were aware of assuming the primary caregiving role and were part of their atypical sibling’s co-residential transfer plan, the transition itself occurred abruptly without time to properly organize. For participants who described having an unplanned transition, two participants described a non-fluid transition and one participant explained her transition was fluid. These findings showed that the majority of participants (n = 8) experienced a non-fluid transition.
Structural Analysis

Research question 1:

*How do typical adult siblings make meaning of their experience and identify as a caregiver following the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care?*

Since participants at the time of interview already held the co-residential caregiving role for a period between six months to 3.5 years, there was little time to reflect on the post-transitional experiences related to how they adapted to the role. With this in mind, the stories of transition were believed the most appropriate instrument for how caregivers understood, made meaning of, and identified with their experience.

Each individual analysis was organized around the participant’s story of transition and organized according to the following format: a) participant profile, b) participant’s story of transition (including a table summarizing the researcher’s interpretation, and researcher’s analysis), c) interviewer’s reflexive thoughts, and d) summary. In the sub-section, b) participant’s story of transition, data presented in italics represents the participant’s spoken story about the transition. Non-italicized text represents the researcher’s analysis. Each story analysis begins with an opening quote from the sibling caregiver giving context and further meaning to the caregivers’ lived experiences.

**Story of Nancy (Date of interview: November 13, 2015).** *It’s my brother. I love him. Is it [caregiving] going to take a lot out of me? Yes. But, when we go out somewhere and we’re kidding, joking and laughing, I love that he’s such a fun guy.*

**Participant profile.** Nancy is a 45-year-old woman who moved from Maryland back to the family house in South Carolina to assume the role as co-residential caregiver to her 39 year
old brother with DD. Nancy comes from a family of six, and has an older sister, 49 years of age, and younger sister, 43 years. Though Nancy’s mother passed away approximately 13 years prior to this interview, her father, 69 years of age, remarried in 2012 after 10 years of being single. Nancy was not certain about the origin of her brother’s disability. However, she stated he was intellectually disabled likely due to a lack of oxygen during his birth. Nancy is African American and currently completing her Bachelor’s degree in Human Services. Nancy is not presently, nor has been married.

**Nancy’s story of transition.**  My brother didn’t come to live with me.

I came to live with my brother. That would be the proper way to put it. I never thought I would be his caregiver. But I also never thought my mother would have passed away at such a young age. She was the first person I know of in the family to have cancer. She had it in her pancreas and it was very aggressive. It was not long before she collapsed and passed away. It was extremely painful for my brother. What happened after my mother’s death is that we left him here with my father for six months. My little sister was here living in the house and teaching. Then, she moved and took my brother to South Korea for six months. But while he was over in South Korea, he would look through pictures of my mother and people would ask him over-and-over again how he was doing. Then, he would have to think about it, and he lost a lot of weight; just skin and bones. It was very painful for him. So, he came back to live with our father. But when my mother passed away, my father was so wrapped up in grief and feeling guilty about my brother having a disability that he allowed him to do anything he wanted. Eventually, what happened is my dad decided to remarry last October.
My mom had been deceased for 13 years. In January, we went on a family trip to the Bahamas, and my siblings and I were talking about what was going to happen to my brother; mostly my younger sister and I were talking about it. And we just kind of decided that I would be the one to come back home. My younger sister lives in England. She’s at the Department of Defense school. She could have taken him over as a dependent, no problem, but she did not want to do that. She’s known since he was nine years old that he’s very routine-oriented. And just living anywhere else would be a problem for him. So, I’m single. I have no children. I have no husband and I began to pray about it. In November of 2012, my father told me that he was going to ask my new stepmother to marry him. And, we broached the subject with my brother, and it just went from there. And on January 16th, 2013, I moved from Maryland back home. And now, it has been 2 years and 3 months.

Table 4.2. Analysis of Nancy’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Due to father’s grief and inability to properly care for brother with DD, Nancy took over the caregiving responsibilities.</td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Mother had passed. Father unable to properly care for his son with DD due to grief. Sisters agreed to plan where one sister, Nancy, would assume caregiving role and move into the family house.</td>
</tr>
<tr>
<td>Characters</td>
<td></td>
<td>Nancy, mother, father, younger sister, older sister, and brother with a disability.</td>
</tr>
<tr>
<td>Place</td>
<td></td>
<td>Family home</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td>January 2013</td>
</tr>
<tr>
<td>Structural Elements</td>
<td>Structural Sub-Elements</td>
<td>Researcher’s Interpretive Summary</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Mother diagnosed with cancer (crisis), and eventually passed (turning point). Brother with DD moved with sister to South Korea. Brother with DD had challenges managing grief of mother’s death in South Korea (crisis), and returned to father’s home in South Carolina (turning point).</td>
</tr>
</tbody>
</table>

**Complicating Action** (what happened next) | What does narrative mean? | Father decided to re-marry and sisters made decision on who would assume caregiving role (turning point). Middle sister, Nancy, agreed to take on role, leave job, and move from Maryland to family home in South Carolina. |

**Resolution** (resolving the plot) | Nancy stated that the sisters discussed Nancy moving into family home and assuming the caregiving role. |

**Coda** (ends narrative; returns listener to present) | In January 2013, Nancy moved from Maryland back to SC. |

How is praise represented in the story? | Praise provided to deceased mother, and younger sister. |

How is blame represented in the story? | Blame is directed towards father. Brief reference to older sister, but had limited involvement. |

**Context** (sociocultural, political) | Patriarchal influence of the military, which directed the family culture. It also created sense of obligation that the women in the family assumed the caregiving responsibilities. |

**Meaning** | Duty and responsibility to the sisters and whole family for taking on caregiving role. Story exposes gendered nature of caregiving in patriarchal culture. |

Nancy’s story of transition begins prior to her move from Maryland to the family home in Columbia, South Carolina in January 2013. Nancy’s story discusses the collective decision made among the sisters, while on vacation about one year before, that Nancy would assume the
caregiving role for her brother. Though this transition was planned, it was not planned in the formal sense, where Nancy’s parents would have discussed with Nancy and other family members this potential outcome.

Nancy began her story emphasizing that she came to live with her brother, and not the other way around. This description is an important piece to the narrative as it indicated a dynamic where Nancy was a returning outsider. Most transitions of a sibling with DD are perceived to involve a move from the parental to sibling caregiver’s home. In this case, however, Nancy made the move to live with her brother.

The main characters of this story include Nancy, her deceased mother, father, and younger sister. Brief mention is also made about her older sister and step-mother. Ironically, while the story revolves around her brother with DD, he is not a central character.

At the outset of her story, Nancy explained how her mother passed away at a young age due to cancer. The diagnosis of her mother with cancer was a crisis for the family, yet her mother’s passing was also a turning point. Nancy stated that her mother was the first person in the family to be diagnosed with cancer, demonstrating some level of surprise of this unexpected outcome. Nancy also highlighted the type of cancer (pancreatic) and its nature suggesting that it was beyond the family’s control to solve the situation. In how Nancy heralded her mother, it appears her mother was a central figure in maintaining familial balance. When referring to her mother’s death, Nancy stated it was not long before she collapsed and died. This is the story’s second turning point. But rather than explain her own experience and emotion related to this event, Nancy talked about the effect on her brother and the pain he felt regarding the mother’s death. She also discussed her sister taking her brother to South Korea for a short stint following her mother’s death and then leaving her brother with her father for six months upon his return.
This implies the sisters’ understanding of her father’s inability to care for her brother, and her attempt to avoid a challenging situation of her father as caregiver to her brother.

The move to South Korea is another turning point where it was explained that the brother further experienced emotional pain due to reminders of his mother’s death. Thus, there are hints of no formal support provided to assist him with the grief of his mother’s loss. Nancy explained that this crisis resulted in his brother coming back to live with her father; however, Nancy follows back to her mother’s death to explain her father’s grief around her mother’s death. Nancy also indicated some sense of guilt within her father for her brother’s disability explaining that her father allowed her brother anything he wanted. The suggestion of guilt over her brother’s disability is a likely theme representing a solidly patriarchal family with strong military roots throughout the lifecycle of the family. This part of Nancy’s narrative implies a crisis.

Nancy stated that eventually her father decided to re-marry. This is another turning point in the story. As a result, the sisters got together to decide who would take on the caregiving role of her brother. Nancy emphasized that the decision of her transitioning to the caregiving role was developed mostly by her and her younger sister. Nancy also mentions that part of the decision included the fact that her brother was routine-oriented, and she was single with no husband. This can indicate a lack of self-worth and limited self-regard for taking on the role, but she implies she prayed about this responsibility suggesting a desire for some sense of spiritual endorsement and support. As a resolution to the story, Nancy stated that the sisters discussed the move with their brother, but she did not identify whether her brother was included in that decision or supported the new arrangement. Nancy offers praise to her brother with DD as well as her deceased mother. But blame is directed towards father. Nancy also offers a brief reference to her older sister and step-mother, but indicates they had limited involvement.
The context of this story involves a patriarchal influence, which directed the family culture and set up role identities where the women of the family decided on the caregiving duties. There is an assumption that the father’s choice to remarry was to avoid the responsibility of caregiving for what he may have perceived was not his role. It also created a sense of obligation on the females in the family to take on that role. The story’s overall meaning is about duty and responsibility to the family and, in turn, the caregiving role. In assuming the new role, Nancy is reclaiming the role of her mother. The family’s patriarchal, military roots strongly influenced this outcome.

**Interviewer’s Reflexive Thoughts.** Nancy was my first interview, and I was very excited to begin the process of collecting data and finding out how the people I was interviewing would respond to the questions. As it was my first interview, I not only focused on the interview questions but also attempted to see if anything unique was being stated that involved further exploration. It is important to note that Nancy came from a strong military background. The way she described her story hinted at a strongly patriarchal culture, lending to the family’s military roots. I detected feelings of anxiety, frustration, and self-doubt in Nancy while she described her story, as she was working to understand herself and navigate her responsibility within the caregiving role.

2. **Story of Debbie (December 6, 2015).** Sometimes they [mother and sister] were teenagers, and sometimes they were 60 years old living together.

**Participant profile.** Debbie is a 45-year-old, white, college educated woman, living in Texas with her husband, 49 years of age, daughter, 18 years old, and son, 15 years old. Debbie is the oldest of three children. Her youngest sister has no disability and lives in Delaware. Debbie’s middle sister has a developmental disability. Debbie’s sister moved from Mississippi to her home
in Houston in December 2014. Debbie’s mother is deceased. Debbie has a step-father who lives in Mississippi who had been married to her mom for over 30 years.

**Debbie’s story of transition.** The circumstances surrounding the transition—my mother got sick in December of last year, December 11th, 2014. I, at least, had to go to Mississippi to help take care of her. And we were fortunate enough that she got well enough to be able to come to Houston. She came to Houston for Christmas and then ended up back in the hospital in Houston on December the 26th of 2014, and then subsequently passed away on January the 18th of 2015...My sister, more or less, basically, came to live with us on a temporary basis because I work fulltime, my husband works fulltime, and she also came back to Houston in December...When my mother passed away she (Debbie’s sister) moved in immediately with my family because the dynamic she came from was that my mother was married to our stepfather—and they’d been married a long time, like 30 years—but he just did not have the ability to care for her. He doesn’t have the temperament. He couldn’t handle it...Looking back on it, my sister thought when she first came here, “I get to go visit big sis, and I get my own room.” But after six weeks, she wanted to go home. I told her, “You can’t go home. This is your home.” She had outbursts, behavioral problems and threw things. Then I’d say, “Well, you know what mama would say?” She responded with, “I don’t want to talk about mama. I miss mama.” And I’d say, “I know. But we’re going to talk about her.”
Table 4.3. Analysis of Debbie’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td>Due to mother’s death and inability of stepfather to assume a caregiving role, sister with DD permanently moved from Mississippi to live with her sister and her family in Houston, TX.</td>
<td></td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Mother became ill, and Debbie brought her mother (who got well enough to travel) and sister from Mississippi to her house in Houston, TX in December 2014. Debbie’s mother became more ill in mid-December and ended up in hospital where she passed away in January. Debbie decided to assume the co-residential caregiving role and kept her sister with her DD in Houston since she believed her stepfather incapable of fulfilling the caregiving role.</td>
</tr>
<tr>
<td>Characters</td>
<td>Debbie, Debbie’s mother, Debbie’s stepfather, Debbie’s sister with DD, Debbie’s husband, and her children (indirectly referenced when citing “family”)</td>
<td></td>
</tr>
<tr>
<td>Place</td>
<td>Mother’s home, Mississippi and Debbie’s home, Houston, TX</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>December 2014 to January 2015; during Christmas 2014</td>
<td></td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of events/actions revealing crisis/turning point</td>
<td>When living in Mississippi, mother became sick (crisis), and Debbie brought her mother (who became well enough to travel) and sister with DD to Houston in what was believed to be a temporary situation (turning point).</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>In Houston, mother became more ill and ended up back in the hospital (crisis) where she passed away in mid-January (turning point) resulting in Debbie making the decision to become the co-residential caregiver to her sister with DD and have her sister remain permanently in Debbie’s home.</td>
<td></td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotion on the story’s meaning)</td>
<td>What does narrative mean? What is its function? How is it described?</td>
<td>Sister with DD thought she was visiting her sister in Houston. But was not provided opportunity to contribute to decision on where she could live, resulting in behavioral difficulties (crisis).</td>
</tr>
</tbody>
</table>
Table 4.3. Continued.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resolution (resolving the plot)</td>
<td></td>
<td>Debbie took on the co-residential caregiving role, and her sister transitioned to Debbie’s home.</td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td></td>
<td>Narrative ends where Debbie discusses the challenges of her sister’s realization that the transition is permanent.</td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td></td>
<td>In this story, Debbie discusses herself, mother, husband and family favorably.</td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td></td>
<td>Debbie places blame on poor planning that resulted in a ripple effect involving profound loss for her sister with DD (i.e., loss of mother, home, friends, and “job”), in addition to chaos in her own household.</td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>The mother’s death and sister’s permanent transition to her home occurred at a time when Debbie and her husband are in middle adulthood, and her children were teenagers. The story took place in December, close to Christmas, which inferred further challenges.</td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td>The story’s meaning is to show the need for future planning, to make life-end plans that include ensuring a stable situation for adult children with DD to minimize loss following the parent’s death.</td>
</tr>
</tbody>
</table>

Debbie’s story highlights a sense of obligation to continue in her mother’s role as it was her mother’s wish for her to become her sister’s primary caregiver. More importantly, the story illustrates the post-transitional effects that can occur without proper planning. The participants in this story include Debbie, her mother, sister with DD, and stepfather in Mississippi, and her husband and family (indirectly referencing her two children) in Houston. Debbie explained that her mother (former caregiver to her sister with DD) became ill in December 2014 just before Christmas. This event exposed the initial crisis, and Debbie traveled to Mississippi to oversee her
mother’s well-being. Debbie also stated that “we were fortunate enough” to bring her mother to her home in Houston revealing the first turning point of this story. Debbie’s reference to the word “fortunate” reflects a positive opportunity of being there for her mother and sister, and possible novelty of having her mother and sister for the Christmas holidays. But Debbie also emphasized that this event was challenging since she and her husband both worked full-time. Thus, bringing her mother to Houston could allow Debbie to continue working without any significant gap.

When bringing her mom to Houston, Debbie’s sister with DD also came for what everyone believed was a temporary stay. Debbie’s use of the term “temporary” implied not being prepared to take on the caregiving role of her sister; however, another significant crisis arose where her mother became ill, returned to the hospital in Houston, and passed away in mid-January. Her mother’s death was an additional turning point for Debbie since it resulted in the permanent unplanned transition of her sister with DD to her home. This is also the story’s resolution, and a significant turning point for Debbie, her sister with DD, and family. Debbie’s evaluation of this complicating action (permanent, unplanned transition of her sister with DD) indicated that her stepfather was not capable of properly caring for her sister. In how Debbie described the events, she indirectly praises herself and husband as being there for her family while working “full-time.” But Debbie infers blame on not properly planning for her sister’s long-term stability. Having no plans in place created challenges for Debbie and her family. In addition, she did not anticipate her sister’s experience related to profound loss involving her mother’s death, loss of home, loss of friends, and loss of her “job.” As a resolution to this story, Debbie describes a final turning point where her sister realizes the transition is permanent that
results in problem behaviors. Debbie describes the effort to deflate her sister’s emotional outbursts by using a persuasive approach from her mother to calm her sister.

When considering the story’s context, both Debbie and her husband are in mid-life, work full-time, and manage a household with two high school-aged children. Clearly, the importance of family plays a big role in Debbie’s life. When Debbie first talked about her sister with DD, it was in reference to taking care of her sister temporarily. This indicates she was not prepared for the caregiving role and adjustment to new family dynamics. The coda to this story involves her sister’s revelation that the transition is permanent. This was a crisis for Debbie, her sister and family, since the sister and family members were unable to properly grieve yet required to quickly adapt.

**Interviewer’s Reflexive Thoughts.** Debbie was my second interview, and I was still becoming familiar with the interview questions in the context of story-telling. Through this interview, I tried to focus on allowing the interview to flow and asking for stories to explain certain events. Regarding my thoughts of Debbie and her family, as the permanent transition of her sister occurred one year prior, it appeared that the family was still adjusting but much had been settled. Debbie demonstrated some great insight into the relationship between her mother and sister with DD that can explain the relational dynamics of older parents who co-reside with their adult child with DD. Debbie emphasized a high level of support from her family (husband, daughter and son). But there was also some concern and possible guilt for the high level of responsibility her daughter (a high school senior) took on to help maintain family balance. However, I also felt Debbie believed she had no other option as she tried to keep it all together.

**Story of Maggie (December 30, 2015).** *It’s not like being a caregiver was so much of a choice than it wasn’t a choice. It was just, this is what I had to do. Do I wish it could have been*
different? Sure, but there’s a lot of things in life that people wish could be different. And yet, it could be much, much more difficult. My sister is sweet and kind. Sometimes, she’ll look at me and say, ‘You’re the best sister in the whole world.’ She means it from the depths of her toes.”

**Participant profile.** Maggie is Caucasian, 60 years of age, a high school graduate, and resides in Ohio with her husband, aged 63 years, son 26 years, and sister with DD, 54 years. Maggie’s sister is diagnosed with Cornelia de Lange syndrome as well as some level of autism. Maggie also has another son, aged 31 years, who is married and lives in his own residence. Maggie discussed having another sister with no disability who is 10 years older but is not involved in the care of her younger sister with DD. Maggie’s parents were the former caregivers to her sister with DD. Her father passed away in 2010, and mother passed away in 2013.

**Maggie’s story of transition.** My husband and I started living with my sister full-time in 2013. It was actually Labor Day. My mom fell and broke her hip. We had stayed with her [my sister] a couple of times before that. But twenty years ago, my husband built a second floor onto my parent’s ranch. So, the house became a duplex and there’s a fully functioning home upstairs. We lived upstairs to, sort of, help my parents. But we were in a separate unit. And if my mom would get sick—she had nursing home visits a couple of times before she fell and broke her hip—I would just come downstairs and stay, and my husband would stay upstairs. When my mom passed away we shut everything down upstairs around where she broke her hip. I moved downstairs and my husband stayed upstairs. My son happened to live here at the time. We had a spare bed downstairs, and I came and slept down here with my little sister so she wouldn’t be scared. After about a month and a half it became apparent that my mom was
not going to recover from the broken hip. She had a bunch of other things with her kidney; she was 84. It’s been a while so I can’t remember it all. That was the Labor Day of 2013. Around November 2013, my husband and I were told that my mom wasn’t going to come home. We started the process of moving our bed downstairs and rearranging the house the way we wanted. Just a little, bit by bit. It was awkward because it was still mom’s house down here. But it was nice having my husband downstairs. My mother passed away in December of 2013. At that point, we knew we’d be taking care of my sister full-time.

Table 4.4. Analysis of Maggie’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td>Following mother’s illness/injury where she fell and broke a hip, Maggie and her husband moved from top part of the family duplex to the ground level where her parents used to live and sister with DD currently resided. This move resulted in Maggie becoming the full-time co-residential caregiver to her sister with DD.</td>
<td></td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Maggie’s mother, 84 years, broke her hip due to a fall, and had other health difficulties with her kidneys. As a result, she was admitted in to hospital and did not return home. Maggie and her husband re-organized the house and moved to the bottom level, in large part, for Maggie to assume the co-residential caregiving role to her sister with DD.</td>
</tr>
<tr>
<td>Characters</td>
<td>Maggie, sister with DD, husband, mom</td>
<td></td>
</tr>
<tr>
<td>Place</td>
<td>Family duplex in Ohio</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>January 2013</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.4. Continued.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>On Labor Day, 2013, Maggie’s mother fell (in what is believed Maggie’s residence) and broke her hip (crisis). Maggie stayed with her sister in the family duplex’s lower level in what was her parents’ and sister’s residence (evaluation).</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>What does narrative mean? What is its function? How is it described?</td>
<td>In October/November 2013, it became apparent that Maggie’s mother was worsening and would not return from hospital (turning point). Maggie assumed the caregiving role, and Maggie and her husband re-organized the family duplex and permanently moved to her parents’ and sister’s residence on the lower level (evaluation).</td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotional reactions? on the story’s meaning)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td>Maggie and her husband re-organized the family duplex for Maggie to successfully transition into the co-residential caregiving role of her sister with DD.</td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td>When her mother passed, Maggie knew she would become the full-time co-residential caregiver to her sister.</td>
<td></td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td>Maggie praises herself, husband, mother and sister.</td>
<td></td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td>No blame presented other than explaining the move was little-by-little to indicate no alternate motive.</td>
<td></td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>Parents have both aged out, and Maggie and her husband are in late adulthood nearing retirement.</td>
</tr>
<tr>
<td>Meaning</td>
<td>Duty and obligation to family.</td>
<td></td>
</tr>
</tbody>
</table>

In her story, Maggie explained that her husband built an upper level to her parents’ home 20 years prior as a means of helping her parents. Thus, Maggie lived in direct proximity of her parents since her mid-30s, indicating a commitment from her and her husband to “sort of” help her parents. Maggie did not explain the origin of how the building of a second floor and living...
above her parents evolved, but this is a turning point for Maggie where she realized an
instinctive commitment to the caregiving role. It was also a turning point for her family as her
husband was a partner to this future role.

Maggie’s mother’s injury resulting in a broken hip and move to the hospital is considered
a crisis. Maggie moved temporarily to her parent’s bottom floor residence to ensure her sister
was doing well and “not scared.” Her husband, however, remained in their upper floor residence.
The significant turning point is suggested in Maggie’s realization that her mother would not
return home.

When considering the transition of a brother/sister with DD from parental to sibling co-
residential care, there is an assumption that the sibling with DD would move to the typical
sibling’s residence. However, similar to Nicole, Maggie and her husband moved to the parents’
residence.

Much of Maggie’s discussion regarding the transition to the caregiving role, including
living close to her parents for 20 years, indicated an inherent commitment to her family’s well-
being. Maggie’s effort to stay close to her sister during this immediate crisis (mother’s fall and
broken hip) and turning point (realizing her mother would not return home) demonstrated an
understanding of her sister’s needs and well-being. Maggie was quite clear, however, to state that
they resided in a separate unit, perhaps attempting to confirm nothing strange about this
arrangement.

Maggie only presents praise, and not blame, to the characters involved in her story. The
resolution to her story is the reorganization and move from the upstairs dwelling to her parents’
and sister’s residence on the lower level. The end to this narrative confirms her commitment to
the caregiving role when she states that at the point when her mother passed, she knew she would
be the full-time caregiver to her sister. The meaning of this story is the commitment to the family’s well-being. However, Maggie’s story can also show how consistent family engagement can ensure fluidity during challenging transitions within life trajectories.

**Interviewer’s reflexive thoughts.** Maggie was my third interview. Her story represented the commitment and obligation among typical female siblings to their family’s well-being. When considered contextually, her story represents the strength of women who are the glue that keeps the family together.

**Interview with Ruth (January 14, 2016).** *I am who I am, but the caregiving is relentless. It’s not like the big bird grows up and flies away. The baby bird is plateaued at best, and then will decline. And there I meet what my mother must have met.*

**Participant profile.** Ruth is a 51-year-old, Caucasian woman, and holds a Master’s degree in narrative therapy. Ruth lives in Massachusetts with her husband, 52 years old, and two children, a 17-year-old son, 11-year-old daughter, and brother with DD who is 54 years. Ruth’s brother was adopted by her parents before she was born, and is diagnosed as intellectually disabled as well as cerebral palsy, muscular dystrophy and scoliosis. Ruth has two younger sisters, about one year and two years younger. In addition to providing co-residential caregiving support to her brother, Ruth continues to provide care to her mother who is living in a “rest home.” Ruth’s father is deceased.

**Ruth’s transition story and structural analysis.** *Okay, I’ll give you the elevator pitch that I do and then we can go from there. Coincidentally, on 1/11/2011, one-one-one-one-one, my father passed away, which is five years ago this past Monday. And when he did, the trio of my mother, my father and my brother dissolved, which we knew it would. We just didn’t know in what fashion. I*
essentially begged my parents for years to do something in anticipation of their mortality but they hadn’t. So, then, we had to spend about a year trying to re-stabilize the new configuration of my mom and my brother, to no avail. At that point my mother was 80 years old; she’s now 85. I’ll describe the trine in more detail, but the trine didn’t work. So, it was essentially we can have again all our lives being my family of progeny or whatever you’d call us. But it’s wreaking havoc in my family, my sister’s life and to a large extent, my mom and brother’s life too. Long story short, we tried to find a placement for my brother we thought was good. And, we really tried. This is one moment in the story when people have said, “Did you really try? If you failed maybe you just didn’t try it enough.” So, we did try and it failed again and again, more than once. But after a lot of soul searching and being in this really incredible marriage, my husband and I agreed to offer my mother the option of having her and my brother move in with us. But it’s more complicated than that because they lived in a little house in Somerville [Massachusetts] and we lived on a little farm in Western Mass. And neither house is suitable for both our families to live together.

So, within a six month period, I sell my mother’s house, rent out the house we were living in because we didn’t necessarily know if we wanted to sell it, and bought a house we can actually renovate with the proceeds from the sale of my mother’s house. And I find temporary housing for my brother because the house we were moving into is not handicapped accessible. Most aren’t really. So, finally, we do this. We start this grand experiment of my mom, my brother, my husband, my son and my daughter. And we all begin living together. But during the time
she [Ruth’s mom] is here, at least once a year, she is having a major health crisis which requires hospitalization and rehab and returning to our home, etcetera. My brother, not surprisingly, sort of remarkably thrives. And I actually still can’t really see it the way people on the outside can; my sisters who come and go, or friends who watched this over the years. But my brother is very stable and surprising. Now, I never thought I would be doing this [caregiving] forever; I’m not my mother. And I never wanted to do it by myself which is the way my parents did it. They never ever had any help to do it. They chose not to or didn’t have the resources, whatever. I knew I didn’t want to do it that way. But anyway, the journey is still unfolding.

My mom goes into the hospital in May, and in and out of rehab. She’s in one place now but they just told us that she has to leave, and my brother’s still here. But there’s a way that it’s connected to this because when we buy this house, my husband and I, we can afford a mortgage but we can’t afford to pay for all of it. So, my mom pays for her portion of the house and my brother’s, and we just pay a mortgage for the rest of it. Her half pays enough that we could just keep paying the mortgage we’ve been paying and rent out our other house and those tenants pay the mortgage there. But now, what’s going on, just bringing you up to date, we’ve now found out after going to a lawyer right away who was like an elder services lawyer who knew friends with people that had a disabled child. It turns out, if my mother in fact needs to go into a nursing home, there’s a very good chance they would try to take her half of the house, which is very upsetting. And we’re just trying to live in the now and deal with one problem at a time. We
really didn’t want to put our home in jeopardy. In fact, what we wanted to do was create stability. But the ironic thing is, if my brother had gone to a group home that would’ve solved the problem, in a way. So, for right now, for my husband and I, my daughter, my son who is in his second year of school, and my mom who’s at a rest home, we live in a temporary holding place. And my brother is still here.

Table 4.5. Analysis of Ruth’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Ruth organized alternate living environment that involved Ruth’s family living together with her mother and brother with DD following her father’s death. But instability ensues due to mother’s illness and need to live in a rest home that could jeopardize her mother’s monthly financial contribution to the mortgage, and family’s residential stability.</td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Father passed away in 2011, and Ruth worked over past five years to re-stabilize the configuration of relationship of mother and brother from former trine of her father, mother and brother’s relationship. This effort included Ruth’s mother and brother moving in with her family in a newer house retrofitted to her brother’s disability. However, mother is ill and may have to transition to a rest home jeopardizing her mother’s contribution to the monthly mortgage.</td>
</tr>
<tr>
<td>Characters</td>
<td>Ruth, Ruth’s husband, father, mother and brother.</td>
<td></td>
</tr>
<tr>
<td>Place</td>
<td>Mother and brother’s home, and Ruth’s family’s home in Massachusetts</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>2011 to 2016</td>
<td></td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Death of father in 2011 (turning point). Trine of mother, father and brother dissolved (evaluation and turning point).</td>
</tr>
<tr>
<td>Structural Elements</td>
<td>Structural Sub-Elements</td>
<td>Researcher’s Interpretive Summary</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Complicating Action (what happened</td>
<td>What does narrative mean? What is its function? How is it described?</td>
<td>Unsuccessfully tried to source an alternative residential placement for her brother. The failure to find a placement resulted in “soul searching” and agreement from husband to have mother and brother move in (turning point).</td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns</td>
<td></td>
<td>Brother still remains content in Ruth’s family home.</td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td></td>
<td>Ruth extends praise to herself and her husband.</td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td></td>
<td>Blame is described as the trine of her mother, father and brother who are in an enmeshed relationship, and unwilling to look towards greater independence of her brother.</td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>Ruth is at the stage of middle adulthood. Given her responsibilities for providing care to an ill parent and brother with DD, she represents elements of both compound and sandwich caregiving (See Appendix A for definitions of compound caregiving and sandwich caregiving).</td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td>Highlights need for proper planning, as well as informal (familial) supports and formal (governmental) supports can result in fluid transition. Story exposes the vulnerability of aging parents and the co-dependency and enmeshed relationship that can develop between the adult child with DD.</td>
</tr>
</tbody>
</table>

Ruth began her narrative with a turning point involving the death of her father that resulted in the dissolution of what she described as the “trio” and “trine” of her mother, father and brother. The use of these terms (i.e., trio and trine) implies some level of enmeshment and
co-dependence within the relationship of her father, mother and brother. This notion is supported from what Ruth explains as begging her parents five years prior “to do something,” recognizing their increasing age and the need to plan for her brother’s future. Ruth’s discussion indicates some frustration due to having worked “to no avail” to re-stabilize the configuration of her mother’s and brother’s relationship in the past year following her father’s death. But in addition to Ruth’s suggestion that the trine did not work, she stated that the recent re-stabilization efforts had significantly impacted her immediate family, her sisters’ lives, and mother and brother’s lives too.

During this period, Ruth stated she also tried unsuccessfully to source a residential placement for her brother. This failure is indicated as a crisis and became another turning point. It resulted in Ruth renting out her house, selling her mother’s house, and building a house over a six-month stint where Ruth’s family, mother and brother began living together. Ruth continues the transition-related narrative discussing the effects of her mother’s developing health issues and impending move to a nursing home. This outcome is presented as a crisis since it is explained that the nursing home, in which her mother may transition, will likely require payment that is currently used to help pay the mortgage of the newly built home. Again, Ruth shows some frustration and disappointment, re-emphasizing that the issue may have been resolved if the parents had accepted placing her brother into an alternative residence.

In this narrative, there is no true resolution to the story given the implied fear regarding the possible inability to afford, and resulting loss, of the newly built home. Again, at this point in her narrative, Ruth indicates worry and frustration since their effort was to achieve stability but feels her living environment is in jeopardy. How Ruth explains her story indicates some level of frustration and blame with the triad of her father, mother and brother, and unwillingness to look
at alternative residential options. Praise is clearly extended to her husband for his willingness to partner with Ruth in taking care of her mother and brother. Interestingly, brief mention is made of her sisters, including the challenges they also experienced during Ruth’s efforts to re-stabilize her mother and brother’s relationship. Yet, Ruth did not explain further their level, if any, involvement in the decision to becoming the primary caregiver.

The context in which Ruth explains her narrative, includes her parents in old age and Ruth’s middle adulthood. Contributing to the challenges related to the transition of her brother, Ruth has taken on responsibility for her ailing mother resulting in compound caregiving (i.e., providing care to both her brother and mother). Ruth’s story underscores the need for proper planning, informal (familial) supports, and formal (governmental) supports. It also exposes the vulnerability of aging parents who can potentially become too enmeshed and co-dependent with their adult child with a disability. Ruth’s narrative also implies the challenges of sibling caregivers following the co-residential transition of their sibling with DD who must work hard at the outset to balance the challenging transition of their sibling to a new environment.

*Interviewer’s reflexive thoughts.* Ruth was my fourth interview, and she was very excited to be a part of this study. Prior to engaging in the interview questions, Ruth stated she was unaware of other siblings who shared a similar experience as co-residential caregiver to their brother/sister with DD. When asked if she would like to participate in the study, Ruth stated “So much so, I’m grinning from ear to ear.” In part, this eagerness was due to the chosen research design (i.e., narrative inquiry) since she was a narrative therapist, and had engaged in qualitative research at the School of Education, Harvard University. Ruth’s responses were somewhat cerebral, and she looked at items with a critical eye. In part, Ruth had time to think about the interview over the three-week period from when we first connected to the actual interview. But
Ruth’s professional and educational background also provided her with a different skill set for looking at her responses. Overall, for this interview, there was a greater ease in delivering the questions likely due to a developing understanding of the relational dynamics between the caregiver, family members and sibling with DD. But I also asked questions related to the adjustment and mental well-being of the sibling with DD despite not having included these questions in the interview guide. It became apparent during the initial three interviews that limited efforts were made to support the sibling with DD with the grief and loss of his/her parent, physical move to the typical sibling’s residence, manage the role change of his/her typical sibling with DD to caregiver parent, and adjust to having new family members (e.g., typical sibling’s spouse and children). Thus, I made a point to look at this area as it became an unanticipated theme.

**Story of Heidi (February 19, 2016).** There’s not really a true understanding of autism. Sometimes I don’t know how to connect with him or understand what he’s thinking. There was a situation where he had strep throat, didn’t tell anyone, and it turned into a huge infection. I just felt so helpless because I had no idea how to help him calm down.

**Participant profile.** Heidi lives in Arizona and is 37 years old. She is Caucasian, married with one daughter, and has an Associate’s degree. Her husband is aged 42 years, and daughter is 6 years. Heidi comes from a large immediate family and is one of five siblings. The oldest sibling, a brother, lives in Illinois and has “not much” communication with the family. Her brother, aged 39, is developmentally disabled and resides with Heidi and her family. Finally, Heidi has two younger twin sisters. One sister has a mild developmental disability and lives independently, and the other sister has no disability. Both sisters also live in Arizona. Heidi’s parents are both deceased. Her father passed away in 2001 and mother passed away in August.
2015. Regarding the nature of her siblings’ disability, Heidi explained that both her brother and sister with DD are diagnosed with autism, and each has an intellectual disability. Heidi’s sister is described as having a mild intellectual disability and can live independently. Her brother, however, has a higher level of intellectual disability and cannot reside alone.

Heidi’s story of transition. It [death of Heidi’s mom] was definitely unexpected.

My mom had been the primary caregiver to my brother and sister, and they were both living with her back in Illinois, in the Western Suburbs. I received a phone call from my sister [sister with DD] one morning. She saw my mom unresponsive and it appears that she had a heart attack. She’d [Heidi’s mother] been diagnosed just recently with COPD from smoking. It was sort of one of those things. She didn’t have the best insurance, and the doctors hadn’t done a lot of testing. They didn’t do a heart screen or anything like that. Most likely her heart was weak. She had been laboring for breath that day. She just didn’t want anybody to know about it except for my sister who was living with her. But I don’t think she could hide it from my sister, because my sister and brother were living with her. But it was kind of like, I don’t want to worry anyone. The other thing is my mother really wanted to stop smoking, but just was unable to. I think she was trying to hide that from everyone. I think there was a fear of “If I let anybody know what’s wrong, they’ll know I’m smoking.” So, she suffered a heart attack. That was basically what happened. That was August, 21 of 2014. Then, I got the phone call that morning and went on a flight immediately to Chicago. I knew immediately what was going to happen. It was something that I had always planned for. My mom never really liked to talk about the future. But I had
mentioned to her, if anything were to ever happen to her, I would take on the responsibility of my brother. I had to stay in Chicago from August all the way to October, to close out the estate and get them ready to come move to Arizona. I had to pull my daughter from pre-school. She was four at the time. I had actually just started working as a teacher’s assistant at her school. My spouse was actually in Chicago at the time for something he had to do with his friend. We got a flight out there and then had to stay for about 3 months. My other sister who lives here [in Arizona], and the twin to my sister [with DD], is not delayed at all. She was there. And then my older brother—he definitely stepped in and helped with getting the house organized. I also had aunts and uncles, my mom’s sister and her husband, they were extremely instrumental in helping with all of that.

Table 4.6. Analysis of Heidi’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Abstract (point/summary of story)</strong></td>
<td></td>
<td>Heidi’s mother, former caregiver to her brother and sister, each with DD, passed away resulting in Heidi moving her siblings from Chicago to Arizona and assuming the co-residential caregiving role to her brother and caregiver to her sister.</td>
</tr>
<tr>
<td><strong>Orientation (setting—who, when, where)</strong></td>
<td><strong>Situation</strong></td>
<td>Heidi’s mother, a smoker and diagnosed with COPD, was primary caregiver to her brother with DD and sister with DD (twin to a sister with no disability). Despite mother’s desire to quit smoking, she had a weak heart that was not properly tested for by doctors, likely due to poor health insurance. On August 21, 2014, Heidi received a call from her sister with DD that mother had passed away from a heart attack. Heidi traveled with her daughter from Phoenix to Chicago to honor a promise that she would become the caregiver to her brother with DD. Thus, she had to remove her daughter from pre-school and give up a new job and spend three months to close out her mother’s estate and bring her brother and sister down to Phoenix. Heidi had assistance from her brother and sister with no disability, and her mother’s sister and her husband. Heidi mentioned her husband had also been up to Chicago during this period but did not state whether he helped.</td>
</tr>
</tbody>
</table>
Table 4.6 Continued.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Characters</td>
<td>Heidi, mother, sister, brother, daughter, doctors, Heidi’s husband, and Heidi’s aunt and uncle</td>
</tr>
<tr>
<td></td>
<td>Place</td>
<td>Mother’s home, Chicago, Illinois, and Heidi’s home in Phoenix, Arizona</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>August-October, 2014</td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Discusses poor health insurance and doctors’ lack of testing for not recognizing the degree of her mother’s health issues (crisis). Heidi received call from sister that her mom was unresponsive and had a heart attack (evaluation and turning point). Resulted in Heidi flying to Chicago to clean up her mother’s house. No mention of funeral (evaluation).</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>What does narrative mean? What is its function? How is it described?</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td>Heidi cleared out her mother’s estate over three-month period with assistance from her typical brother and sister as well as aunt and uncle.</td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td>Heidi discussed the support she received in Chicago from her sister and brother (with no DD), and her mother’s sister and sister’s husband (Heidi’s aunt and uncle).</td>
<td></td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td>Heidi extends praise to her mother, sister with DD, brother, sister, aunt and uncle.</td>
<td></td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td>Blame is extended to health insurance and doctors.</td>
<td></td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>Heidi is nearing middle adulthood and has a young family. Heidi is taking on the caregiving commitment at point when she is building her family.</td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td>Honoring a promise and commitment to the parent to take on caregiving.</td>
</tr>
</tbody>
</table>

Heidi described the situation as following a phone call from her sister in Chicago that her mother had just passed, she traveled with her daughter to mother’s home. This was the turning point in Heidi’s story. In doing so, Heidi and her siblings cleaned up her mother’s estate, and Heidi also prepared her brother and sister, each with DD, to transition to Phoenix. As part of this
transition, Heidi’s brother moved to her residence, and her sister with DD was able to secure independent living.

Heidi began her story stating that “It [her mother’s death] was unexpected,” referring to her mother’s death. But she also discussed her mother’s diagnosis with COPD and struggle with quitting smoking. In how Heidi explained her story, she extends praise to her mother stating she was the primary caregiver to both her brother with DD and sister with DD. In addition, she honors her mom for this commitment and attempts to discount the effects of smoking on her life, stating she was unable to hide it, especially from her sister who lived with her mom, and did not want anyone to worry. Heidi also lends praise to her typical brother and sister for helping her to with her mother’s estate. Blame is essentially extended to the doctors for not properly diagnosing her mother and the healthcare system for its limited insurance coverage. This is also the origin of the crisis leading to Heidi transitioning to the caregiver role.

While Heidi stated her mother’s death was unexpected, she also knew the future outcome. As she said, she had planned for this event indicating some level of mental preparation. She does state, however, that her mother did not like to discuss the future. This may lend to her mother’s concerns about her own demise. Heidi reinforces her promise and commitment and caregiving stating she had to leave a job and pull her daughter out of pre-school.

The resolution to this story is implied and involves closing out the estate of her mother and returning to Phoenix with her two siblings. The story’s coda reflects on the assistance Heidi received from her family. The family life cycle (story’s context) looks at Heidi nearing middle adulthood and beginning a family since her daughter is four-years-old. But, in how Heidi describes her story, there was a point in either her youth or early adulthood where she promised to take on the caregiving role to her brother and sister with DD. Heidi honors this
commitment/promise demonstrated with her leaving a new job and spending three months preparing for her brother and sister’s move to Arizona. Though Heidi begins her story suggesting that the transition was unexpected, she later suggests that she always knew she would assume the caregiving role. Heidi’s story gives meaning to the loyalty, honor and commitment within families.

**Interviewer’s reflexive thoughts.** I spoke with Heidi in February 2016, a little more than a week after my father passed away. At times during our interview, I felt somewhat emotional and disconnected. Thus, I perceived Heidi’s responses as somewhat impassive. This view shifted after reviewing the interview transcript. Not surprisingly, Heidi also reflected on what I perceived as a pragmatic characteristic. But following my analysis of the interview transcript, it was apparent that Heidi provided some strong responses with deep answers.

**Story of Andrea (June 19, 2016).** When I was three and my sister was six—it was July 4th—my sister insisted on walking up the street where we lived to take a stagecoach ride. I demanded she not go but she went anyways. I remained on the corner scared but relieved the stagecoach came back around. I was aware of the fact that my sister was older than me. But it was the exact moment I knew I would have to take care of her.

**Participant profile.** Andrea resides in rural Iowa and comes from a very large family. Andrea is aged 52 years, and lives with her husband, 63 years, son, 25 years, and sister with a disability, 55 years. Andrea explained that during her mother’s pregnancy, the umbilical cord was wrapped around her sister’s neck restricting oxygen. This resulted in her sister being intellectually disabled and having mild cerebral palsy.

Andrea is Caucasian, and stated she has a certification but no degree. Andrea comes from a large extended family. Both parents are deceased. Alongside her sister with a disability, Andrea
has an older sister and five older brothers. Andrea’s older sister lives in a different town, but the brothers live close by. Andrea stated that all siblings have some involvement and help out with her sister with a disability.

**Andrea’s story of transition.** Both of our parents were diagnosed with terminal cancer within a couple of months of each other. So, my sister had obviously lived with them her whole life. They [A’s parents] actually died within 7 months of each other. So, we did have time to plan. My parents were concerned about her. I told them a long time ago, like when I was in my twenties that they did not need to worry about my sister; I will always take care of her. I had not released myself from that promise but they had released me of that promise when my first husband died. But then I got married again. My second husband was also very agreeable to that [becoming the caregiver to A’s sister with a disability]. He knew it was what I wanted to do. So, when my parents were sick we had time to discuss all of that. They [A’s parents] were very concerned about what was going to happen to my sister and who was going to take care of her. When I told them that they did not need to worry about that, and that I was still going to do that, they were relieved and we started the planning process. She [A’s sister with a disability] knew she was going to come live with me. My parents were pretty involved in helping make decisions about how that was going to happen. While they were still alive we had an addition built onto the back of our house so my sister could have a little privacy and we could have a little privacy. But we are still connected—we just go out our kitchen door. It used to go out to the back porch, and now it goes into her space. She calls it her apartment...When
my parents were diagnosed, their health quickly declined. My dad was first diagnosed; then my mom had a reoccurrence with cancer. She was diagnosed terminal. So, they both went into hospice care. We were looking at them probably having to go into a long term care setting or a hospice house, or something. My oldest sister actually quit her job. She did not tell any of us. She just quit her job and moved in with them. She took care of them for over a year. That also allowed my sister, our disabled sister, to stay at home for that extra time too. As we were building on to our house—she calls it her apartment—she was actually kind of excited about that. My dad passed away first. Then seven months later my mom passed away. When my mom passed away, all of the siblings got together and discussed how to handle things with my disabled sister. We were concerned how she was going to take this, and were kind of playing out scenarios on how we can handle different things. So we decided, or my oldest sister just said, I will stay for a few weeks and then our disabled sister could just slowly visit her apartment. And then maybe, she can spend a night at her apartment. The idea was we were going to slowly transition her into the apartment thinking this is going to be a really hard change for her. But she [disabled sister] told us the day of my mom’s funeral, after we all came back to the house, she just announced “Tomorrow I am moving to my apartment.” So, we said, you want to move into your apartment tomorrow and she said “Yes! It’s my apartment. Mom and dad are not here anymore. I don’t want to be here.” So, literally the next day, we moved her into her apartment. And as far as the adjustment from being in our parents’ house to her apartment. I would never have imagined it would be as smooth as it was.
Table 4.7. Analysis of Andrea’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td>Family cohesion, self-determination and desire for independence among persons with DD</td>
<td></td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Both parents sick with terminal cancer and died within 7 months of each other.</td>
</tr>
<tr>
<td></td>
<td>Characters</td>
<td>Parents, Andrea, husband, Andrea’s older sister and five older brothers, sister with developmental disability</td>
</tr>
<tr>
<td></td>
<td>Place</td>
<td>rural Iowa</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>2013—sister w DD was 49 years when parents passed, but was currently 52 when Andrea completed interview</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Both parents diagnosed with terminal cancer within two years of each other (crisis), but died within 7 months of each other (crisis/turning point). This resulted in having time to plan and prepare for her sister’s transition (evaluation). In this regard, an addition to the house built to facilitate caregiving of her sister with DD (evaluation).</td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotion on the story’s meaning)</td>
<td>What does the narrative mean? What is the function? How is it described?</td>
<td></td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td>Sister with DD wanted immediate occupancy of “her apartment.”</td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td>Andrea finishes narrative exclaiming how smooth the transition took place.</td>
<td></td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td>In how the narrative is described, there is praise to her parents, older sister, sister with DD, and other siblings. Andrea’s story demonstrates the benefits of a cohesive family that shows how working together is a protective factor. Included in this praise is her husband, who Andrea implies had an understanding how important it was for her take on the caregiving role.</td>
<td></td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td>There is no blame presented in this narrative.</td>
<td></td>
</tr>
<tr>
<td>What is the causal relationship (change in one factor causes change in another)?</td>
<td>Mother and father each diagnosed with cancer within short timeframe of one another (crisis). Resulted in time to plan/prepare for transition of sister (evaluation).</td>
<td></td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>For Andrea, the transition takes place in middle adulthood. While Andrea has a son, the son is not included in the story related to the transition of her sister with DD to her home.</td>
</tr>
</tbody>
</table>
Table 4.7 Continued.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning</td>
<td></td>
<td>Shows deep inherent bond as well as duty and responsibility to atypical sibling. The story also provides understanding of how proper planning can support a fluid transition, since having time to prepare/plan and coordinate with parents and rest of family helped atypical sibling begin to mentally prepare and look forward to the transition. Story reveals desire among persons with DD to be independent and considered as everyone else.</td>
</tr>
</tbody>
</table>

While one of the main features of this story is the events leading up to the transition of her sister, how the narrative is explained emphasizes the importance of family cohesion, especially when planning for the transition. In addition, the story demonstrates the desire among persons with DD for self-determination and independence. The starting point of Andrea’s story is in 2013, beginning with her parents’ being diagnosed with terminal cancer within two months of each other. Andrea’s story takes place in small town Iowa, and its main participants include herself, her parents, husband, older sister, and sister with developmental disability. She also referenced her five older brothers. Though her parents’ diagnoses of terminal cancer are the situation leading to her sister’s transition, it is also considered a crisis. Andrea assumes a knowledge that her sister “obviously lived with them her whole life”, but this indicates the depths of their relationship, as well as concern and challenge of her sister adjusting to the time they are no longer there. Andrea also indicates a sense of relief in having time to plan for the transition. Following this indication, Andrea explains her adoption of the caregiving role indicating an inherent feeling of obligation and desire to take on the role that she had promised to her parents in her twenties. Andrea also explained her deep commitment and connection with her sister. This connection is also indicated when Andrea stated that her sister with DD also knew she would live with her. Andrea further emphasized this notion stating she had not released
herself of this responsibility, despite the parents releasing her of this duty following the death of her first husband years prior. Andrea’s use of the word “release” emphasizes her feeling of obligation, commitment, and responsibility to the role. She stated her second husband was agreeable to this responsibility, and it is assumed that her commitment to the caregiving role undergirded the type of partner she selected. Andrea noted that her parents were relieved when she stated she would provide the care for her sister. Alongside her obligation to be her sister’s caregiver, Andrea uses this narrative to highlight her commitment to the family and her parents.

The parents died within seven months of each other. This is a significant turning point in the story. At this point Andrea explains that an addition for her sister with a DD was built onto her house so her sister, as well as Andrea and husband, could have privacy. Andrea emphasized that alongside the privacy, the current structural setup allows them to be connected, also symbolic of the relationship Andrea feels with her sister. Andrea explained her sister calls it her apartment indicating a sense of self-determination, independence, and ownership from having her own space.

At the story’s mid-point, Andrea comes back to explaining that the health of her parents declined quickly, and briefly mentions that the cancer was a reoccurrence (indicating prior cancer). Andrea discussed the commitment of her older sister who quit her job to help her parents and sister with DD. Andrea stated that the outcome of her parents’ most current diagnoses signaled a need for a long-term care facility or hospice home where they ended up. This indicated a significant decline and further crisis. Andrea described this as a turning point where the siblings got together to discuss the transition of their sister to the apartment, believing the transition to be a challenge to her sister. However, following the mother’s funeral—a final
turning point to the story—Andrea presented surprise and relief explaining her sister’s decision to immediately transition to her apartment.

As viewed in this story, there is no blame presented in this narrative. In how the narrative is described, there is praise to her parents, older sister, sister with DD, and other siblings. Andrea’s story demonstrates the benefits of a cohesive family and shows how working together is a protective factor to support the transition of a sibling with DD. Included in this inherent praise is her current husband, who Andrea implies had an understanding of how important it was for her take on the caregiving role. For Andrea, the transition takes place in middle adulthood. While Andrea has a son, the son is not included in the story related to the transition of her sister with DD to her home. For an overall meaning, having time to prepare and achieve a consensus can result in a much smoother transition. Having this time to prepare/plan also helped Andrea’s sister with DD mentally prepare and desire this transition. Furthermore, this was a stage in the life cycle where Andrea’s sister wanted to have her own independence.

**Interviewer’s reflexive thoughts.** I spoke with Andrea towards the end of June. She was one of the final interviews, and I had a better idea of the interview structure. In my interviews, most participants discussed a sense of obligation and responsibility to take on the caregiving role. But, for Andrea, she described something deeper in terms of a connection with her sister. I was also struck by what I sensed was a strong, positive level of cohesion between Andrea, her parents, and her siblings. As Andrea described it, her family was close, made decisions together, and physically supported each other by taking on responsibilities. This high level of connection positively resulted in what was described as a smooth transition.

**Story of Jane (July 15, 2016).** *When he [brother with DD] first came to live with me we were flying by the seat of our pants. So, I started to process. It took me a lot longer than it should*
have to get him on medical assistance ‘cause my parents didn’t have him on that. Upon reflection, I wish I would’ve had more things in place than we did. I also wish that there would’ve been someone that could have walked me through the process.”

**Participant profile.** Jane is a 54-years-old, Caucasian woman living in rural Minnesota. Jane holds a Bachelor’s degree in elementary education, and is divorced six years after being married for close to 20 years. Jane has a son, 26 years of age, and a daughter, 22 years. Jane has a brother, 56-years-old, who has a developmental disability. Both of Jane’s parents are deceased, and she lives together with her brother. Her son is the personal care attendant to her brother. Jane explained that when her brother was young, it was suggested he was autistic, but following an assessment from a case worker, he did not receive an official diagnosis other than being told he had a mental disability. Jane explained his disability by level of functioning, including being able to prepare small snacks and pouring a bowl of cereal. However, she did not believe he would exit the apartment they lived in if there was a fire alarm.

**Jane’s story of transition.** We grew up in a very small town.

*My mom was a psychiatric nurse. And close to the town where we grew up, there was a state hospital. Back in those days both my parents worked there. Dad started out as an intern. But right before they closed it down, he was head of the pay-for-work program—there’s so many. At that time, they called them patients. They saw so many patients dropped off who never saw their families again. My mom and dad just didn’t want that to happen to their son. Being in a small town, my brother just lived with them all his life. My mother retired in 1976; she developed a degenerative disease. So, my father was basically the caregiver to both her and my brother. The only time they were not with my*
brother was if they were in the hospital. They didn’t have respite care. In 1997, I started pushing my parents to have a will. A friend of mine died in a car accident and her husband had a tough time because he did not have a will. But towards, probably, in about 2002, they finally got my brother a case worker with me pushing them a lot, but they didn’t try to get any benefits or anything like that. However, they did get him into a day program that he went to two days a week. He went to that program probably for about six years. But that was two days a week and only during the summer months because they were winter Texans. I’m from Minnesota, and that was about the only experience away from my parents my brother had. He’d get picked up at 8 in the morning, and dropped back off at 4 o’clock in the afternoon. Otherwise, he was always with my parents. So, first my mom passed away and then dad was his sole caregiver. And if dad had to go in the hospital whether in Minnesota or Texas, either I would go to be with him or my kids would go and watch my brother. When dad passed away, my son was with my brother at the time. The case worker filled out all the paper work to have me as co-guardian. I never thought I would be his caregiver. I do remember my mom and I talking one time. The case worker in Minnesota had phoned a group home up by where they lived that would be able to take my brother on emergency basis until we could find a permanent home for him. When dad passed away, my daughter and I flew down to Texas and packed up the trailer because I knew we wouldn’t be back. We packed up everything that we wanted and drove back to Minnesota for two-and-a-half days of driving. In that time, I weighed all the pros and cons and that was when I decided I was going to bring him to live with me. It
didn’t seem fair to have his whole world turned upside down with one he didn’t know. That was one thing I had talked to my mother about. When I thought about putting him in a group home, I’d asked if I could put him in one down here, close to the city by me because my parents were too far away. My mom asked, “Why would you do that?” I told her so I could see him. That made her feel better. It just seemed the right choice to do. And that’s how he came to me.

Table 4.8. Analysis of Jane’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Following the death of her father (sole caregiver to her brother) in Texas, Jane closed up the family trailer with her daughter giving her time to think about the pros and cons of her brother living with her. Subsequently, Jane decided it was the right thing to do.</td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Jane’s parents made an early commitment that their son would not be institutionalized and assumed his care. Despite her father taking on a compound caregiving role for her mother and brother with DD, Jane’s brother was always with her parents. After her mother died, her father was the sole caregiver to her brother with DD.</td>
</tr>
<tr>
<td>Characters</td>
<td>Jane, father, mother, son, daughter, and institution</td>
<td></td>
</tr>
<tr>
<td>Place</td>
<td>Parent’s winter trailer, Texas and Jane’s apartment, Minnesota</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>No time given.</td>
<td></td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Mom and dad worked at psychiatric facility (turning point). Having this experience resulted in the decision to assume the full-time care of their son with DD rather than place him in the psychiatric facility (evaluation).</td>
</tr>
<tr>
<td>Structural Elements</td>
<td>Structural Sub-Elements</td>
<td>Researcher’s Interpretive Summary</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>What does narrative mean? What is its function? How is it described?</td>
<td>Her mother retired in 1976 due to a degenerative disorder (crisis and turning point). Resulted in her father become a compound caregiver to both his wife and son with DD (evaluation and crisis). This extended effort prompted Jane to request her parents get a case worker and additional services (evaluation). As stated, Jane never anticipated taking on this role.</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td>Decision to have her brother live with her rather than a group home.</td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td>Jane believed it was the right choice and right thing to do to assume the co-residential caregiving role to her brother.</td>
<td></td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td>Jane extends praise to her mother and father for their commitment to their brother, son for providing care to her brother with DD, and daughter for her support.</td>
<td></td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td>Blame is not clearly defined in Jane’s story. Jane’s mention of parents dropping off and abandoning their children with DD shows disapproval when recognizing the commitment and dedication of her parents to her brother and persons with DD within the field.</td>
<td></td>
</tr>
<tr>
<td>Meaning</td>
<td>Duty and commitment to family. Highlights stigma associated with persons with DD. Exposes developing co-dependence between co-residential parents and their children with DD.</td>
<td></td>
</tr>
</tbody>
</table>

Jane explained that the situation involving the transition of her brother to her followed the death of her father. After he passed, Jane and her sister traveled to Texas to clean up her parents’ winter home. During the drive back, Jane decided to have her brother come live with her rather than putting him in a group home.

Jane begins her narrative explaining that her mother and father both worked locally, in rural Minnesota, at an institution. This was a turning point for her parents as their experience and
what they witnessed at this facility prompted them to take on caregiving duties for her brother. In her description, Jane indirectly highlights the stigma associated with persons with disability during this period, including calling individuals patients (lending to a medical model) and the disturbing reality of families abandoning their members with DD to the institution. Jane explains that at some point in her mother’s career she had to quit her job due to a degenerative disorder. This was another significant turning point as he father took on the compound caregiving duties for her mother and brother. This is also viewed as a crisis, which prompted Jane to request her parents get a case worker and additional services for her brother. The final turning point to Jane’s story is the death of her father. This prompted Jane to reflect on her parents’ efforts and her own loyalty to her brother and family resulting in her taking on the co-residence and care for her brother with DD.

The main characters in Jane’s story are her father, mother, son, daughter and society, through the institution. Jane extends praise to both parents, positively reflecting on their work efforts at the local institution and their commitment to her brother. Jane’s commitment to take on the caregiving role is to honor the efforts of her parents. Jane also offers praise to her son as the companion to her brother with DD, and daughter for her support. Blame is not clearly defined. Her mention of families abandoning their children with DD shows disapproval when compared to recognizing her parent’s dedication and commitment to her brother and persons with DD.

*Interviewer’s reflexive thoughts.* I felt somewhat sorrowful during my interview with Jane. Throughout most of our interview, I felt that Jane was being careful to respond with what she believed were appropriate answers. However, when I finished with the questions, we spoke more candidly. At that point, Jane exposed more of her emotions indicating some personal
challenges. I felt that one of these challenges included a desire for but fear of the ‘road ahead’ that involved a life ahead with her brother and new role as co-residential caregiver.

**Story of Denise (July 16, 2016).** We were very church-going people. And, my dad; he had his own issues. He went to the priest, and the priest told him that my sister was like this because of his sins. My dad didn’t hear anything after that; he just stuck on that and thought it was his fault. But, it’s a genetic thing. It was not because of my father.

**Participant profile.** Denise is a 44-year-old, Caucasian woman who lives in Florida. Denise holds a Master’s degree, and resides with her husband, 44 years of age, daughter 22 years, and sister with DD, 41 years. Denise stated that her sister was diagnosed with Down syndrome. Denise’s husband has two children from a previous marriage, aged 18 and 19, who live with their mother. Denise’s mother passed away close to 15 years ago. Denise’s father has since remarried. Denise discussed extended family and has a younger sister, 38 years of age.

**Denise’s story of transition.** My sister has been with us this time for a month; previously we had her for 18 years. This time we got her June, I think. June 17 we got her back. We put her in a residential facility. That was last year, at the beginning of the year of 2015. At the time, we were looking for a home. We found one with an opening that was five minutes from our house and about seven miles away. So, the owner of the house, it is not the owner but the president because it’s a nonprofit, his daughter actually lived there. Plus, it was Christian-based. And we were like “Oh, how bad can it be?” Growing up, group homes were not places you wanted your family members to stay. So, it took a lot for us to even get to that point. We discussed it for years, my husband and me. And when my sister was here the first time, we could only take her so far cognitively,
emotionally, and educationally. It was hard for me to accept that maybe somebody could do different things to help her. So, when she got into the home we were told to get extra services, behavioral and occupational therapy. Things she wasn’t getting at our house because in the family home here you don’t get funding; you’re just supposed to take care of them. So hearing that she could get extra services was awesome. And she's also around her peers, and can make friends and stuff like that, outside of just being my family. But as things progress, there were issues; neglect and inadequate supervision. We met with the house manager to discuss some of my concerns, and things got worse from there.

In the next few weeks, I started seeing some more issues. They weren’t really bad at first, but just different for my sister. So, I started to think I was going to take her, and she could live at my house again. I deal more in my emotions and my husband is more logical. He wanted me to talk to them again to know their plans for Tammy and give them the opportunity to address our concerns. But after addressing our concerns, her behaviors got worse and she started turning against me. She didn’t want to talk to me on the phone, and when I went to the house she didn’t want to see me. She would start yelling at me and didn’t even want my husband to pick her up. Sometimes, she deals better with men, like an authority daddy thing. But this was completely out of the norm for her. One weekend, I got her and she had a burn mark on her arm. We had been talking to her case manager to make arrangements to bring her back to my house. So, the case manager was aware. And once we saw the burn on Tammy’s arm, she was able to identify how it happened. Tammy said she was working with the staff and she did
it during dinner time. But there was no incident report and nobody addressing it either. So, my husband and I agreed that they were not doing anything better or different than we did originally other than getting money from the state and my sister to not watch her, not help her, and not assist her with her needs. But she did make friends, and her attitude with me changed because I didn’t have to be her mom or her boss per se. I got to be her sister. We never had that relationship since my mom passed. I had to become her mother. And she didn’t get a self-identity in that home, so that didn’t help her. And on June 17, she moved back to the house. She has a companion 12 hours per day. So, she’s got one-on-one personal attention which has been awesome.

Table 4.9. Analysis of Denise’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Story explains the emotional investment of sibling caregivers and role shift towards becoming a parent.</td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>After her sister moved to the residential facility, Denise noticed some changes, including neglect and inadequate supervision at the home. Despite a meeting with the residential manager to discuss concerns, Denise saw more issues. After a troubling incident, Denise and her husband took Tammy back to live in their home.</td>
</tr>
<tr>
<td>Characters</td>
<td></td>
<td>Denise, husband, sister with DD, group home manager, staff, case manager, society</td>
</tr>
<tr>
<td>Place</td>
<td></td>
<td>Tampa, Florida</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td>18 years co-residential caregiving, 1.5 years in residential facility, and 1 month re-residing together</td>
</tr>
</tbody>
</table>
Table 4.9 Continued.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>After providing care to her sister for 18 years and believing there may be further opportunities for her sister to enhance cognitively, emotionally, and educationally, sourced a group home. (belief was a turning point) Denise and her husband found a Christian-based (evaluation—assumed a greater safety) residential facility where Denise moved for a year.</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>What does narrative mean? What is its function? How is it described?</td>
<td>After her sister moved to the residential facility, Denise noticed some changes, including neglect and inadequate supervision at the home. In addition, her sister would not respond to her phone calls and reacted negatively when she visited (crisis). One weekend when visiting her sister, Denise noticed a red burn on her sister’s arm (crisis). There was no accompanying incident report and staff stated they were unaware of the mark. (turning point).</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td></td>
<td>Denise and husband removed her sister from the group home to live again at their house.</td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td></td>
<td>Moving her sister to a group home was an opportunity for Denise to remove some responsibility but also provide her sister opportunities for more services, supports and achieve greater independence.</td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td></td>
<td>Denise extends praise to her husband and sister with DD</td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td></td>
<td>Denise extends blame to group home manager and staff</td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>Context involves Denise replacing and assuming mother’s role in early adulthood. The years’ burden of assuming this role and her life stage in middle adulthood resulted in her encouragement of sister to transition into group home. This provided opportunity for reflection and shifted the dynamics of the relationship with her sister when returned to live with Denise.</td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td>Emotional and financial burden of caregiving. How siblings take on a parental role post-transition as it is the role they understand. Shows opportunity for encouraging independence in atypical sibling.</td>
</tr>
</tbody>
</table>
Denise’s story of transition is somewhat unique since there are two periods in which she had taken on the co-residential caregiving role. Prior to the most recent stint of one month in providing care, Denise assumed the role in her mid-20s for over 18 years. But at the end of 2014, Denise found a residential facility for their sister that was “Christian-based” and “close to her home.” The Christian-based label assumes a belief of safety, order and goodness in the care provided to the facility’s recipients; however, the reason for this new residential direction was an acceptance over time that her sister needed and other persons who could provide better cognitive, emotional and educational supports. Plus, Denise explained she was “told” she could get these further supports if she was at a residential facility rather than the family home. Denise remarked that families “are supposed to just take care of them,” and there are limited funds for families, thus extending blame to the system for not providing better supports. The decision to transition her sister to a residential facility is a turning point in Denise’s story. Denise believed that this move could help her sister gain more independence and make friends. Furthermore, Denise could relieve herself of the duty as her sister’s mother and have a sibling relationship with her. After her sister moved to the residential facility, Denise noticed some changes, including neglect and inadequate supervision at the home. In addition, her sister would not respond to her phone calls and reacted negatively when she visited. This became a crisis and Denise and her husband began to discuss the idea of having her sister come back to live with her. One weekend when visiting her sister, Denise noticed a red burn on her sister’s arm. There was no accompanying incident report and staff stated they were unaware of the mark. This is another turning point in the story that resulted in Denise and her husband taking Tammy back to live in their home.

The story’s main characters include Denise, her husband, sister with DD, group home manager, group home staff, her sister’s case manager, and society. In this narrative, Denise
extends praise to herself, her husband and her sister for their former and current efforts to oversee the present and future well-being of their sister. Denise stated that they discussed putting her sister with DD in an alternative residential facility for a number of years implying a struggle of likely guilty feelings for transitioning her sister to a new home, recognizing the need for her sister to have greater independence, and a self-desire for Denise to have some sense of freedom given the burden of providing care in her early and middle-adulthood. Unfortunately, the facility did not meet expectations that followed an assumed belief regarding its religious roots. Furthermore, there is an inferred blame on society since it does not support families to enhance their well-being. Denise suggests her sister began to show newly developing behaviors indicating a negative environment where sister was living.

The resolution to this story is a return of Denise’s sister to her home. The end to this narrative suggests a newly formed relationship with her sister with DD, including more positive functioning between Denise and her sister due to greater recognition of independence. Denise stated she felt like a mother to her sister in the past but now can enjoy the relationship as an actual sister.

Denise’s story reflects the years’ long burden of caregiving, plus it illustrates how siblings can take on a parental role post-transition as it is what they have seen from their parents, and the role they understand. Finally, the story shows the benefits of building self-determination in persons with DD to gain some level of independence.

*Interviewer’s reflexive thoughts.* I connected to Denise through my workplace supervisor who knew Denise’s background and fit for my study. Denise also works for the same organization as myself but in a different capacity. I had no prior knowledge of Denise and her background as a co-residential caregiver. In addition, Denise was the only interview that did not
properly record the first time. Thankfully, she was gracious to re-do the interview the following day.

It is also important to note an indirect connection to Denise that became apparent during our interview. Before my current role as a faculty instructor in social work at a Tampa-based university, I directed a local agency for adults with developmental disabilities. As Denise explained her story, I realized that at a certain point in her story she was talking about her aunt and cousin who attended the day program of this local agency. In other words, I knew these individuals quite well. I shared that information with Denise towards the end of our phone meeting.

While Denise had provided caregiving to her sister for a number of years, in the past two years, her sister resided in a group home. More recently, her sister transitioned back to Denise’s home. The stories of transition have many different meanings. For Denise, this story represented resilience and a resolution to some tough challenges throughout the years.

**Story of Andrew (July 23, 2016).** I would say for me the difference between the two situations [co-residence and non-co-residence] is my wife and I have our life back. For him, the difference is that his world is bigger now; he has more opportunities and his world is more about his needs and his life. He has the opportunity to have a life he never expected.

**Participant profile.** Andrew is a 35-year-old, Caucasian male living in Maryland. Andrew has a wife, 47 years of age, and formerly co-resided with his brother, aged 32 years. Andrew’s brother is diagnosed with Angelman syndrome. Andrew’s mother is deceased, but he has a father and step-father. Andrew stated he and his brother are currently estranged from his
father. However, they continue to maintain contact with his step-father who lives in Calgary, Alberta.

Table 4.10. Analysis of Andrew’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td>Explaining the events resulting in Andrew taking on the co-residential caregiving role and fulfilling his responsibility.</td>
<td></td>
</tr>
<tr>
<td>Orientation (setting— who, when, where)</td>
<td>Situation</td>
<td>Andrew’s mother died, and his step-father attempted to provide the caregiving to his brother with DD. However, his step-father’s efforts did not work out and Andrew took on the caregiving role, with the support of his wife.</td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Characters</td>
<td>Andrew, mother, step-father, father, wife, brother with DD</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>Place</td>
<td>Calgary, Alberta, and Maryland</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>Time not provided.</td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>Sequence of Events/Actions</td>
<td>Mother and father divorced (crisis).</td>
</tr>
<tr>
<td></td>
<td>Revealing Crisis/Turning Point</td>
<td>Father was addicted to narcotics (crisis). Andrew and brother with DD estranged from father (evaluation). Mother remarried to step-father (evaluation).</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td>Mother diagnosed with and died from cancer (crisis). Step-father assumed the caregiving for approximately one year but this did not work out (turning point). Andrew’s brother with DD moved from Alberta to Andrew’s home in Maryland where Andrew assumed the caregiving role along with the support of his sister (evaluation).</td>
<td></td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td>Andrew took on the caregiving along with the support of his wife.</td>
<td></td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td>As Andrew explained, his brother traveled across state lines to live with him and his wife.</td>
<td></td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td>Praise is extended to his mother, step-father, himself and his wife.</td>
<td></td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Blame is extended to his father for his addiction resulting in both brothers being estranged from their father as well as efforts to protect his brother from his father.</td>
<td></td>
</tr>
<tr>
<td>Meaning</td>
<td>Andrew stated that he always knew he would be the caregiver to his brother indicating having this knowledge in his youth. This role acceptance facilitated the transition of his brother to his home and taking on the co-residential caregiving role.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fulfilling a promise to parent (mother).</td>
<td></td>
</tr>
</tbody>
</table>
**Transition story of co-residence.** My brother came to live with me shortly after my mother passed away from cancer. Let me roll back a little bit further. I realize it’s more complicated. So, my biological parents divorced and we are largely, kind of estranged from our father. That’s partly due to him being a narcotics addict and somehow, we felt we actually needed to protect my brother from him. So, there’s a bit of an estranged relationship there. My mom remarried and then we had a step-father. Then, she was diagnosed with cancer and passed away from that. My stepfather attempted to take over my brother’s care because at that point my mother was his primary caregiver, 24/7, 365 days of the year. My brother had aged out of the public school system and he was just living in the house with her before she married again. And I was in a different state. So, after my mom died, my step-father tried to do the caregiving for about a year and it wasn’t working out. We knew that I was always going to be the long term plan. So, we just kind of accelerated that plan. And he came across state lines to live with me and my wife.

Andrew’s narrative focused directly on the events resulting in him taking on the co-residential caregiving role and transition of his brother with DD to his home. Andrew begins by providing some brief history where his mother and father divorced when they were young. This is considered a crisis. Within this crisis, Andrew explained that due to his father’s addiction to narcotics, he and his brother were estranged from their father. Through this suggestion, there is indirect blame for not fulfilling his duty to Andrew and his brother. Furthermore, they felt the need to protect his brother from their father. But offering some evaluation to the story, Andrew explained that his mother re-married, and it appears that this was a positive outcome. As a
significant turning point to the story, Andrew’s mother passed away from cancer and his step-father tried to assume the caregiving role. In this part of the narrative, Andrew implies a level of praise to his step-father for his efforts. But Andrew discusses always knowing he would be the long-term plan. The estrangement from their father at a young age provides the context for understanding he would assume this role. But this obligation is also the resolution to the story. Andrew indicates some level of distance of bringing his brother across state lines to his home as the coda to this story. The meaning of this story involves a focus on fulfilling the responsibility of the caregiving role.

**Story of co-residence and transition to group home.** It was stressful.

My wife and I weren’t married at the time but we had reached a point in our relationship where we were living together. When my mother was terminally ill, we knew my brother was coming sooner than later. So, we bought a house. But we had kind of established a lifestyle together already. And my brother kind of put that on hold because he was not receiving any services and required 24/7 supervision. That meant we were paying out money for people to watch him during the day just so we could go to work. And then every evening and every weekend we were his caregivers. It was basically just a huge pause button on our lives. Having grown up with my brother, I knew what I was getting into. But my wife didn’t really know, didn’t fully understand what was involved.

So, around the time we were doing this transition, we were also talking to the Angelman Foundation and were put in contact with a staff member who also had a son with Angelman syndrome. This person had her son in an independent living situation and invited me over to see it. By that point, we kind of felt like we
were going to have to, long term, put him in a group home which is not what my mom wanted. And I wasn't really happy with the group home situation either. But to see somebody my brother’s age with Angelman syndrome living in his own residence with the supports of a caregiving staff, I said that’s what we have to do. So, we moved my brother here, hired some lawyers, and filled out the local state paperwork to try and plug him into the Maryland services system. That was a little interesting because the services system in Maryland at that time, and maybe still, is streamlined for persons born in Maryland who have gone through the Maryland school system and come out the other end. So, my brother blipped onto the radar late, and we had a lot of issues because they didn’t know what to do because of that. But we are a geographically smaller state and our waiting list typically takes nine years to get through. We got my brother through in three. But that was not passively waiting around. And it involved a lot of help.

Table 4.11. Analysis of story of co-residence and transition to group home.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Story is used to explain reasons for transitioning brother with DD to live independently in his own apartment in the community.</td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Andrew started living together with his girlfriend (now wife) and bought a house to take on co-residential caregiving role of brother after mother diagnosed with terminal illness. This responsibility proved greatly stressful, and he connected with person whose son had same disability. Person exposed Andrew to group home that could properly manage his brother’s needs. Despite difficulties navigating the Maryland disability service system, Andrew was successful (with supports) to attain residential services and transition his brother into a group home.</td>
</tr>
<tr>
<td>Characters</td>
<td></td>
<td>Andrew, mother, wife, acquaintance with child with Angelman syndrome</td>
</tr>
<tr>
<td>Place</td>
<td></td>
<td>Maryland</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td>Time not disclosed.</td>
</tr>
<tr>
<td>Structural Elements</td>
<td>Structural Sub-Elements</td>
<td>Researcher’s Interpretive Summary</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>The caregiving of his brother with DD proved stressful, especially for his girlfriend who did not know what to expect (crisis). Resulted in Andrew connecting with individual with child with same disability (evaluation).</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>Through persistence and supports, Andrew was successful in attaining residential services for his brother to overcome the waiting period for services from nine to three years (evaluation).</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td></td>
<td>Andrew’s persistence and navigating external supports resulted in his brother achieving residential services within three years as opposed to nine years.</td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td></td>
<td>Andrew ends the narrative with a sense of pride explain his success in achieving services through supports in three years rather than the nine years it typically takes.</td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td></td>
<td>Blame is extended to the state system for the challenges in sourcing services for persons with DD. and waiting list issue perhaps?</td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>Context is an important factor as Andrew is beginning his relationship with a goal towards marriage. However, the challenges of co-residential caregiving, his girlfriend’s not understanding the difficulty of the responsibility, and potential burden on relationship resulted in efforts to transition his brother to a group home.</td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td>Physical and financial challenges and burden of caregiving justified the transition of his brother to a supported living.</td>
</tr>
</tbody>
</table>

**Interviewer’s reflexive thoughts.** Andrew was one of two male caregivers interviewed for this study. I connected with him quite early on into my research when I began recruiting potential individuals. Like the other male participant, Andrew co-resided with his brother with DD for two years. In this regard, Andrew and his wife provided direct care to his brother, which was suggested as quite challenging and overwhelming given Andrew’s brother’s disability. But
given Andrew’s young age and the new marriage to his wife, Andrew put a lot of thought into the ideal situation for himself and his brother. I did not feel guilt or any negative feelings for transitioning his brother to a group home. In fact, it appeared a great opportunity for Andrew to remain his brother’s caregiver and allow his brother to have his own life and engage in activities that enhanced his well-being.

**Story of Gary (July 24, 2016).** I don’t know if I feel ‘quote-unquote’ good about being a caregiver. A lot of friends of mine around the country think it’s really terrific that I am looking after my sister. And I’m thinking, ‘Why?’

**Participant profile.** Gary is a 69-year-old, Caucasian male, living in the Chicago area. Gary has a sister with DD, aged 64 years, with whom Gary formerly resided. Gary explained that, while pregnant with his sister, his mother developed German measles that was not well treated. Though it was not evident that his sister had a disability during her infancy, at about two to three years of age it became clear she was not developing normally. At some point in her early childhood, Gary’s sister was diagnosed as learning disabled. More recently, Gary’s sister transitioned to a group home close to where he lives. Gary’s parent’s divorced when he was young, and his father re-married. Gary’s parents are both deceased.

**Gary’s story of transition.** Back then, my parents were not communicating;

it was not a terribly friendly divorce. For a short period of time, my sister lived in a state facility. It was the only one available at the time in Dixon, Illinois which is about 80 miles west of Chicago. The only reason anybody’s ever heard of Dixon is because President Reagan was born there. It was an absolutely filthy facility. You could smell it blocks away when you were near it. And after every time we’d take her out for a visit, she thought we were picking her up for good.
But she would get upset when we dropped her off, and thought we were punishing her when she had to go back there.

After a number of months, this would be sometime during 1962, our dad took her out of there for good and said she’s going to live with me. He took her home to his residence and she lived there until his death in 2000. When she lived there, she was being cared for by my dad, his parents who lived next door, and other family members. This was fundamentally a happy time for my sister. While all of this was going on, I was living on my own and I would see her from time to time.

Jumping ahead to 2000, upon our father’s death, my sister relocated to our mother’s home in Chicago, which is about a mile from my own. My mother and I both lived in the city and worked here. And my sister lived with our mother for 8 years until her death in 2008. Before that time, and I’m near the end of the story, when my sister was living with our dad, she had been neglected. Our dad was involved with a woman who was mentality unstable. I’m sorry to say this but my dad would sometimes travel on his job and this woman would have full access to my sister. And sometimes, there was some physical abuse. It was very unfortunate.

In 2000, our sister relocated to our mother’s apartment. My mother accepted a lot of input from me because she [my mother] was older then and elated to get back custody of my sister. My mother felt guilty all those years and was not allowed to see her. My sister’s name is [name given]; I may have emailed you some pictures.
Anyways, we got my sister into medical and dental care, evaluated psychologically and then, into a day program in Chicago; a day activity program where she could be with other learning disabled people.

I took her in my car in the morning and brought her home at the end of the day for quite a long time. At some point, we were able to get her into a government service where she could ride a taxi to this program and back. I got her into that. But in the middle of 2008, our mother took sick and she was hospitalized with something that eventually took her life over a period of two to three months. So, my sister had to be somewhere and I was able to have her live with me.

Gary presents the story of his sister’s transition to his home as a journey where following his parent’s divorce, she lived in different settings (i.e., state institution, father’s home, mother’s home, and finally, Gary’s home). The characters in Gary’s story, include himself, his sister, mother, father, step-mother and paternal grandparents. Gary described different settings where his sister resided, including the state institution in Dixon, Illinois, his father’s residence from 1962 to 2000, mother’s residence from 2000 to 2008, and finally Gary’s residence up to 2010. To understand the transition, Gary represented his parent’s divorce as the starting point of his sister’s journey. The divorce is demonstrated as a crisis and described as not terribly friendly. However, it was also a turning point for his sister as it resulted in her move to a state institution.

As Gary stated, the institution also became a crisis as he explained that it was a filthy facility. Implicit in this description was the poor treatment of institution residents. Gary stated that his sister thought she was being picked up for good when they visited and would become upset when she was being returned.
Table 4.12. Analysis of Gary’s Situation.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Point is to explain/honor the journey of his sister through challenges growing up to her current, more stable residence.</td>
</tr>
<tr>
<td>Orientation (setting—who, when, where)</td>
<td>Situation</td>
<td>Parents divorced. Gary lived with mother, and sister moved to state institution. In 1962, dad removed sister from state institution to live with him due to institution’s poor status. While at father’s, sister experienced support from family members, but also was abused by step-mother when father would travel for work. After father’s death in 2000, sister was moved in with mother. Following mother’s death in 2008, sister was moved to live with Gary.</td>
</tr>
<tr>
<td>Characters</td>
<td></td>
<td>Gary, sister, mother, father, step-mother, and paternal grandparents.</td>
</tr>
<tr>
<td>Place</td>
<td></td>
<td>State institution in Dixon, IL; father’s residence in IL; mother’s residence in Chicago, IL; and, Gary’s residence in Chicago, IL.</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td>1962-2013</td>
</tr>
<tr>
<td>What is causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Parents divorced (crisis and turning point). Sister was relocated to institution (evaluation). Institution emerged as poor environment (crisis and turning point). Father relocated sister to his residence (evaluation).</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td></td>
<td>Father passed away (turning point). Sister moved into mother’s residence (evaluation).</td>
</tr>
<tr>
<td>Evaluation (soul of the story—narrator communicates his/her emotional on the story’s meaning)</td>
<td>What does narrative mean? What is its function? How is it described?</td>
<td>Mother passed away (turning point). Sister moved into Gary’s (brother’s) residence (evaluation).</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td></td>
<td>There is no resolution to the story of transition.</td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td></td>
<td>Gary stated he chose to take on the co-residential caregiving role for his sister as she had to go somewhere.</td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td></td>
<td>Gary extends praise in his story to his father, mother, himself and family members for the care and support provided to her sister.</td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td>Family Life Cycle</td>
<td>Blame is presented when discussing the poor nature of the state-run institution, as well as the step-mother. The divorce of Gary’s parents resulted in the transition of Gary’s sister to the state-run institution. Fulfilling a promise to his family and a commitment to his sister.</td>
</tr>
</tbody>
</table>
The negative elements associated with the facility became a turning point where, in 1962, his father removed his sister from the institution to come live with him. But Gary’s narrative indicates a likelihood of guilt from his father resulting in him removing his sister. Though the early to mid-part of this period where his sister resided with her father, Gary explains that this was a positive period due to family supports. However, he stated that his step-mother (father’s wife) was abusive towards his sister. The death of Gary’s father in 2000 was another turning point where his sister moved in with his mother. Gary describes this period when his sister lived with his mother favorably, but he also explains that his mother’s efforts were a means of correcting her lack of involvement in prior years. The final turning point was in 2008 when his mother passed, and his sister transitioned to Gary’s home.

In Gary’s story, he extends praise to his father, mother, himself and other family members who were involved in the care and welfare of his sister. Blame is presented to his abusive step-mother as well as the poor nature of the state-run institution. When considering the context of this story, much of his sister’s journey stemmed from his parent’s divorce. The divorce took place in the early 1960s at a time when it was not well accepted. Thus, there was likely significant conflict in Gary’s parent’s relationship that led to their divorce. The transition of his sister to the state-run institution reflects this conflict likely due to his parent’s inability to discuss a more appropriate arrangement.

There is no true resolution to Gary’s story since his sister’s journey continued by transitioning from Gary’s home to a group home. For the story’s coda, Gary stated that he chose to take on the co-residential caregiving role since his sister had to go somewhere. The meaning of this story is to explain the events of his sister’s journey that followed conflicted family
dynamics. The dynamics involved guilt of his parents where his sister lived in different residential settings.

**Gary’s story of transition to group home.** It’s, you know, it’s a labour intensive thing caring for someone who has significant learning disabilities. But I had the great fortune to have made plenty of money during my career. I’ve had some successful investments and I’ve been a lawyer since 1974. So, I could do this. And, I’ve known for a lifetime that I would eventually be called upon to do this. I’ve had four grandparents and two parents who also knew this. So, if I wouldn’t have had the money set aside, they made sure to set aside some of theirs so that it wasn’t really a money problem. But from May of 2008 until December of 2010, my sister lived with me. She then relocated to a group home 40 miles away. It should have happened sooner, but there were some bureaucratic glitches. A case worker was assigned to me who was new to her job. She didn’t understand that a sibling taking care of a disabled person in the state of Illinois gets a greater priority for placement and various sources of assistance then a learning disabled person living with a parent. And because this young girl assigned to me didn’t know the rules as well as she should have, and because I didn’t want to make her look bad, I didn’t go over her head and my sister could have been relocated sooner. Truthfully, she probably should have been relocated to where she is now during the 1970s. The reason I say that is because it was the perfect storm. Because the place she lived in Dixon was so filthy, our dad said she is never going to live in a place like that again. And he didn’t know, our mother didn’t know, and I didn’t know that much better alternatives were available. So my sister
lived with him much longer then she should have. It was sort of a state of the time, of that idea, of the stigma associated with this population. It wasn’t until the 1950s that these ARCs that were actually put together by families started to come about. I think families were like, you are not going to put my kid into a home. But it was sort of a redeveloping philosophy on how we look at things which happened over a period of time.

For me, it was never really discussed other than my dad saying that you know the day will more likely come when your sister is going to need care and the rest of us may not be around. And because I adore my sister, and I guess that’s not the universal situation all the time, because she lives in a house with five or six other ladies, some of them have family who never ever visit. I probably should have pushed for the kind of situation my sister has now long ago, but it was never any of my business when she was living with our dad.

Gary begins the narrative of his sister’s transition from his residence to the group home by using the word “intensive” to describe the challenges as a co-residential caregiver to a person with a learning disability. Indirectly, this description provides justification for this discussion. Gary also explains that through his profession and support from his family, there were strong financial provisions to support his transition to the caregiving role. Within this narrative, Gary explains that he always knew he would take on this role and the funding was available to facilitate this opportunity. Later in the story, Gary stated that his dad would remind him of this potential and future opportunity. In essence Gary extends praise to this father for recognizing the poor living environment and making the sacrifice to takeover the co-residential caregiving role.
Table 4.13. Analysis of Gary’s Story of Transition to Group Home.

<table>
<thead>
<tr>
<th>Structural Elements</th>
<th>Structural Sub-Elements</th>
<th>Researcher’s Interpretive Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract (point/summary of story)</td>
<td></td>
<td>Identifying the process and reasons for her sister’s successful transition to a group home.</td>
</tr>
<tr>
<td>Orientation (setting— who, when, where)</td>
<td>Situation</td>
<td>Gary begins narrative stating it’s challenging to be the caregiver to a person with a learning disability. With a strong financial foundation, he provided was his sister’s co-residential caregiver from 2008 to 2010. After discovering that the state is obliged to provide residential services when the caregiver is a sibling (and despite the bureaucratic snags where siblings received priority), his sister moved to a group home, 40 miles away.</td>
</tr>
<tr>
<td>Structural Sub-Elements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characters</td>
<td></td>
<td>Gary, state social worker, father, mother, and sister</td>
</tr>
<tr>
<td>Place</td>
<td></td>
<td>Gary’s residence and group home, both in Illinois</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td>2008-2010</td>
</tr>
<tr>
<td>What is the causal relationship? (Change in one factor causing change in another)</td>
<td>Sequence of Events/Actions Revealing Crisis/Turning Point</td>
<td>Gary explained that being co-residential caregiver was intensive for someone with a learning disability (crisis and turning point). Relied on case worker support who delayed process due to inexperience (crisis). Gary’s sister transitioned from his home to a group home (evaluation).</td>
</tr>
<tr>
<td>Complicating Action (what happened next)</td>
<td>What does the narrative mean? What is its function? How is it described?</td>
<td>Gary describes having a strong financial background, provided by himself and family, to support him and his sister (evaluation).</td>
</tr>
<tr>
<td>Resolution (resolving the plot)</td>
<td></td>
<td>Sister transitioned to a group home that is presented as optimal outcome.</td>
</tr>
<tr>
<td>Coda (ends narrative; returns listener to present)</td>
<td></td>
<td>Gary stated that he should have pushed for sister to be in group home long before but was not provided that authority.</td>
</tr>
<tr>
<td>How is praise represented in the story?</td>
<td></td>
<td>Gary extends praise to himself, group home, and father.</td>
</tr>
<tr>
<td>How is blame represented in the story?</td>
<td></td>
<td>Gary extends blame to the state case worker and state institution.</td>
</tr>
<tr>
<td>Context (sociocultural, political)</td>
<td>Family Life Cycle</td>
<td>Gary indicated that sister should have been placed in group home earlier in her life. But stigma and lack of available small, community-based group home residences during that period resulted in her initial transition to the state-run institution.</td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td>Physical challenges and burden associated with caregiving provided justification for why sister is in group home.</td>
</tr>
</tbody>
</table>
Gary’s brief mention of the intensiveness of the co-residential caregiving role is a crisis and turning point resulting in his sister transition from his residence to the group home. However, the discussion was not made about his sister’s initial adjustment to this new environment. But there is strong displeasure and blame with the state as identified by the state case worker’s lack of knowledge and experience that could have facilitated his sister’s more rapid transition to a group home. In addition, Gary discusses again the filthiness of the state-run institution, and identifies with his father who permanently removed his sister from that facility. Gary explained that his sister should have been put into a group home much earlier indicating the inconsistencies of her living arrangement and caregiving challenges. Gary also highlights the stigma associated with persons with developmental disabilities resulting in families developing facilities for their children with DD. The description of the stigma and familial push for better opportunities for their children with DD provides the context that resulted in the different transitions his sister experienced.

Gary emphasizes his adoration for his sister and describes a resolution where he indicates that he is there for his sister, in a situation where family may not ever visit their member with DD in the group home. Gary presents this idea as a resolution to the challenges his sister experienced throughout the years. The coda to this narrative involves some regret from Gary for not pursuing this outcome earlier; however, he explained that he did not have the authority to do so. The meaning of this narrative is to justify the decision for his sister’s final transition to the group home.

*Interviewer’s reflexive thoughts.* Gary was my last interview, and he was very eager to tell his story. At moments during the interview, I felt some of the sadness associated with the
challenges his sister and family faced growing up. But I also felt a very strong emotional bond and deep love for his sister.

**Summary of Structural Analysis**

Table 4.14 represents the emergent constructs from participants’ stories that conceptualize the meaning participants ascribed to and identified with their experience as co-residential caregiver. Column 1 identifies the construct, column 2 shows the participant type (i.e., MFC [married female participant with children], DF [divorced female participant], SF [single female participant], MM [married male participant], and SM [single male participant]) whose story is associated with the construct, and column 3 highlights the total number of stories that support each construct.

<table>
<thead>
<tr>
<th>Construct</th>
<th>Participant Type</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duty/responsibility/obligation/commitment to family</td>
<td>MFC-4</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>DF-1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SF-1</td>
<td></td>
</tr>
<tr>
<td>Honoring a promise to a parent to fulfill caregiving role</td>
<td>MFC-2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>MM-1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SM-1</td>
<td></td>
</tr>
<tr>
<td>Burden (emotional, financial and physical) of caregiving</td>
<td>MFC</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>MM-1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SM-1</td>
<td></td>
</tr>
<tr>
<td>Co-dependency/enmeshment of the parent-atypical sibling relationship</td>
<td>MFC-2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>DF-1</td>
<td></td>
</tr>
<tr>
<td>Duty/responsibility to atypical sibling</td>
<td>MFC-1</td>
<td>1</td>
</tr>
<tr>
<td>Gendered, patriarchal nature of caregiving role</td>
<td>SF-1</td>
<td>1</td>
</tr>
</tbody>
</table>

The most high-ranking construct that emerged from participants’ narratives (MFC: 4; DF: 1; SF: 1) was the sense of duty, responsibility, obligation, and commitment to family. This construct characterized the meaning participants mostly ascribed to and identified with the caregiving. Four stories (MFC: 2; MM: 1; SM: 1) suggested honoring a promise to their parent
for how participants identified with the role. Three stories (MFC: 1; MM: 1; SM: 1) highlighted the burden of caregiving and how some participants viewed the caregiving experience. In particular, both male participants similarly described honoring a promise to their parents; however, they also identified physical and financial challenges as reasons for sourcing alternative housing for their atypical siblings. Two stories (MFC: 2) characterized the caregiving role as having the potential for co-dependency and enmeshment between the caregiver and individual with DD based on observations of the relationship between their parent and atypical sibling. One participant’s narrative described a deep bond and loyalty to her sister as the meaning of her experience, including an inherent commitment to the role. One narrative (SM: 1) implied a gendered, patriarchal nature of caregiving giving emphasis to how society may view caregiving.

**Thematic Narrative Analysis**

This section used a thematic narrative analysis (across-case analysis) to respond to the remaining research questions with themes that emerged across participants’ narratives. Within this approach, language was the tool for determining themes by focusing on the stories’ content (what is said in stories) rather than their structural form (how a story is told) (Riessman, 2008). This dissertation’s research questions and theoretical framework each provided the categories and subcategories to guide the development of themes. Tables were developed to reflect the categories, subcategories, and themes. For each theme, participant type (i.e., married female participant with children [MFC], divorced female participant with children [DFC], single female participant with no children [SF], married male participant with no children [MM], and single male participant with no children [SM]) was highlighted to indicate the source of references (i.e., participants story excerpts) for each theme, and number of references per theme was calculated. Where applicable, themes were organized to reflect participants’ positive and negative
experiences, and in some cases, participants described both positive and negative aspects regarding categories. Occasionally participants also provided one or more references related to a theme. With this in mind, calculation of references does not reflect participant type. In all tables, themes were organized in descending rank-order from highest to lowest number of participants per theme. It is important to note that, in most cases, married female participants provided the greatest number of theme-related references given their significantly higher proportion within the study sample. In this regard, it was difficult to make any valid finding regarding patterns generalized to a specific participant type; however, where observed, some findings emerged relative to family characteristics and gender. Tables are included in the appendix section at the end of this dissertation.

**Research question 2**

*What is the effect on typical adult siblings’ well-being after assuming the caregiving role following the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care?*

The concept of overall well-being (i.e., quality of life) is operationalized according to three domains: objective indicators (i.e., objective assessment of physical, emotional, social and material well-being, and development and activity), subjective indicators (i.e., how participants perceive their happiness according to life satisfaction and positive/negative affect with respect to physical, emotional, social and material well-being, and development and activity), and personal values and aspirations (perceived importance of physical, emotional, social and material well-being, and development and activity) (Felce & Perry, 1995; Sirgy, 2012). Each domain is organized according to five sub-domains: I) physical well-being, II) emotional well-being, III) social wellbeing, IV) material well-being, and V) development and activity (Felce & Perry,
In this section, each sub-domain is presented with its relative categories and subcategories. Categories and sub-categories represent items considered objective indicators (e.g., types of activities for the subcategory of activities-events within the category of community within social well-being) attained from participants’ narratives. Themes were developed through the assessment of objective and subjective indicators as interpreted by the researcher from participants’ stories. In this section, the relative categories and subcategories are presented, including their associated themes, number of references related to each theme, and associated participant type. Supporting references extracted from participants’ narrations are shown in italics.

**Physical well-being.** Physical well-being (see Table 4.15) is a component of health well-being that comprises four subdomains: A. fitness (i.e., physical exercise), B. health (i.e., physical health), C. mobility, and D. personal safety (Felce & Perry, 1995; Sirgy, 2012). Physical well-being considered the individual’s physical functional status where objective indicators of well-being (e.g., types of physical exercise; overall health status; motor functioning; and, safety from accidents, illness, and injury) were positively related to subjective well-being (i.e., perceived happiness) (Sirgy, 2012). No references or themes were described for mobility and personal safety.

**Table 4.15.** Physical Well-Being.

<table>
<thead>
<tr>
<th>Categories and Sub-Categories</th>
<th>Themes</th>
<th>Participant Type Providing References</th>
<th>Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Fitness (Physical Exercise)</td>
<td>Using physical activity, such as walking outdoors, running/using treadmill, yoga, meditation/mindfulness and general exercise/going to gym, to find solitude</td>
<td>MFC MM</td>
<td>12</td>
</tr>
<tr>
<td>B. Health (Physical) Positive</td>
<td>Ensuring proper sleep and preparing healthy meals to support physical health</td>
<td>FMC MM SF MM SM</td>
<td>5 6</td>
</tr>
<tr>
<td>B. Health (Physical) Negative</td>
<td>Feeling physically exhausted due to role responsibilities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Themes: 3 References: 23
**Fitness.** One positive theme and 12 references emerged for fitness. Participants discussed different types of physical exercise as a means of having time to themselves (i.e., “along time”), keeping themselves active to manage the exhaustion related to caregiving, and engaging in fitness to counter the mental challenges related to their role. One positive theme emerged for this category.

*Positive*

*Theme: Using physical activity, such as walking outdoors, running/using treadmill, yoga, meditation/mindfulness and general exercise going to gym, to find solitude.* Participants (MFC; MM) described how the burden of caregiving left little time alone, and the need to engage in physical activity to cope with the mental challenges of their role.

**Health (Physical).** Health considers one’s assessment of personal health factors and their effect on subjective well-being. One positive theme (5 references) and 1 negative theme (6 references) emerged for this category.

*Positive*

*Theme 1: Ensuring proper sleep and preparing healthy meals to support physical health.* Only two items emerged (i.e., ensuring proper sleep and preparing healthy meals) for how participants (MFC; MM) described efforts to maintain personal health. Two participants (MFC; MM) described the need for proper sleep. Another participant (MFC) with two siblings with DD reflected on her mother’s poor healthy food habits and the poor physical health of her siblings prior to becoming their caregiver. She described the importance of nutrition, and her success in shifting her siblings (mostly her brother) to a healthy lifestyle.

*There was an adjustment period for my brother and sister because my mom was so much more passive. They were both in very poor health, extremely*
overweight, with high cholesterol, high blood sugar, and high blood pressure. I’m a total health nut, so we really did a revamp of everything they were eating. That was an adjustment period, especially for my brother because he compulsively eats. We had to kind of figure out, how does this get regulated? So, we did little things like putting a lock on the fridge. He really had to get used to the fact that there are rules set in place. If those rules aren’t followed there are consequences which he wasn’t used to.

Negative

Theme 1: Feeling physically exhausted due to role responsibilities. Participants (SF; MM; SM) with no children described their exhaustion with having sole responsibility for their siblings. The married male participant explained having support from his then-spouse. Both male participants described having siblings with significant physical impairments that presented great challenges (physically and financially). The single female participant discussed the challenges of not feeling supported in her role. This discussion contained a patriarchal undertone related to the female gendered principle of caregiving.

I worked a lot of hours caring for my family member. It takes from you physically. It takes from you emotionally. It takes from you mentally. It’s hard. It takes a lot of fortitude. If you don’t love, you won’t continue to do it. I tell my brother all the time, ‘You better be glad I love you.’ Boy, he’s stubborn, and that has nothing to do with his ability.
<table>
<thead>
<tr>
<th>Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Faith-Belief</td>
<td>Positive Feeling joy and serenity by identifying with and/or engaging in a formal or self-ascribed spiritual belief</td>
<td>MFC, DFC, SF</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Negative</td>
<td>MFC, DFC, SF, MM, SM</td>
<td>8</td>
</tr>
<tr>
<td>B. Fulfillment</td>
<td>Positive Using social and physical activities to feel mentally fulfilled, such as spending time with friends and/or practicing mindfulness, yoga, taking walks, running, attending events (e.g., opera), and going to gym</td>
<td>MFC, SF, MM, SM</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Negative Low mental fulfillment due to exhaustion, role captivity, and difficulty managing responsibilities</td>
<td>MFC, SF, MM, SM</td>
<td>8</td>
</tr>
<tr>
<td>C. Positive Affect</td>
<td>Positive Using tools to manage anxiety and stress by engaging in activities such as opera, massage, running, general exercise, yoga, and taking walks; creating ‘alone time’, and spousal counseling</td>
<td>MFC, SF, MM, SM</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Negative Feeling anxiety, stress and depression due to caregiver responsibilities, combination of job stress and caregiver role responsibilities, discord with atypical sibling due to caregiving, and grieving for parents while maintaining caregiver role</td>
<td>MFC, DFC, SF</td>
<td>6</td>
</tr>
<tr>
<td>D. Self-Esteem</td>
<td>Positive Achieving satisfactory sense of self through supports such as counseling</td>
<td>MFC</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Negative Described unsatisfactory sense of self due to loss of independence, self-reported depression, unsatisfactory support from friends/extended family, and isolation</td>
<td>MFC, DFC, SF, MM, SM</td>
<td>10</td>
</tr>
<tr>
<td>E. Status-Respect</td>
<td>Positive Feeling honor and respect from spouse and/or children</td>
<td>MFC, DFC, MM</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Negative Feeling disrespected from atypical sibling and/or extended family</td>
<td>MFC, SF</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total: 9</td>
<td>References: 50</td>
</tr>
</tbody>
</table>
**Emotional Well-being.** Emotional well-being (see Table 4.16) considered feelings of affection, joy and serenity relative to five categories: A. faith-belief, B. fulfillment, C. positive affect, D. self-esteem, and E. status-respect (Felce & Perry, 1995; Sirgy, 2012).

**Faith-belief.** Feeling a spiritual belief and connection was associated with subjective well-being and one’s ability to cope with difficult life issues (Sirgy, 2012). One positive theme and 8 references were cited for this category.

*Theme: Feeling joy and serenity by identifying with and/or engaging in a formal or self-ascribed spiritual belief.* Most female participants (MFC; DFC; SF) described the importance of faith. Though most participants identified as Christian, some explained they did not follow an organized religion reflecting satisfactory emotional well-being through a self-ascribed sense of spirituality. This sentiment reflected one participant (MFC), formerly Catholic, identified as Quaker.

*I'm an attending Quaker. I have a whole ceremony, baptism or whatever. I go to this Sunday meeting and I sit and meditate with other Quakers at a Quaker meeting house. That helps in having a support committee. But I married a Jew who is not religiously Jewish. For a long time, my husband and I just started just figuring stuff out for ourselves. If we did anything that was ritualistic, it was usually something Pagan, like a solstice or whatever.*

**Fulfillment.** Fulfillment looked at engaging in opportunities leading to a perceived meaningful experience (Sirgy, 2012). One positive theme (8 references) and 1 negative theme (6 references) were cited for fulfillment.
Positive

Theme: Using social and physical activities to feel mentally fulfilled, such as spending time with friends and/or practicing mindfulness, yoga, taking walks, running, attending events (e.g., opera), and going to gym. Activities, such as socializing and engaging in physical activities, were means of mental fulfillment described by participants (MFC; SF; MM; SM) to offset the emotional challenges of caregiving. Both male participants described the need to participate in activities as a distraction from the mental drain experienced during the period of co-residence with their siblings with DD.

Negative

Theme: Low mental fulfillment due to exhaustion, role captivity, and difficulty managing responsibilities. All participants (MFC; SF; DFC: MM; SM) described some mental challenge related to caregiving resulting in reduced feelings of emotional fulfillment. Much discussion across participants described feeling captive to the caregiving role. The married male participant discussed his experience.

The difficulties of caregiving are that you’re always a caregiver. So, the buck stops with me. And, if there’s an emergency or something, I am the one. If we want to go on vacation, it’s constantly in the back of our heads. It is limiting to be a caregiver; it means I’m not living my life 100% for myself.

Positive Affect. Affect is associated with subjective well-being (i.e., relative happiness) (Bradburn, 1969; Chamberlain, 1988; Kim & Mueller, 2001; Sirgy, 2012). Positive affect considered joy, pleasure, and contentment, and negative affect included anger, depression and
anxiety (Sirgy, 2012). One positive theme (5 references) and 1 negative theme (6 references) were cited that related to positive affect.

Positive

Theme: Using tools to manage anxiety and stress by engaging in activities such as opera, massage, running, general exercise, yoga, and taking walks, creating solitude, and spousal counseling. Most participants (MFC; SF; MM; SM) described engaging in activities to achieve a positive affect. Although exercise and counseling were cited the most, one participant (MFC) discussed the benefits of solitude.

I think the number one thing is understanding how important boundaries and peaceful discipline are in adults or children with special needs. Also—moms do this all the time—but as any kind of caregiver, it’s figuring out a way that you can distress, or have alone time.

Negative

Theme: Feeling anxiety, stress and depression due to caregiver responsibilities, combination of job stress and caregiver role responsibilities, and discord with atypical sibling due to caregiving. References from participants (MFC; DFC; SF) mostly focused on the challenges of caregiving and their implied association with anxiety, stress and depression. One participant described her stress as follows, “There’s a responsibility I feel at times that almost makes me crazy.” This idea implies a feeling of captivity associated with the caregiving role.

Self-Esteem. Self-esteem looked at one’s self-worth and was directly related to overall happiness (Sirgy, 2012). One positive theme (4 references) and 1 negative theme (11 references) developed for self-esteem.
Positive

Theme: Satisfactory sense of self through supports such as counseling. Few participants (MFC) provided stories that referenced a positive component for this category. One participant described counseling and its contribution to positive self-esteem.

One thing we requested that was available when we did take over was counseling. We found wonderful counselors through the County. She comes twice a month. It’s actually not really for my sister but to help us as a family.

Negative

Theme: Unsatisfactory sense of self due to loss of independence, self-reported depression, unsatisfactory support from friends/extended family, and isolation.

All participants implied feeling low self-worth at some point within their caregiving experience due in large part to the challenges of the role. One participant (MFC) described feeling isolated as a caregiver and inferred these sentiments were a result of low support.

I think caregiving is an old world thing. You take in family when they can’t take care of themselves. People in undeveloped countries still do it. But middle class white people, I don’t know. Maybe I’ve got to meet these people. It’s going on almost four or five years and there’s this isolation. People don’t really know, even the people who are in my life. My sister is now finally realizing it. She took in my brother for three days over Christmas. She’d never done it before.
She’s said, “Oh my god. I had no idea it was 24-7.”

Status-Respect. One positive theme (8 references) and 1 negative theme (2 references) emerged for how participants regarded their status (i.e., self-value) and perceived respect.
Positive

Theme: Feelings of honor and respect from spouse and/or children. Almost all participants with a spouse and/or children provided references indicating a respect from family members for their contribution to caregiving. Though one participant (MFC) described positive support from her children, she also implied emotional guilt for not being there to support her children who were grieving the loss of their grandparent and having to remain focused on helping her sibling with DD transition.

My kids are okay with it. They pretty much grew up knowing my sister and knowing that she was going to come live with us someday. But now, they actually see that I’m a lot more relaxed—not that they don’t miss their grandparents. We all do. But, there’s a lot of suffering that they went through. They appreciate what we’re doing. They’re also kind of protective of me. They say, “You know mom? You’re not going to do this forever.” They want to make sure of that.

Negative

Theme: Feeling disrespected from atypical sibling and extended family. Two participants (MFC; SF) described the challenges managing their atypical sibling, and the little support, respect and understanding for their caregiving efforts. One participant (SF) described her challenges trying to solicit support from her father who appeared to have ignored her desire to be recognized for her efforts.

My father treats me like a child. I want to be independent but I feel like he treats me like a kid. My younger brother also leaves the house without letting me know and then acts like it’s wrong that I say something about it. I told him he’s allowed to hang out with his friends but he has to be back at a certain time and let
me know where he’s going. When I talk to my brother about things, I talk to him as an adult man and explain that kids sneak out of the house.

**Social well-being.** Social well-being (see Table 4.17) considered the degree to which individuals were satisfied or happy with their social life, satisfaction with and attachment to the community (social capital), as well as the number and quality of friends and family they can depend on (Auh & Cook, 2009; Coleman, 1988; Hahn, Cella, Bode, & Hanrahan, 2010; Keyes, 1998; Larson, 1993).

Social well-being was organized according to two categories: A. community involvement (i.e., how caregivers connected with their community), and B. interpersonal relationships (i.e., how caregivers connected with other persons) (Sirgy, 2012). Nine themes and 92 references were identified for this domain.

<table>
<thead>
<tr>
<th>Categories and Sub-Categories</th>
<th>Themes</th>
<th>Participant Type Providing References</th>
<th>Number of References Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Community Involvement</td>
<td></td>
<td>MFC</td>
<td>16</td>
</tr>
<tr>
<td>Acceptance-Support</td>
<td>Feeling attached to the community through service supports, including family counseling, waiver services/government supports, social security, disability insurance, Medicaid, respite care, and formal caregiving</td>
<td>DFC</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative</td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Past memories of feeling unsupported by the community because of challenges receiving/attaining service supports due to unacceptable waiting lists to attain services, confusion navigating system, state of system, not providing enough services, and poor evaluation of atypical sibling’s needs</td>
<td>MFC</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Lingering memories of having felt unaccepted from the community due to former stigma towards families with a disabled member</td>
<td>DFC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>MM</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SM</td>
<td></td>
</tr>
</tbody>
</table>
### Table 4.17. Continued.

<table>
<thead>
<tr>
<th>Activities-Events</th>
<th>Community attachment through types of activities and events, including charity/volunteering (mother &amp; daughter volunteering for local charity, atypical siblings volunteering at local library), organized activities (atypical sibling participating in Special Olympics, Karate, and formal civic partners [visits to understand law enforcement, and fire department])</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MFC</td>
</tr>
</tbody>
</table>

#### B. Interpersonal Relationships

**Family-Household Life**

| Positive          | Caregiver emotionally connected with family and extended family members, including: caregiver and spouse/children/atypical sibling/extended family; children and atypical sibling; spouse and atypical sibling; and, family as a whole |
|-------------------| MFC | DFC | MM | SM | 20 |

| Negative          | Caregiver feeling abandoned and unsupported by extended family |
|-------------------| MFC | SF | 6 |

| Negative          | Caregiver feeling disconnected from spouse, and stress on spousal relationship due to challenges of caregiving |
|-------------------| MFC | MM | SM | 5 |

**Friends-Social Life**

| Positive          | Caregiver maintaining some existing friendships but establishing new friendships through church, local persons in common, and persons in common through social media |
|-------------------| MFC | DFC | SF | SM | 16 |

| Negative          | Feeling disconnected, abandoned and isolated from friends due to role responsibilities and perception of friends’ discomfort with atypical sibling |
|-------------------| MFC | DF | SF | MM | SM | 10 |

**Themes:** 9

**References:** 92
Community Involvement. Community involvement was composed of two subcategories: i) acceptance-support, and ii) activities-events.

Acceptance-support. One positive theme (16 references) and 2 negative themes (13 references in total) emerged for acceptance-support.

Positive

Theme: Feeling attached to the community through service support, including family counseling, waiver services/government supports, social security, disability insurance, Medicaid, respite care, formal caregiving. Participants (MFC; DFC; MM; SM) described different ways of feeling connected to and supported by the community through availability of service supports. Both male participants discussed satisfaction with current services, including the alternative residential services in which their siblings with DD currently resided. One participant (MFC) described the benefit of having supports through formal caregiving. Despite its positive aspects, this participant pays out of pocket for the service and also reflected on the social and political reality that did not fully value caregiving.

I have somebody here, he’s a little Tibetan guy who barely knows English. But he’s completely competent and very kind. I paid him $16 an hour because I want him to have a good job. And 16 times 12 equals about $200 a week. So, for somebody from Katmandu who doesn’t speak good English, he’s glad to have it. Ironically, I get paid the least even though I do it most.

Negative

Theme 1: Past memories of feeling unsupported by the community because of challenges receiving/attaining service support due to long waiting lists to attain services, complex navigating system, not providing enough services, and poor evaluation of atypical sibling’s
needs. Eight references from participants (MFC; DF; MM; SM) expressed how they felt disconnected from their community due to difficulties attaining resources. These references highlighted the limited availability and difficulty attaining resources from the community. Both male participants described their prior difficulties, echoing currently co-residing participants, about not knowing where to source or navigate for services post-transition. Though participants’ narratives differed regarding individual challenges receiving services, the stories share an implicit theme that the larger community did not understand or recognize the needs of caregivers of persons with DD.

\textit{Theme 2: Lingering memories of having felt unaccepted from the community due to former stigma towards families with a disabled member.} Seven references cited memories of stigma for having an atypical family member. Participants (MFC; DFC; SF; MM; SM) discussed childhood memories of health professionals telling their parents the family would be better off institutionalizing their child with DD. Though the current emphasis for persons with DD is community inclusion, participants’ stories demonstrate a lingering memory of this former negative trend. One participant (DFC) described being told about her parent’s experience.

\textit{With the state hospital system, and especially here in Minnesota, somebody told me that when my brother was young, people would say to my parents, “You don’t need to concern yourself with your son. The state can take care of him. You have a life to live. Just put him at the hospital and don’t worry about him.” I don’t recall anyone ever saying that to my parents, but I’m sure someone probably did. I was pretty young. You wonder how many people were told that you don’t need to worry about being a parent.}
**Activities-events.** One theme (6 references) emerged for this category.

*Theme: Community attachment through types of activities and events, including charity/volunteering (mother & daughter volunteering for local charity, atypical siblings volunteering at local library), organized activities (atypical sibling participating in Special Olympics, Karate, and formal civic partners [visits to understand law enforcement, and fire department]).* Six references provided positive aspects for how participants (MFC; DFC; SF) used activities and events to feel attached to their communities. One participant (MFC) described attending events and engaging in activities with her children to ensure they received the same level of attention as she gave to her sibling with DD. Two participants (MFC; SF) engaged their siblings with DD in volunteer activities as a means of keeping their siblings active. However, while most participants’ parents did not seek formal services for their siblings with DD, these two participants came from a patriarchal culture that opposed receiving government services. Two participants (DFC; SF) discussed engaging their brothers with DD in activities such as the Special Olympics and Karate. Both participants lived alone with their atypical siblings likely indicating more opportunity to focus on organizing activities. One participant (DFC) described how having her brother participate in an activity exposed a skill in which she was unaware.

*Sometimes, you see the little things and you feel so accomplished. One time, my work had a bowling fundraiser. I brought my children and my brother. We found out that my brother loves to bowl. I never knew he knew how to bowl. So, there’s a really active Special Olympics bowling group where I live. I got him involved, and he’s been doing that for the last two years. It’s been wonderful for him, just seeing what he’s learned and all the changes. I’ve really learned to take those joys and think “Yeah, we did this.”*
**Interpersonal Relationships.** Interpersonal relationships looked at how persons are connected to other persons (Sirgy, 2012), including family members and friends. This category was composed of two subcategories: i) Family-Household Life, and ii) Friends-Social Life.

*Family-Household Life*

One positive theme (20 references) and 2 negative themes (11 references) appeared for family-household life.

**Positive**

*Theme: Caregiver emotionally connected to family and extended family members.*

Twenty references were identified for this theme. The majority of participants (MFC; DFC; MM) described an emotional connection between themselves and their spouse, their children, their atypical sibling, or the family as a whole. Two participants (MFC) described supports through extended family members (i.e., local aunt). These findings imply a satisfaction among most participants with household life.

**Negative**

*Theme 1: Caregiver feeling abandoned and unsupported by extended family.* Six references from participants (MFC; SF) described feeling abandoned and unsupported by extended family resulting in dissatisfaction with household life and the caregiving role. Two participants (MFC) described how their sisters ‘disappeared’ to avoid having to help with caregiving. Another participant (SF) discussed her frustration due to little support from her father for caregiving, resulting in her atypical sibling shrugging his responsibilities and ignoring household rules.

*My father always felt guilty for my brother having his disability. When my mother passed away, my father was so wrapped up in his grief he let my brother...*
have everything he wanted, coming in at 3 in the morning with nobody asking anything. When I got here, I had to put on restraints. But my father treats me like a child. I am trying to be a caregiver, but I feel like he treats me like a kid.

Because I don’t have his backing, my brother leaves the house without letting me know anything. I’ve tried to use these moments to teach my brother to be a man. I let him know that a man doesn’t sneak out of the house. You don’t get to pick and choose when you want to be a kid and then be treated like an adult.

**Theme 2:** Feeling disconnected from spouse, and stress on spousal relationship due to the challenges of caregiving. Five references from participants (MFC; MM; SM) emerged for this theme describing the potential burden of caregiving on the spousal relationship. One participant (MM) described the emotional and financial stress on his relationship due to co-residence and caregiving. Later in this participant’s story, he discusses his relief and greater independence for his atypical brother after his brother transitioned to supported living. However, this reference describes the challenges of caregiving many participants experienced.

*It’s very stressful. My wife and I weren’t married at the time but we had reached a point in our relationship where we were living together. We had just bought a house because you know Maryland was paying people to buy a house. So that sounded like a good financial decision and we knew we were heading down that path. But we also knew when my mother was terminally ill that my brother was coming sooner than later. So, we bought a house with this in mind but we’d also kind of established a lifestyle together already. When my brother came, we had to put everything on hold since he was not receiving any services and he required supervision 24-7. That meant we were paying out money for*
people to watch him just so we could go to work. Then, every evening and every weekend, we were his caregivers. It was basically just a huge pause button on our lives.

Friends-Social Life

One positive theme (16 references) and 1 negative theme were found for friends-social life.

Positive

Theme: Caregiver maintaining some existing friendships but establishing new friendships through church, local persons in common, and persons in common through social media. A number of participants (MFC; DFC; SF; SM) described maintaining close ties with good friends. Some participants told stories of finding new friendships with persons in common (e.g., other siblings with a brother or sister with DD), as well as describing the church as a means of social connection. Some participants discussed engaging in social media as a vehicle for new friendships with persons sharing a similar experience. One participant (MFC) summed up her overall experience maintaining old friends, establishing new ones, and the status of her social life.

Most of my friendships are online. But, I also have some siblings I’ve gotten to know locally in my sister’s ADT—the group my mother helped co-found. There’s also a group of long time families that have always gotten together. Those are the people I am friends with. A lot of my other friends—I maybe have three that I can count on my fingers—have stood by throughout because things go by
the wayside when you are caring for elderly parents in the hospital, a sister with a
disability, and working six days a week...Social life—it’s weird. Social life is I go
to a party for my sister and hangout with other siblings. That seems to happen a
lot.

Negative

Theme: Feeling disconnected, abandoned and isolated from friends due to role
responsibilities and perception of friends’ discomfort with atypical sibling. Half of the
participants (MFC; DFC; SF; MM; SM) described a feeling of isolation that they attributed to
feeling abandoned by existing friends due to caregiving. Both male participants described an
awkwardness from some friends because of a perceived discomfort of their siblings with DD.
One participant (MFC) discussed the difficulty maintaining friendships due to behavioral
chalenges related to her sibling with DD.

Okay, so my social life has gone basically to zero. That has been the
biggest casualty. I used to be the lady who lunches. I don’t do that anymore. We
used to have a dinner party at least once a month. I’d have a dinner party with
groups of people. My sister is more stable now but we wouldn’t do dinners
anymore because we never know what her reaction is going to be. I had friends in
town I went to high school with. They came over one night and had dinner with
us. One friend, my sister remembered him. But it was not a good night. My sister
ended up going off to bed and would not go to sleep. My friend, he was sitting and
talking to my husband. My sister was having an outburst and throwing things. I
came down and said, “I hate to ask you to leave but you're going to have to because it’s 10:30.”

**Material well-being.** Material well-being (see Table 4.18) considered stability and security according to five categories (i.e., objective indicators of material well-being): i) Finance-Income, ii) Housing Quality, iii) Meals-Food, iv) Transport, v) Possessions, and vi) Privacy (Felce & Perry, 1995; Sirgy, 2012).

**Finance-income.** One positive theme (6 references) and 1 negative theme (8 references) were cited for finance-income.

**Stability-Security**

**Positive**

### Table 4.18. Material Well-Being.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A: Finance-Income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stability-Security</td>
<td>Positive Financial stability/security due to increased work hours, strong family resources, and satisfactory government financial supports</td>
<td>MFC, DFC, SM</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Negative Financial instability/insecurity due to reduced work hours due to unsatisfactory government service supports for atypical sibling forcing caregiver to reduce work hours, shame receiving government financial supports for atypical sibling, and limited family financial resources</td>
<td>MFC, SF, MM</td>
<td>8</td>
</tr>
<tr>
<td><strong>B: Housing Quality</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stability-Security</td>
<td>Negative Fear of meeting household expenses due to caregiving, and having limited resources from extended family to cover expenses</td>
<td>MFC, SF, MM</td>
<td>3</td>
</tr>
<tr>
<td>C: Meals-Food</td>
<td>Stability-Security</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Positive</strong></td>
<td>Material security through healthy preparing healthy meals</td>
<td>MFC</td>
<td>5</td>
</tr>
<tr>
<td><strong>Negative</strong></td>
<td>Exhaustion of caregiving duties resulted in poor meal preparation</td>
<td>SM</td>
<td>1</td>
</tr>
<tr>
<td>D: Privacy</td>
<td>Reconfiguring physical house to achieve greater privacy for caregiver and spouse, and atypical sibling</td>
<td>MFC</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td></td>
<td>23</td>
</tr>
</tbody>
</table>

**Theme:** Financial stability/security due to increased work hours, strong family resources, and satisfactory government financial supports. Participants (MFC; DFC; SM) described financial security resulting from increased work hours, unearned family resources, and satisfactory government supports. One participant (SM) discussed the strong financial resources he and his family created over the long term to ensure a financial safety net for himself and his sister.

*I’ve had some successful investments, and I’ve been a lawyer since 1974.*

*I’ve known for a lifetime that I would eventually be called upon to be my sister’s caregiver. I’ve had four grandparents and two parents who have also know this.*

*They set aside money, and so money wasn’t really a problem.*

**Negative**

**Theme:** Financial instability/insecurity due to reduced work hours due to unsatisfactory government service supports for atypical sibling forcing caregiver to reduce work hours, shame receiving government financial supports for atypical sibling, and limited family financial resources. Participants (MFC; SF; MM) discussed frustration and disappointment with government service supports resulting in caregiver’s inability to work full-time, financial
instability due to caregiving taking a priority over working, and poor family resources to provide for long term supports. One participant (MFC) echoed a familial culture that looked dishonorably on government funding. This sentiment reflected her parents’ resentment to society for its negative view towards having a disabled family member. This participant did not enroll her sibling with DD in government programs and worked a second job to meet financial demands.

*I remember my dad coming home and being upset because the county social worker had come to his workplace to get him to sign up for welfare because he had eight kids. He said I didn’t have eight kids so that somebody else could pay for them. We chose to have eight kids, we will take care of them ourselves. He was very offended and my mom was as well. When my sister was growing up she could have received SSI because of her disability. But my parents didn’t take any money until she turned 18. I suppose it’s instilled in me and my siblings that you take care of your own and your siblings. And you don’t ask for handouts if you don’t need to. So, I don’t.*

**Housing quality.** One negative theme (3 references) emerged for this category.

**Stability-Security**

**Negative**

**Theme: Fear of meeting household expenses due to caregiving and having limited resources from extended family to cover expenses.** Participants (MFC; SF; MM) discussed unique challenges related to meeting household expenses affecting material well-being. One participant (MM) described the challenges he faced prior to transitioning his brother to supported living.
The co-residency was for a lack of a better word, toxic. It is ultimately a toxic situation that I wouldn’t necessarily wish on anybody because it robs both sides of their independence. I hardly think that somebody in their right mind would actually agree to this. And even when they do, the waiting lists are so long. You hear these horror stories of people losing their houses while being on the waiting list because they are in similar situations where they have to pay money just so they can go to work. I was in that situation, and we were not going to make it a fourth year. There was no way. We would have been out of money, foreclosed upon, and my brother would have been homeless. Then, he would have been put into services while we would have been left in a smoking crater. So, to me, it was already a life or death situation from day one.

Meals-food. One positive theme (5 references) and 1 negative theme (1 reference) emerged for meals-food.

Stability-Security

Positive

Theme: Material security through healthy preparing healthy meals. Some participants (MFC; MM) described placing an emphasis on preparing healthy meals. One participant (MFC) reported how this effort resulted in a much healthier lifestyle for her brother with DD than when the brother lived with their mother.

Negative

Theme: Exhaustion of caregiving duties resulted in poor meal preparation. One negative theme emerged where a participant (SM) discussed his exhaustion providing care to his sister prior to her transition to a group home. This participant explained his sister’s exhaustion after
coming home from a day program, falling asleep, and waking at a late hour wanting food. This disruption resulted in the participant giving whatever easily prepared junk food was available.

**Privacy.**

**Theme: Reconfiguring physical house to achieve greater privacy for caregiver and spouse, and atypical sibling.** One participant (MFC) discussed building an addition onto her home, called the “apartment,” for her sister with DD. This participant explained how the additional space positively contributed to privacy within the household, as well as greater independence the self-growth/development of her atypical sibling.

**Development and activity.** Development and activity (see Table 4.19) considered that developing and mastering a skill can increase one’s self-determination (through increased competency, autonomy, and relatedness [intrinsic motivation]) to engage in and successfully complete an activity/task (Deci & Ryan, 1985; Ryan & Deci, 2000; Sirgy, 2012). In this regard, increased self-determination is positively related to increased happiness and positive subjective well-being (Sirgy, 2012). Learned skills can cross life domains (i.e., horizontal spillover); for example, skills learned through education can transfer to skills needed to manage at work (Staines, 1980). Likewise, social skills learned within the family can transfer to understanding how to engage with employees at work. In turn, low competency and inadequate mastery of a skill reduces one’s self-determination and motivation to manage a caregiving activity, resulting in low life satisfaction and negative social well-being.

Development and Activity was divided into five categories: a) Self-determination, b) Education, c), Homelife-Housework, d) Jobs, and e) Leisure-Hobbies. Education, homelife-housework, jobs, and leisure-hobbies were viewed according to the positive or negative production and/or contribution made to these activities (Staw & Barsade, 1993).
**Self-determination.** One positive theme and 10 references, and 1 negative theme and 7 references were cited for self-determination.

**Positive**

**Theme:** Increased self-determination through supports, such as sharing responsibilities with spouse and children, receiving government services, and achieving greater reciprocity (independence) of supports from atypical sibling) that facilitate development and competence over caregiving skills and increased motivation for successfully achieving caregiving tasks. All participants (MFC; DFC; SF; MM; SM) described how having supports facilitated a greater opportunity for developing the skills to successfully complete and master caregiving tasks. Both male participants described greater self-determination following the transition of their siblings with DD to alternative residence. Though these participants described an ease in burden of responsibility from their prior duties, they also explained how their atypical siblings experienced greater independence after transitioning to alternative residence. The single male participant discussed the challenges of co-residence and how things improved after his sister moved to a group home.

<table>
<thead>
<tr>
<th>Categories and Sub-Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Self-Determination Positive</td>
<td>Increased self-determination through supports, such as sharing responsibilities with spouse and children, receiving government services, and achieving greater reciprocity (independence) of supports from atypical sibling) that facilitate development and competence over caregiving skills and increased motivation for successfully achieving caregiving tasks</td>
<td>MFC</td>
<td>10</td>
</tr>
</tbody>
</table>

153
Table 4.12. Continued.

| Negative | Having few supports (i.e., from extended family and through government services) resulting in lower self-determination and difficulties developing competence and mastery over skills to complete caregiving activities | MFC | 7 |
| B. Education | | DFC | |
| Productivity- Contribution | | SF | |
| Positive | Caregiver attending or planning to attend higher education | MFC | 1 |
| Negative | Caregiver unable to engage in higher education due to caregiving responsibilities | SF | 1 |
| C. Homelife- Housework | | MM | |
| Productivity- Contribution | | | |
| Positive | Homelife satisfaction due to engagement in housework activities (e.g., organizing family responsibilities, including atypical sibling’s ADLs, meals, appointments, and transportation) by caregiver and other shared supports such as caregiver and spouse, children and atypical sibling | MFC | 19 |
| Negative | Dissatisfaction with homelife due to poor supports from spouse and atypical sibling for completing housework activities | MFC | 6 |
| D. Jobs | | DFC | |
| Productivity- Contribution | | MM | |
| Positive | High job productivity/contribution due to workplace supports and gratitude for having job | MFC | 8 |
| Negative | Reducing work hours or not working to fulfill demands of caregiving | MFC | 2 |
| Taking on second job due to limited funding for sister and needed additional household income | SF | |
| E. Leisure- Hobbies | | MFC | |
| Productivity- Contribution | | DFC | |
| Positive | Contribution to leisure activities and hobbies, including exercise, vacation, engaging in local entertainment, socializing with friends/extended family, spending time with spouse, spending time with atypical sibling, getting a massage, attending church, volunteering, participating in Special Olympics, reading, and arts and crafts | MFC | 12 |
When she was going to the day program—and I’m just giving you this as a
typical example of what goes wrong when you have one person responsible for
caregiving—my sister would come back. She would be crabby, totally exhausted,
and wanted a big bowl of popcorn. So, I’d give her a big bowl of popcorn,
sandwich, and some kind of junk food. She would be dead tired, and go take a
nap. She might wake up at 10:00 at night and be unable to sleep. That was a
problem for me, and I was exhausted all the time. Now, she’s in the group home
and has a routine. And I have my life.

Negative

Theme: Having few supports (i.e., from extended family and through government
services) resulting in lower self-determination and difficulties developing competence and
mastery over skills to successfully complete caregiving activities. Participants discussed
challenges that resulted in difficulties completing caregiving tasks. While only 1 reference came
from a female participant with children, the remaining references came from participants with no
children indicating participants with no familial supports had greater difficulties managing
activities, and lower self-esteem. The married male participant provided the following narrative
that looked at how caregiving placed an unhealthy demand on himself and his then-fiancée.

It was an interesting situation when my brother moved in because he
wasn’t getting services and we were paying for everything out of a savings
account that had almost reached the bottom. So, we were basically paying out of pocket for caregivers for us to go to work. And, we didn’t necessarily always want to pay caregivers to go on a date. So, for a large part we ended up having like these micro dates that would happen really after work, like you go you get a drink and that’s it. It was very stifling to the relationship and we didn’t have much time for ourselves. That was part of the motivation to get him through this waiting list as quickly as possible. I think we probably wouldn’t have survived a full nine year wait to be honest. I was actually surprised we lasted the three year wait. It always felt out of control.

**Education.** Few references were made for education. One positive theme (1 reference) and 1 negative theme (1 reference) described the development of education as an activity.

*Productivity- Contribution*

**Positive**

*Theme: Attending higher education to build career.* One participant (MFC) discussed attending and completing graduate school as a contribution to building her career.

**Negative**

*Theme: Caregiver unable to engage in higher education due to caregiving responsibilities.* One participant (SF) discussed her disappointment and frustration for being unable to attend higher education due to caregiving duties and not receiving the needed support from her father to facilitate her education goals.

**Homelife-housework.** Homelife-housework considered the productivity and contribution to housework activities and its effect on homelife. Factors associated with homelife include: housing conditions, housing space and quality, landscape, daylight throughout home,
and housing amenities (Auh & Cook, 2009; Davis & Fine-Davis, 1991; Wiedemann & Anderson, 1985). This category contained 1 positive theme (19 references) and 1 negative theme (6 references).

Productivity-Contribution

Positive

Theme: Attending to housework activities (e.g., organizing family responsibilities, including atypical sibling's ADLs, meals, appointments, and transportation) by caregiver and other shared supports such as caregiver and spouse, children, and atypical sibling to develop a satisfactory homelife. Participants (MFC; DFC; MM) described feeling some level of satisfaction with homelife due to shared supports in housework activities with spouse, children or atypical sibling. One participant (MFC) discussed the positive development in her brother with DD by increasing expectations of his contribution to household chores. Her story implies how sibling caregivers often see greater capabilities and require more from their atypical siblings than their parents believed.

Since he moved here, my brother is doing a lot more than he used to do with my mother. He loves laundry. That’s one of a couple of things he likes to do. But it was also a challenge for me. I had to let go of having things the way I like them done, and just accepting. It’s not like he loves to do the dishes. Or he’ll throw laundry in and some of the stuff goes in a little haphazardly. But that was really something I had to learn how to let go of, because at first it was a little bit irritating. I’m used to doing stuff the way I want it done. And, he’ll also do dishes for me, put them away, and load the dish washer. Overall, he likes to keep his
room clean. He's actually better at keeping his stuff organized than my sister is. He hangs up his own clothes. Yeah, he definitely does more now.

Negative

Theme: Dissatisfaction with homelife due to poor supports from spouse, atypical sibling, and extended family for completing housework activities. Two participants (MFC; SF) described receiving little contribution from their spouse, extended family member (i.e., father) and atypical sibling resulting in low productivity towards housework activities and unsatisfactory homelife. One participant (DFC) described a dissatisfaction in self due to her current life status (i.e., her sentiments for being divorced and single living with her brother with DD), and how depression and low contribution from her brother with DD resulted in a poor effort completing housework activities and unsatisfactory homelife.

Sometimes when the depression is overtaking me, I let things go at home. It's easier to just sink into my room and not do any cleaning or things like that. Again, that's something I'm working on. But, sometimes my brother will talk insensitively. It's just what he does; he's always talking. He’ll ask questions and the same question three or four times. I’ve found that I can be in another room and he’s still asking questions even if there's nobody there to answer them.

Sometimes I'll say, “I'm having a bad day. I just need you to stop talking for 5 minutes.” And, he won't stop, but he’ll whisper so I don't hear him.

Jobs. Competence and mastery of one’s job can result in job satisfaction (Sirgy, 2012). Considering the spillover effect, job satisfaction can also result in life satisfaction. Job satisfaction is influenced by one’s productivity, aspects of job, workplace environment, demands
of job, interaction with co-workers, and relationship with manager. One positive theme (8 references) and 2 negative themes (3 references) resulted for this category.

**Productivity- Contribution**

**Positive**

*Theme: High job productivity/contribution due to workplace supports and gratitude for having job.* Most participants (MFC; DFC; MM) described high productivity towards their jobs due to workplace supports from colleagues and managers. One participant (MM) discussed the flexibility he was given to manage his caregiving duties.

*I recognize that I’m lucky. I have an employer and a job that allows me to be very flexible. Over the years, I’ve needed work on occasion to be flexible. There’s usually once or twice still, even though my brother is in an independent living situation, where I just happen to tell my boss, “Hey, I’m leaving because of my brother.” And, I just run out the door.*

**Negative**

*Theme 1: Reduced work hours or not working due to increased demands from caregiving resulting in low job contribution.* One participant (MFC) described having to reduce work hours and another participant (SF) discussed being unable to work, each due to the demands of caregiving. The single female participant framed her inability to work as a requirement of the caregiving role.

*I can’t see it [caregiving] affecting my work but work affected it. I had to scale back some of my hours because my brother was being ignored and that’s not the reason I moved home. My brother is not second to my job. And I also realized*
I was working myself into exhaustion because I was making sure he got everywhere.

Theme 2: Taking on second job due to limited government funding for sister and needed additional household income. One participant (MFC) discussed the pride within her family for opposing formal financial supports for her sister. This notion was the basis for taking on additional work on top of her full-time job to increase household income.

I have taken on additional work outside of my full time job. That is because although my sister gets some social security—I think it’s based on my father’s social security—she gets hers and it doesn’t come close to what it costs someone to live. So, I have my full time job which again is overwhelming at times; I average probably 50 hours a week there. But I took on cleaning on the side. I clean businesses and probably work another 15 hours to 20 hours a week doing that. So, I have very long weeks. But you know, people say just sign up for Medicaid and this and that. I don’t know; maybe someday. But right now, I’m not ready to do that. I don’t want to do that.

Leisure-hobbies. Leisure and recreational activities (i.e., hobbies) have a significant influence on subjective well-being since they are efforts to engage in passive (e.g., watching TV, surfing the Internet, sleeping, and reading) and active activities (e.g., socializing, and exercising) (Lyubomirsky, Tkach & DiMatteo, 2006; Lyubomirsky, 2007). However, persons experience greater happiness when engaging in activities with other persons than when alone (Pavot, Diener, & Fujita, 1990). One positive theme (12 references) and 1 negative theme (8 references) were presented for this category.
Productivity- Contribution

Positive

Theme: Contribution to leisure activities and hobbies, including exercise, vacation, engaging in local entertainment, socializing with friends/extended family, spending time with spouse, spending time with atypical sibling, getting a massage, attending church, volunteering, participating in Special Olympics, reading, and arts and crafts. All participants described some level of engagement in leisure activities and hobbies. Some participants described the joys they experienced engaging their atypical siblings in leisure activities. One participant (DFC) described the success of engaging her brother in Special Olympics and the reward she experienced for this effort.

Sometimes you learn the little things that make you feel so accomplished.

One time my work had a bowling fundraiser. I brought my children and my brother. We found out that my brother loves to bowl. I never knew that he knew how to bowl. My daughter suggested we look into the Special Olympics. There’s an active Special Olympics bowling group where I live. He’s done that for the last two years. It’s been wonderful for him. Just seeing what he’s learned and the changes. I’ve really learned to take those joys and think, “Yeah, we did this.”

Negative

Theme: Low productivity/contribution to leisure activities and hobbies due to role captivity/feeling trapped in role, and isolation from friends. Some participants (MFC; DFC; MM; SM) discussed feeling captive to the caregiving role, and isolation from friends as a reason for not being able to engage in leisure activities and hobbies. One participant (DFC) explained
her success engaging her brother with DD in Special Olympics but ignored her own desires to participate in social activities.

*I think the most challenging thing is not having any spontaneity.*

*Sometimes I feel trapped; I feel like I don't have a social life. I have to plan so far in advance to do something out of work, things like that. It gets planned around whether my son can take care of my brother. Not a lot of people understand that.*

*They know it but they don't understand. So, if I plan something and the plans fall through, they don’t understand how difficult that is.*

**Summary**

**Physical well-being.** Positive physical well-being was described within the context of methods (e.g., preparing healthy meals, getting proper sleep, and engaging in physical exercise/activities) health meals, getting proper sleep) used to manage the exhaustion and physical and mental challenges related to caregiving. Negative physical well-being appeared more prevalent among single participants (SF; SM) with fewer familial supports as well as participants (MM; SM) who described significant physical challenges among their siblings with DD.

**Emotional well-being.** Only female participants provided references describing the positive attributes of faith-belief but reflected on faith as a self-ascribed sense of spirituality in the context of emotional well-being. Fulfillment and positive affect shared similar attributes where positive themes included types of activities (e.g., spending time with friends and/or practicing mindfulness, yoga, taking walks, running, attending events [e.g., opera], and going to the gym) to achieve self-fulfillment and positive affect among participants. These activities were an attempt among participants to balance the negative attributes of low self-fulfillment and
positive affect, including emotional exhaustion, stress and depression related to caregiving. Only female participants (MFC; DFC; SF) provided references that suggested negative feelings related to positive affect. Participants (MFC; DFC; SF; MM; SM) described low feelings of self-esteem and worth at some point within their caregiving experience due to loss of independence, unsatisfactory supports (from extended family and the community [MFC; SF]), and feeling captive to the caregiving role (MFC; DFC; SF; MM; SM), resulting in low emotional well-being. Participants mostly spoke favorably about feeling honored and respected by direct family members (i.e., spouse and/or children) for accepting the role. This finding may indicate that having familial supports can be a key component for achieving satisfactory emotional well-being. One participant implied a sense of emotional guilt for receiving support from her children, but being unable to support them while they grieved for their grandparents, and having to remain focused on supporting her sibling with DD transition into her home.

**Social well-being.** Findings show variability among participants regarding acceptance and support from the community. For the most part, participants (MFC; DFC; MM; SM) with a spouse and/or children indicated satisfaction (i.e., positive subjective well-being) and positive social well-being if they received formal services (e.g., objective indicators including waiver services, social security disability insurance, respite care, and formal caregiving services) resulting in feeling valued and supported by the community. Some participants (MFC; DFC; MM; SM) also discussed prior difficulties post-transition navigating the system to find services. This finding revealed that within the period of, and immediately following, transition participants experienced negative social well-being due to limited resources available to support sibling
caregivers with available services. It may also indicate that parents did not include their caregiving sons and daughters with information to support their atypical siblings.

Two participants (MFC; SF) described a familial culture that opposed taking government services. Other participants (MFC; DFC; SF; MM; SM) still held negative childhood memories of stigma from the community towards their families for having a disabled member. While these individuals recognized improved attitudes towards persons with DD, these lingering memories influenced a perception of not feeling fully accepted by their community for having a disabled family member.

Positive social well-being and high satisfaction with household life was found among participants with a spouse and/or children suggesting that having additional familial supports (i.e., spouse and/or children) can result in increased social well-being. Little satisfaction with household life was observed among participants (MFC; SF) when considering extended family. Two participants (MFC) felt abandoned, undervalued, and isolated when needing respite support from their sisters. Another participant (SF) reported low subjective well-being with household life when describing the little support received from her father for providing care to her atypical sibling.

Participants (MFC; DFC; SF; SM) described feeling satisfied with their social life. But participants (MFC; SF) discussed maintaining friendships with only their closest friends. Other participants (MFC; DFC; SM) discussed creating new friendships with other siblings in common who shared a similar experience. In addition, some described engaging in social media (e.g., Facebook) as a vehicle for social engagement and satisfaction with social life. These sentiments were offset by a number of participants who discussed feeling isolated and abandoned from
friends, due to the duties of caregiving or a perceived feeling of discomfort towards their atypical sibling.

Material well-being. Findings show potential financial instability and lower material well-being among some participants (MFC; SF; MM) due to poor availability of government services and financial supports, resulting in reduced employment to cover caregiving duties. Other potential impediments among participants included opposition to receiving government program supports (demonstrating a former stigma related to receiving government supports) as well as poor resource availability from extended family, indicating a lack of future planning among parents. Some participants (MFC; SF; MM) also described unique challenges to maintaining housing quality that were related to limited financial resources. When referencing meals-food, participants (MFC; MM) described an emphasis on preparing healthy foods; however, one participant (SM) discussed how his exhaustion related to caregiving resulted in unhealthy food choices for his sister with DD. Extending greater privacy post-transition (through a house addition) to her sister with DD was described as an opportunity of independence, growth and personal development for her atypical sibling.

Development and activity. All participants described how having social and/or formal supports provided the opportunity for developing skills, building self-esteem, and achieving a mastery over one’s ability to complete tasks. This finding indicates the ongoing challenges and low self-esteem related to caregiving in isolation, and how supports can ease the burden facing many caregivers. Only two themes (1 positive and 1 negative) emerged from participants (MFC; SF) indicating participation/contribution to and a desire to participate in higher education. Conversely, few other participants described this activity as related to themselves, likely reflecting that this activity was not a priority at this stage in the life cycle. Participants provided
positive references indicating strong contribution to housework activities and satisfactory household through shared supports. In addition, there were more positive than negative references, reflecting strong productivity and contributions among participants (MFC; DFC; MM) to their jobs that they credited to supports from their managers and colleagues. Low contributions to job activities were related to unsatisfactory supports. Though participants described a positive contribution to leisure activities and hobbies, low contribution to this category was related to feeling captive to the caregiving role and isolation from friends.

**Overall well-being.** Findings for overall well-being were mixed. Positive social well-being was reflected as satisfaction with the community among participants who received formal services. Negative social well-being and dissatisfaction with the community was related to participants who described former memories of the challenges trying to navigate for and attain formal services for their atypical siblings, indicating limited service availability. Former memories of stigma from the healthcare profession and perceived discomfort among friends when around their siblings with DD reflected a larger interpretation of how the broader community does not understand (or perhaps, make an effort to understand) the challenges facing families with a disabled member. Participants implied positive social well-being and satisfaction with household life when feeling supported by immediate family members (i.e., spouse and/or children). Participants’ dissatisfaction with household life and negative social well-being was represented as unavailability of supports from extended family members (i.e., living parent, spouse [in one case], and from atypical siblings), resulting in feelings of abandonment, isolation, and being undervalued. Social well-being and satisfactory social life was considered positive among participants who maintained friendships with only their closest friends, as well as those who established new friendships in the community and through social media with persons in
common. Dissatisfaction with social life resulted in negative social well-being for those participants who described feeling abandoned and isolated from friends due to their increased commitment to caregiving, as well as those who perceived a feeling of discomfort from friends towards their siblings with DD.

Positive physical well-being was expressed by participants according to their engaging in physical activities and exercise to counter the negative challenges related to caregiving. When considering faith and belief, findings showed participants demonstrated positive emotional well-being within the context of a self-ascribed belief in a higher being. Increased self-fulfillment and positive affect were achieved through formal and social supports, but these attributes were described as a means of countering feelings of low self-fulfillment and lower affect due to descriptions of emotional exhaustion, stress and depression related to caregiving. All participants expressed negative emotional well-being resulting in low self-esteem at some point within their caregiving experience that was described as loss of independence, unsatisfactory supports from extended family members and the community, and role captivity. Positive emotional well-being considered respect and status through immediate familial supports as important. In contrast, emotional guilt emerged when one participant described receiving her children’s support but being unable to provide support in return due to supporting her sibling with DD through the transition.

Negative material well-being was represented by some participants as financial instability and insecurity resulting from poor availability of government services and financial supports, including reduced employment due to caregiving responsibilities, and lack of needed funds to support housing needs. Most participants reflected positive well-being in income through full employment, as well as satisfactory resources to achieve housing stability. No participant
described lacking financial resources for food. One participant described a familial culture opposed to government financial supports that indicated poor planning for future resources.

A belief in positive social and/or formal service supports was needed to achieve the self-esteem for increasing one’s skills to feel successful with activities, such as education (i.e., in pursuit of higher education), housework (i.e., satisfactory household), job, and leisure activities. Descriptions of feeling unsupported resulted in findings where participants described a desire to engage in education, low household satisfaction due to having to be the only individual contributing to housework, reduced job hours, and feeling captive and isolated, all limiting their ability to engage in leisure/hobbies.

Overall well-being considered the assessment of all subdomains of well-being (i.e., social, physical, emotional, and material well-being, and development and activities). Among overall findings, results showed more positive overall well-being among participants with spouses and/or children and those who received formal supports. Often, participants with no spouses (SF; DFC; and SM) showed negative overall well-being. Both male participants each co-resided with their siblings with DD for three years prior to sourcing alternative residential settings for them. Each attributed this outcome to the high level of physical needs they described as being unable to accommodate. In the case of the married male, he stated that his brother required ongoing caregiving supports in all ADLs and was incapable of providing self-supports. Similarly, the single male participant stated his sister had mobility challenges and used a wheelchair, thus it was apparent she required many supports for all ADLs.

**Research question 3**

*How does the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care affect sibling caregivers' family functioning?*
The family systems framework was the guiding theory for this dissertation, and basis for understanding family functioning. This framework is composed of four domains: I. family characteristics, including all inputs related to A. family definition, size and form, B. family’s cultural orientation and values, and C. life management skills (problem solving techniques), and planning; II. family interaction involving the interaction within the whole family and its subsystems (e.g., caregiver-spouse dyad, caregiver-child dyad, caregiver-atypical sibling dyad, caregiver-extended family dyad), that considers: A. boundaries, B. communication, C. cohesion, and D. adaptability; III. family functioning, including how the family functions according to key outputs: A. daily care, B. educational, C. socialization, D. recreation, E. affection, F. spirituality, G. economics, and H. self-esteem); and, IV. family life cycle (e.g., developmental stages and transitions that can affect the family’s development).

The following thematic narrative analysis (i.e., across-case analysis) looked at patterns, similarities and differences related to the family systems of all participants’ narratives. For this analysis, the participant (i.e., sibling co-residential caregiver to a brother or sister with IDD) is considered the center of the family, and family systems are viewed from the caregiver’s perspective. Many items discussed in this section overlap with items described in the section on well-being. Items related to family systems were viewed for their influence on the whole family, and their related familial dyads, from caregivers’ perspectives. Additionally, participants were identified as ‘caregiver’ rather than participants to honor their role within the family system.

**Family characteristics (inputs).** A family is defined as two or more individuals who view themselves as a family and engage in activities typical of a family (Turnbull et al., 2006).

**A. Family: definition, size and form.** For a definition, see Table 4.20. Ten participants contributed to this study, and each self-identified as a sibling who became the primary co-
residential caregiver to a brother and/or sister with an intellectual and/or developmental disability (notwithstanding the legal competency status of their atypical sibling, which was discussed in only one case). All caregivers met the criteria and identified as a family those instances that included two or more members who engaged in activities as a family. Co-residence was not a required factor for this identity. Eight families (MFC; DFC; SF) included a member with DD who co-resided within the family household. Both male caregivers’ families (MM; SM) included a member with DD who resided in an alternative residential setting.

1. **Size.** Families ranged in size from 2 members (DFC; SF; SM), 3 members (MFC; MM), 4 members (MFC \(n=3\)), to 5 members (MFC \(n=2\)).

   **Table 4.20. Family Definition, Size and Form.**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Characteristics</th>
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</thead>
<tbody>
<tr>
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<td>10</td>
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<tr>
<td>Families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Size (at time of interview, including spouse, children and sibling with DD who resided in/out of home)</td>
<td>2 members</td>
<td>3 (DFC; SF; SM)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 members</td>
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<tr>
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<td>4 members</td>
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<tr>
<td></td>
<td></td>
<td>5 members</td>
</tr>
<tr>
<td>Families (at time of interview) and residence of sibling with DD</td>
<td>Co-residence</td>
<td>8 (MFC; DFC; SF)</td>
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<tr>
<td></td>
<td></td>
<td>Alternate residence</td>
</tr>
<tr>
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<td>Extended family members (not including atypical sibling)</td>
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<td>4</td>
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<tr>
<td></td>
<td></td>
<td>5 and greater</td>
</tr>
</tbody>
</table>
3. **Form.** Family form considered marital status, number of children living in and out of household, residential household composition, number of caregiver’s extended family members, and caregiver’s birth order.

4. **Marital status.** Two households included caregivers who identified as single (SF [n=1]; SM [n=1]), 7 identified as married (MFC [n=6]; MM [n=1]) and 1 was divorced (DFC [n=1]). Among households in which the caregiver identified as married, only 1 married female caregiver had been previously married. In this case, the spouse had passed a number of years prior.
5. **Number of children.** Three families had no children (SF [n=1]; MM [n=1]; SM [n=1]), 4 households identified as having 1 child each (MFC [n=4]), and 3 had two children each (MFC [n=2]; DFC [n=1]).

6. **Residential household composition.** One household included one residential member (sibling with DD resided in group home). Three residential households included two co-residing members: 1 divorced female with children and 1 co-residing atypical sibling (1 daughter and 1 son resided separate dwellings); 1 single female caregiver and 1 co-residing atypical sibling; 1 married male caregiver and spouse (sibling with DD resided in supported living). Two households had four members each: 1 married female caregiver, 1 spouse, 1 co-residing son, and 1 co-residing atypical sibling; 1 married female caregiver, 1 spouse, 1 co-residing son, and 1 co-residing atypical sibling. One household included 4 members: 1 married female caregiver, 1 spouse, 1 co-residing daughter, and 1 co-residing atypical sibling (another atypical sibling resided in her own dwelling). Four households comprised 5 members: 1 married female caregiver, 1 spouse, 2 co-residing children (1 son and 1 daughter), and 1 co-residing atypical sibling; 1 married female caregiver, 1 spouse, 2 co-residing children (1 son and 1 daughter), and 1 co-residing atypical sibling; and, 1 married female caregiver, 1 spouse, 2 co-residing children (2 sons), and 1 co-residing atypical sibling.

7. **Extended family.** Three caregivers (DFC; MM; SM) have no extended family members. Three caregivers each have a living parent (MFC [1 mother]; MFC [1 father]; MFC [1 father]). Two caregivers (MFC) each have one sister. One
caregiver (MFC) has a sister and brother. One caregiver (MFC) has a father and sister. One caregiver (MFC) has a mother and two sisters. One caregiver has a father and two sisters (SF). And finally, one caregiver (MFC) has 1 sister and 5 brothers.

8. **Caregiver birth order.** Seven sibling caregivers identified as the oldest sibling (MFC [n=4]; DFC [n=1]; MM [n=1]; SM [n=1]). Three siblings identified as the sole caregiver (DFC [n=1]; MM [n=1]; SM [n=1]).

**B. Cultural orientation and values.** Cultural orientation (see Table 4.21) considered a family’s cultural background including members’ values, behaviors, and thoughts. This subdomain was influenced by different characteristics, including gender, age, race/ethnicity, religion, language, education, employment, geography, and disability type. Though socioeconomic status was a feature of family inputs, level of income was not discussed.

<table>
<thead>
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<th>Categories</th>
<th>Characteristics</th>
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</thead>
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<tr>
<td></td>
<td>Male</td>
<td>2 (MM; SM)</td>
</tr>
<tr>
<td>Caregiver by age</td>
<td>30-39</td>
<td>2 (35 [MM]; 37 [MFC])</td>
</tr>
<tr>
<td></td>
<td>40-49</td>
<td>3 (44 [MFC]; 45 [MFC]; 45 [SF])</td>
</tr>
<tr>
<td></td>
<td>50-59</td>
<td>3 (51 [MFC]; 52 [MFC]; 54 [DFC])</td>
</tr>
<tr>
<td></td>
<td>60-69</td>
<td>2 (60 [MFC]; 69 [SM])</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>African American</td>
<td>1 (SF)</td>
</tr>
<tr>
<td></td>
<td>Asian/Hispanic</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Caucasian/White</td>
<td>9 (MFC; DFC; MM; SM)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
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<tr>
<td>Religion</td>
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<td>2 (MFC; MM)</td>
</tr>
<tr>
<td></td>
<td>Christian</td>
<td>6 (MFC; DFC; SF)</td>
</tr>
<tr>
<td></td>
<td>Catholic</td>
<td>1 (SM)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1 (MFC)</td>
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Table 4.21. Continued.

<table>
<thead>
<tr>
<th>Education</th>
<th>High school diploma</th>
<th>1 (MFC)</th>
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<tr>
<td></td>
<td>Some college</td>
<td>2 (MFC; SF)</td>
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<tr>
<td>Assoc Degree</td>
<td>1 (MFC)</td>
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</tr>
<tr>
<td>Undergraduate</td>
<td>3 (MFC; MM)</td>
<td></td>
</tr>
<tr>
<td>Graduate</td>
<td>3 (MFC; SM)</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>English</td>
<td>10</td>
</tr>
<tr>
<td>Employment Status</td>
<td>Not employed</td>
<td>2 (1 SF; 1 MFC—receives state-issued stipend)</td>
</tr>
<tr>
<td></td>
<td>Employed part-time</td>
<td>2 (1 MFC reduced hours; 1 MFC reduced hours and received state-issued stipend)</td>
</tr>
<tr>
<td></td>
<td>Full-time employed</td>
<td>4 (2 MFCs; 1 DF; 1 MM)</td>
</tr>
<tr>
<td></td>
<td>Full-time + extra</td>
<td>1 (1 MFC—has extra job)</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
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</tr>
<tr>
<td>Geography</td>
<td>Northeast</td>
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</tr>
<tr>
<td></td>
<td>Maryland: 1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Massachusetts: 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Midwest</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Illinois: 1</td>
<td>5</td>
</tr>
<tr>
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<tr>
<td></td>
<td>Texas: 1</td>
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</tr>
<tr>
<td></td>
<td>Atypical sibling’s disability type, gender, age and status of co-residence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mild ID</td>
<td>SF (45 years): 1 brother (39 years; co-residence)</td>
</tr>
<tr>
<td></td>
<td>Mild ID &amp; Mild Cerebral Palsy</td>
<td>MFC (52 years): 1 sister (51 years; co-residence)</td>
</tr>
<tr>
<td></td>
<td>Moderate ID &amp; autism</td>
<td>DFC (54 years): 1 brother (56 years; co-residence)</td>
</tr>
<tr>
<td></td>
<td>Moderate ID &amp; autism (brother)/Mild ID &amp; autism (sister)</td>
<td>MFC (37 years): 1 brother (39 years; co-residence), and 1 sister (37 years; non co-residence)</td>
</tr>
<tr>
<td></td>
<td>Moderate learning disabled</td>
<td>SM (69 years): 1 sister (64 years; non-co-residence)</td>
</tr>
</tbody>
</table>
Table 4.21. Continued.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Caregiver Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe ID, cerebral palsy, muscular dystrophy, &amp; scoliosis</td>
<td>MFC (51 years): 1 brother (54 years; co-residence)</td>
</tr>
<tr>
<td>Angelman’s syndrome</td>
<td>MM (35); 1 brother (32 years; non-co-residence)</td>
</tr>
<tr>
<td>Cornelia de Lange &amp; autism</td>
<td>MFC (60 years): 1 sister (54 years; non co-residence)</td>
</tr>
<tr>
<td>Downs syndrome</td>
<td>MFC (44 years) 1 sister (41 years; co-residence)</td>
</tr>
<tr>
<td>Prader-Willi Syndrome</td>
<td>MFC (45 years): 1 sister (44 years; co-residence)</td>
</tr>
</tbody>
</table>

1. **Caregivers by age.** Caregivers ranged in age between 30 and 69 years, including:

   2 caregivers (MFC [n=1]; MM [n=1]) between 30 and 39 years, 3 (MFC [n=2]) between 40 and 49 years, 2 (MFC [n=1]; DFC [n=1]) between 50 and 59 years, and 2 (MFC [n=1]; SM [n=1]) between 60 and 69 years.

2. **Race/ethnicity.** With respect to race/ethnicity, 1 caregiver (SF) identified as African American. The nine remaining caregivers (MFC; DFC; MM; SM) identified as White/Caucasian.

3. **Religion.** Two caregivers (MFC; MM) did not disclose their religion. One caregiver (SM) identified as Catholic, 1 identified as other (i.e., formerly Catholic but identified as Quaker [MFC]), and 6 described themselves as Christian (MFC; DFC; SF).

4. **Language.** All participants described themselves as English speaking, where English was the primary language spoken within the household.

5. **Education.** One caregiver (MFC [n=1]) reported having a high school diploma, 2 reported some college (MFC [n=1]; SF [n=1]), 3 reported having an
undergraduate degree (MFC [n=2]; MM [n=1]), and 4 reported having a graduate
degree (MFC [n=3]; SM [n=1]).

6. **Employment:** Two caregivers (MFC; SF) described themselves as not employed
due to caregiving. One non-employed caregiver explained she received a stipend.
Two caregivers worked part-time (MFC [n=2]). One caregiver, employed part-
time, stated she also received a stipend for caregiving. Four caregivers (MFC
[n=2]; DFC; MM) worked full-time. One caregiver (MFC) stated she worked full-
time but took on an extra job to cover costs. One caregiver (SM) identified as
retired.

7. **Geographic Location.** Caregivers lived in the following states: Arizona [n=1],
Florida [n=1], Illinois [n=1], Iowa [n=1], Maryland [n=1], Massachusetts [n=1],
Minnesota [n=1], Ohio [n=1], South Carolina [n=1], and Texas [n=1]. These
states represent 4 of 5 regions throughout the United States, including the
Northeast, Southeast, Northwest and Southwest. There are no caregivers who
lived in the Midwest.

8. **Atypical sibling’s disability type, gender, age and status of co-residence.** All
co-residing and non-co-residing siblings with DD were described as having an
intellectual disability (Male [n=5]; Female [n=5]). Five atypical siblings were
described as having mild, moderate or severe intellectual disability/learning
disability, alongside co-morbidities of autism, cerebral palsy, epileptic seizures,
muscular dystrophy, or scoliosis. Other described disability types, included:
Angelman’s syndrome, Cornelia de Lange, Down’s syndrome, and Prader-Willi
syndrome.
C. Life management skills. Life management skills (see Table 4.22) are problem-solving tools that show how a family solves problems (Hutchison, 2010). These skills include passive appraisal, reframing, spiritual support, social support and professional support. Life management skills were considered from the caregivers’ perspectives in relation to the whole family.

1. **Passive appraisal.** Passive appraisal referred to how families did not allow worries to become too consuming (Poston & Turnbull, 2004). Eleven references were presented for this category.

    *Theme: Managing worries by giving up or moving beyond the idea of controlling challenging situations; and, sharing decision-making and responsibilities with spouse and children to manage difficult challenges.* Some caregivers (MFC; SF) described giving up control and moving beyond the idea of controlling a situation to help ease worrying about it. Other caregivers (MFC; DFC; MM) described sharing decision-making and responsibilities among family members (i.e., spouse and children) as a way to avoid worries and manage challenges. When considering the issue of independence and control, one female caregiver stated, *“I do feel independent but I don’t always feel in control. I’m a big fan of enjoying what I can control and just letting go of what I can’t because if you don’t, it’ll make you crazy.”*

<table>
<thead>
<tr>
<th>Categories and Sub-Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of References per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Passive Appraisal</td>
<td>Managing worries by giving up or moving beyond the idea of controlling challenging situations; and, sharing decision-making and responsibilities with spouse and children to manage difficult challenges</td>
<td>MFC</td>
<td>11</td>
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Table 4.22. Life Management Skills.
2. Passive appraisal. Passive appraisal referred to how families did not allow worries to become too consuming (Poston & Turnbull, 2004). Eleven references were presented for this category.

*Theme: Managing worries by giving up or moving beyond the idea of controlling challenging situations; and, sharing decision-making and responsibilities with spouse and children to manage difficult challenges.* Some caregivers (MFC; SF) described giving up control and moving beyond the idea of controlling a situation to help ease worrying about it. Other caregivers (MFC; DFC; MM) described sharing decision-making and responsibilities among family members (i.e., spouse and children) as a way to avoid worries and manage challenges. When considering the issue of independence and control, one female caregiver stated, “I do feel independent but I don’t always feel in control. I’m a big fan of enjoying what I can control and just letting go of what I can’t because if you don’t, it’ll make you crazy.”
3. **Reframing.** Reframing referred to how family members changed their views about or justified a situation to consider a positive rather than negative outcome or viewpoint (Hastings & Taunt, 2002). Twelve references emerged for this category.

*Theme: Family members (e.g., caregiver, spouse and children) using empathy to consider their own and other members’ feelings.* All caregivers described some level of empathy among family members for themselves or between family members. One caregiver (DFC) described how her children empathized with her experience.

*My children see that I have a lot of things going on and a lot of responsibility, and just emotionally check in on me, which is something they didn't do before that. I try not to make them think about, “If something happens to mom, we’re going to have to step in and be responsible.” But, I try to keep them in the loop of what I’m doing so that they know what’s going on.*

4. **Spiritual support.** Three references emerged from caregivers (MFC; SF) that described spiritual support through a lens of how spirituality is viewed as an aspect of comfort and guidance within the family.

*Theme: Feeling comforted through self-spirituality, including a belief in a higher being, developing a relationship with Jesus, and adopting Quakerism.* Caregivers (MFC) described developing a sense of spirituality that included believing in a higher spirit, developing a relationship with Jesus rather than following an organized, Sunday-attendance religion, and adopting Quakerism. “I'm an attending Quaker. I have a whole ceremony, baptism or whatever. I go to this Sunday meeting and I sit and meditate with other Quakers at a Quaker meeting house. That helps in having a support committee.”
5. **Social support.** Eight references were made by caregivers (MFC; SF) that referred to social support as an opportunity for practical and emotional help from family and friends (Hutchison, 2010).

*Theme: Feeling emotional and practical support through long-time friends, new friends who share a similar caregiving experience, direct family members (i.e., spouse and children), and extended family (i.e., aunt).* Caregivers provided descriptions of their social supports. Regarding family, one caregiver (MFC) described her husband’s discomfort and difficulty adapting to changing family dynamics resulting in negative feelings of support. This caregiver relied strongly on her aunt who lived close by for support. Another caregiver (MFC) described her long-time, close friends that stood by her through the transition. This individual also discussed the support she received from her spouse.

*I have three friends that stuck with me that I meet occasionally for either lunch or coffee. That’s extremely helpful. When my sister goes to her day program, my husband makes sure that he takes a couple of days off when she is gone. We go for rides or do things when we can.*

6. **Professional supports.** Fourteen references described caregivers’ experience with supports through agencies and professionals.

*Theme: Having support through spousal and family counseling, and services for caregiver’s atypical sibling.* Two caregivers (MFC) described receiving formal spousal and family counseling supports. In addition, three caregivers’ (MFC; DFC; SM) siblings with DD were receiving service benefits through a state waiver program (i.e., day program services). One caregiver (MFC) described a great day program that she found for her sister. However, there was concern since the program was private and she was uncertain she could sustain the cost. Both
male caregivers sourced alternative residential settings for their siblings with DD, including day services. One participant (MFC) paid out of pocket for a formal caregiver but also received a stipend as her brother’s primary caregiver. Another participant (MFC) received a state stipend for providing care to her brother with DD. Most caregivers described their frustration with efforts to navigate and source service supports for their atypical siblings. These efforts, however, were met with challenges and many caregivers began their efforts with their siblings on a waiting list.

*My sister is on a full waiver. That helps to pay for me and her day program. She was actually on a waiting list when we first started out. But she was denied. Then, my husband got really mad. So, he went back to them and in less than a week she was approved. Now, she’s on the waiver.*

**Family interaction.** Family interaction (see Table 4.23) was the second domain of the family systems framework looking at the processes of interaction among and between family members within its subsystems (i.e., marital subsystem, parental subsystem, sibling subsystem, and extended family subsystem). Family interaction included the following subdomains: A) factors influencing family processes, such as i) roles, ii) communication/exchange of information, iii) power distribution and iv) rules, B) cohesion, including i) boundaries, ii) engagement between members, and iii) level of independence of members, and C) adaptability (i.e., the ability of family members to manage transitional changes and situational stress). Open systems indicated positive functioning, satisfactory levels of communication/information exchanged, and greater ability to manage conflict (Friedman & Allen, 1997). Closed systems
suggested dysfunction, unsatisfactory levels of communication/information exchanged, and challenges managing stressful events (Friedman & Allen, 1997).

**Factors influencing family processes.** Among factors influencing family members’ transactional processes within its subsystems, roles received the most references, followed by power distribution, communication, and rules.

<table>
<thead>
<tr>
<th>Table 4.23. Family Interaction.</th>
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<tbody>
<tr>
<td><strong>Domains and Subdomains</strong></td>
</tr>
<tr>
<td>A: Factors Influencing Family Processes</td>
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182
### Table 4.21. Continued.

#### B. Cohesion

1. **Boundaries**
   - Described open boundaries resulting in positive emotional bonding between caregiver and atypical sibling subsystem, marital subsystem and atypical sibling, spouse and atypical sibling subsystem and, child and atypical sibling; and, within marital and parental subsystems
   - Setting boundaries within marital and typical-atypical sibling subsystems

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<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>MFC</th>
<th>DF</th>
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<th>MM</th>
<th>SM</th>
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<tbody>
<tr>
<td>Boundaries</td>
<td>Positive emotional bonding</td>
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<tr>
<td></td>
<td>Negative emotional bonding</td>
<td>7</td>
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2. **Engagement**
   - Feeling positive and supportive engagement within familial subsystems through participation in activities together as a family, and members showing each other protection, nurturance, and affection

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<th>Category</th>
<th>Description</th>
<th>MFC</th>
<th>DFC</th>
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<tr>
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<td>Positive engagement</td>
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<td></td>
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<tr>
<td></td>
<td>Negative engagement</td>
<td>7</td>
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3. **Disengagement**
   - Feeling disengaged due to lack of affection, and low commitment and support in marital subsystem, parental subsystem, spouse-children subsystem, and caregiver-extended family subsystem

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<tr>
<th>Category</th>
<th>Description</th>
<th>MFC</th>
<th>SF</th>
<th>MM</th>
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<tbody>
<tr>
<td>Disengagement</td>
<td>Positive disengagement</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Negative disengagement</td>
<td></td>
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#### C: Level of Independence

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<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>MFC</th>
<th>DFC</th>
<th>SF</th>
<th>MM</th>
<th>SM</th>
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<tbody>
<tr>
<td>Positive</td>
<td>Atypical sibling achieving greater independence</td>
<td>9</td>
<td></td>
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<tr>
<td>Negative</td>
<td>Caregiver, spouse and children feeling low sense of independence due to caregiver’s loss of freedom, loss of control, feeling captive to the role; spouse’s loss of freedom; and, child’s difficulty managing with loss of attention from parent due to caregiving responsibilities</td>
<td>13</td>
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#### D: Adaptability Stability and Balance

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<th>Category</th>
<th>Description</th>
<th>MFC</th>
<th>DFC</th>
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<tbody>
<tr>
<td>Positive</td>
<td>Achieving stability and balance among family members through caregiver self-regulation, caregiver taking on new duties, caregiver taking on parental role, caregiver’s spouse and children sharing in decision-making and overall responsibilities (emotional and instrumental support within all familial subsystems), reciprocity between caregiver and atypical sibling, children and atypical sibling learning respect for each other, and increased self-esteem and independence in atypical sibling</td>
<td>23</td>
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<td>Negative</td>
<td>Challenges adapting to and achieving stability due to the abruptness of and having no former knowledge related to managing the changing family dynamic (i.e., transition of atypical sibling to co-residence), and resultant atypical sibling’s problem behaviors from inability to grieve the loss of parents and being forced into sibling’s residence without choice</td>
<td>8</td>
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1. Roles

Theme: Role types adopted, including parental role assumed by caregiver, shared decision-making role with marital dyad, and caregiving proxy role assumed by children.

Eleven references were made by caregivers (MFC; DFC; MM) with a spouse and/or children regarding role shifts. For the process of designating roles, most caregivers explained that roles were negotiated with the spouse and/or children. Caregivers with spouses described that the role of making decisions was, for the most part, a shared responsibility within the marital dyad. Some caregivers described how their children (i.e., teenagers and older) took on greater caregiving duties; however, this role shift reflected a similar past requirement, among siblings for their atypical siblings, when they were their children’s age. Most female caregivers discussed taking on the parent role, describing their siblings with DD as children. This was a consistent theme among female caregivers. One caregiver (MFC) with two siblings with DD described how becoming the primary co-residential caregiver resulted in the role shift from sibling to parent.

My brother and sister really do have to view me as, I mean, a parent totally. Whereas before, they didn’t necessarily feel like they had to heed what I was saying because they were living with mom. Now, it’s, “Yeah, that is what we have to do.” I think my relationship with my sister, a lot of times, even though my sister is so much more high functioning, she actually causes me a greater amount of stress. It’s one of those things where I constantly have to tell myself there is that processing problem because sometimes I think, “Why aren’t you getting this?”
2. **Power Distribution.** Power distribution looked at how family members maintained a level of power to safeguard their personal interests, influenced decisions, resolved conflicts, and promoted the well-being of other members.

Twelve references emerged for this subdomain.

*Theme: Caregivers’ and children’s’ struggles to possess control.* Caregivers (MFC; SF) described their own and, in some cases, their childrens’ struggles to maintain control. This experience may represent power struggles in families when being forced to adapt to new and unfamiliar dynamics. One caregiver (MFC) discussed the following challenges of her son trying to assert control within the changing familial dynamic.

*My sister moved in during the hardest time in my son’s life. He was coming out of junior high into high school when all of this occurred. He’s a late bloomer, and has all of these raging hormones, pushing back on everything. He’s trying to know how to drive. It’s hard enough to be going through that in general. All of these sharp down your throat things, and there's absolutely nothing you can do about it and you can't leave.*

3. **Communication.** Communication looked at the information exchanged between family members to manage conflict and stressful events (Friedman & Allen, 1997). One positive theme (4 references) and 1 negative theme (2 references) resulted for this category.

*Positive

*Theme: Feeling ease exchanging information and communicating with spouse and/or children indicating an open, functional family system.* A small number of caregivers (MFC;
DFC) described ongoing communication among family members to keep each other apprised of
caregiving challenges as well as soliciting help from each other to share caregiving duties. One
caregiver (DFC) described the support she received from her children.

Now that my brother is here, we've kind of had to come together more as a family to talk to and support each another. My kids are more prone now to ask,

“How are you doing?” And, “Are things going okay?” They now see the world as more than just themselves. And seeing that I have a lot of things going on and a lot of responsibility, it is nice that they just emotionally check in on me which is something they didn't do before.

Negative

Theme: Responding angrily to situational stress and verbalizing frustration due to limited supports from extended family members. Caregivers (MFC; SF) described communicating angrily to situational stress and discussing their frustration for not receiving help from extended family members. Anger and frustration were believed to be responses for being able to fulfill caregiving responsibilities despite a lack of support.

I’m always trying to communicate with my sisters. But, there have been moments when it’s been so difficult that my sisters have kind of disappeared, just stopped communicating, because it’s too much. That hasn’t been great for me ever. But I understand it. I totally understand it. I know they may think, “Okay. I can’t deal with it.” They don’t live here. They're two hours away.

4. Rules

Theme: Setting new rules for atypical sibling to stimulate a healthier lifestyle than prior to the co-residential transition. Only 3 references emerged for this subdomain. Rules referred to
how members act and behave, as well as how decisions are made and problems solved (Friedman & Allen, 1997). Caregivers (MFC; SF) described the resistance and challenge from their atypical siblings after setting rules to help their atypical siblings adapt to the new family dynamic. One caregiver (SF) described the difficulty working with her brother with DD.

Getting my brother to see things from other people's perspectives is probably the hardest thing to deal with. There’s a selfishness about what I want. There’s no thought beyond my own rules, what I want. And if you can't give me what I want, then you're the bad guy and you're trying to stifle me and hold me back. That speaks directly to me being his caregiver, his sister. And then he feels like I'm in the role of his mother. I go through great pain to explain to him why this and why that. This is what I mean when I say it took me until the middle of last year to realize that my brother would not understand the definition of every word I said to him in the healing process.

Cohesion (boundaries, engagement and level of independence). Cohesion considered boundaries (i.e., level of emotional bonding), engagement, and levels of independence among family members (Hutchison, 2010). Boundaries referred to demarcation lines or barriers between persons inside and outside the family’s subsystems (Hutchison, 2010; Minuchin & Fishman, 1981). Open or closed boundaries allowed for or impeded individual autonomy or showed how family members supported each other (Summers, 1987). Level of communication and exchange of information between family members provided further indication of whether the family system was open or closed (Turnbull et al., 2006). Cohesion occurred across a continuum that included high cohesion on one end and high enmeshment on the other end (Carnes, 1981).
1. **Boundaries.** Two themes and 24 references emerged for this category.

**Theme 1: Described open boundaries resulting in positive emotional bonding between caregiver and atypical sibling subsystem, marital subsystem and atypical sibling, spouse and atypical sibling subsystem, and child and atypical sibling; and, within marital and parental subsystems.** Nineteen references were made where all caregivers described open boundaries, suggesting positive emotional bonding within familial subsystems. One married female participant described the continued bond she shared with her sister with DD and a growing bond between her husband and atypical sibling. Her story provided confirmation of the positive emotional bond that existed in caregivers’ families, demonstrating positive cohesion among family members.

*My sister is pretty independent. She likes her separate space. I’m glad we built it because she can go to it if she doesn’t want to be around us and vice versa. But there are those nights when she comes down and sits with us, and she’s actually pretty funny. She just sits and jokes with us. And that’s when I feel like, ‘Oh, it’s just us being like when we were younger, not having to really do anything for her or reprimand her, just sitting and visiting.’ And, lots of times she likes to talk about the things we did, things she did that got us in trouble because as I say, anytime she was doing something where I knew she was going to get in trouble or could get hurt, I would just go with her and stop. It was never like, “Hey, you shouldn’t do that.” With my sister, she would just keep on going. She seems to find that amusing now as adults.*

**Theme 2: Setting boundaries within marital and typical-atypical sibling subsystems.** Five references were presented where caregivers (MFC; SF) discussed the need to set boundaries
within the typical-atypical sibling and marital subsystems. This finding suggested identifying areas of poor engagement and establishing strategies for more positive engagement through communication. One caregiver (MFC) discussed how her husband sometimes overstepped his role, and her need to assert her role.

"I think the only thing that has been different between me and my husband is that I feel very protective of my sister. So, there have been a couple of times where he has kind of jumped in on that role and been like, ‘You need to be doing this or doing that.’ I’m like, ‘No, wait a minute.’ I feel like that’s not his place. I let him know I will take care of that and I don’t want him going there. I don’t know; it’s hard to explain. I guess it would be like maybe how a stepparent oversteps boundaries."

2. **Engagement.** One theme and 20 references were made for level of engagement within familial subsystems.

*Theme: Feeling positive and supportive engagement within familial subsystems through participation in activities together as a family, and members showing each other protection, nurturance, and affection.* All caregivers (MFC; DFC; SF; MM; SM) described modes of interaction representing engagement within familial subsystems. Some caregivers discussed moments of positive engagement with their atypical siblings. One caregiver (DFC) described the protection and support received from her children. Both male caregivers described an improved relationship after transitioning their sibling with DD to alternative housing. Each inferred a closer relationship when both lived independently of each other, since the typical sibling was not challenged with their atypical sibling’s direct care, and could engage in a more affectionate, emotional and giving relationship. This outcome marked a shift from an instrumental to emotional support; a return to the typically-described relationship (i.e., emotional support)
among typical siblings prior to assuming the primary caregiving role. Both male caregivers also described greater independence for both siblings with DD. The single female caregiver described greater empathy for her atypical sibling resulting in an improved relationship with her brother with DD. The divorced female participant described greater affection for her son and atypical sibling. Her story describes the personal growth of her brother with DD since living with her parents. The personal development of siblings with DD, post-transition, was a commonly heralded theme among caregivers who were proud of inspiring their siblings towards greater self-growth.

When my son got married—it was an outdoor wedding—my son was going to walk me and my brother would follow. I still can’t call him [name]. Before we walked down the aisle I just looked at my brother and said, “Do you want to tell [my son] anything before he gets married?” And, my brother looked at my son and said, “Thank you for taking care of me and being there for me.” You know, this is a person who doesn't say more than two words unless he's mimicking. And that just started it. My son walked down the aisle. And you know it was heartfelt. It showed how good my brother felt about himself. It made for a real feel-good moment.

3. **Disengaged.** Eight references were made describing disengagement among some familial subsystems.

Theme: Feeling disengaged due to lack of affection, and low commitment and support in marital subsystem, parental subsystem, child-atypical subsystem, and caregiver-extended family subsystem. Some caregivers (MFC; SF; MM) described feelings of disengagement, including low feelings of affection, commitment, and support within the child-atypical subsystem, where the child and atypical sibling experienced challenges adjusting to each other. The male caregiver
(MM) participant felt challenged in his caregiving role following his mother’s death, claiming he and his brother were estranged from their natural father. In this case, there was nobody to rely on for support. Given the extended physical needs of his atypical sibling, he suggested that providing co-residential care to his brother with DD put a tremendous strain on the relationship with his then-spouse. Other caregivers (MFC; SF) described the challenges of not receiving help from extended family (i.e., fathers, and sisters) that resulted in feelings of isolation and feeling captive to the caregiving role. Regarding the limited support from fathers, these caregivers’ stories reflected a patriarchal ethos where women are believed to be the intended caregivers. The following narrative explains the frustration with extended family.

> I talked to my baby sister where she doesn’t get to be dis-involved and just put everything on me. So, she has to take some responsibility too. When my sister [with DD] lived in the group home before coming back to my house, my husband and I were able to just take off. We were able to think about what we wanted to do for the weekend. So, in that respect, we were independent. When I had my sister [with DD] before she went to the group home, I didn’t feel independent. We were always together. This goes back to how you can feel isolated from your family.

**Level of independence.** One positive theme (9 references) and 1 negative theme (13 references) emerged for how caregivers recognized independence among family members.

**Positive**

*Theme: Atypical siblings achieving greater independence.* All caregivers (MFC; DFC; SF; MM; SM) described increased independence of their sibling with DD after transitioning from the parental home. Some caregivers described the former relationship between their atypical sibling and parent as enmeshed, but how understanding their atypical sibling’s potential
for growth, re-establishing rules, and encouraging greater responsibility resulted in their sibling’s increased self-esteem and independence. Both male caregivers described the increased independence of their siblings with DD after transitioning to alternative residence. However, the married male caregiver’s narrative implied feeling some emotional guilt for going against his mother’s wishes, not maintaining the co-residential aspect, but also knowing it was the appropriate decision.

Well, I mean the independent living situation, in general, has been great for my brother. But I think that even if my mother saw what I saw, she would still been hesitant for putting him in independent living because to her it would have been probably a degree of giving up control that she’s not comfortable with. I know I’m not there with my brother all the time. So I don’t have that direct control all the time. And, I’m not always comfortable with that but for most part I am. But I know from that he is living in an apartment in his community. And, they get him out for walks. And so he meets a lot of other people he hasn’t met before. They have a pool at the apartment. So, he’s been to the pool, and playing with other folks and the caregiver. So I think at this point he has been to every caregiver’s grandparent’s house. They all basically adopted him. So, his social circle has really grown especially, and a lot of this stuff happened in the evenings and on the weekends where traditionally he was in residence with us.

Negative

Theme: Caregiver, spouse and children feeling low sense of independence due to caregiver’s loss of freedom, loss of control and feeling captive to the role; spouse’s loss of freedom; and, child’s difficulty managing with loss of attention from parent due to caregiving
responsibilities. Thirteen references were made where all caregivers referenced some loss of independence within the family and between family members. A common theme among caregivers was feeling captive to the caregiving role. One caregiver discussed how she relied on her daughter’s help for caregiving. Her story gives reference to her daughter’s feelings of burden, and how immediate family members may also share a similar sentiment since the new family dynamic would take on this responsibility.

Even when I was at the office this week, I said to them [co-workers],

“When my daughter goes to college in July—because she’s thankfully on a soccer scholarship—she’ll have to start early. But, what am I going to do every morning and every afternoon to get my sister to the bus in that afternoon time?”... But she has said to me, “I’ll be glad to go to college so I have less responsibility.”

Adaptability. Two themes, 1 positive and 1 negative, emerged that looked at the processes for, and challenges achieving, stability and balance within the family unit.

Theme 1: Achieving stability and balance among family members through caregiver self-regulation, caregiver taking on new duties, caregiver taking on parental role, caregiver’s spouse and children sharing in decision-making and overall responsibilities (emotional and instrumental support within all familial subsystems), reciprocity between caregiver and atypical sibling, children and atypical sibling learning respect for each other, and increased self-esteem and independence in atypical sibling. Twenty-three references were presented in which all caregivers described ways in which the various familial subsystems contributed to maintaining stability and balance within the family unit. The married male participant described the shared contribution of his then-spouse that demonstrated how couples adapted by sharing roles and responsibilities.
Early on again, that [providing for atypical sibling’s physical needs] fell on my shoulders. But my wife has picked up more of it because that’s kind of what she does in her day job. It’s a skill set she has that I don’t necessarily have quite as well. So, in that sense, the responsibility has become more 50/50.

Negative

Theme: Family members’ (i.e., caregiver, spouse, children and atypical sibling) challenges adapting to and achieving stability due to the abruptness of and having no former knowledge related to managing the newly changing family dynamic (i.e., transition of atypical sibling to co-residence), and resultant atypical sibling’s problem behaviors from inability to grieve the loss of parents and being forced into sibling’s residence without choice. Eight references resulted in how caregivers (MFC; SF) described family members’ difficulties maintaining stability due to the suddenness of and being unequipped to manage a rapidly changing family dynamic (i.e., due to the transition of the atypical sibling from parental to sibling co-residential care). Caregivers also described these difficulties in the context of atypical siblings’ problem behaviors, including angry outbursts and passive aggressiveness that were related to not having an opportunity to grieve and adapt to the changes. All references were made by married female caregivers with children. One caregiver (MFC) described the challenges of encouraging her atypical sibling’s adjustment to the new household.

The other thing that has also been a challenge, that’s been a huge transition for her [sister with DD], is I’ve been married almost 25 years and my other sister has been married I think almost 20. So, basically, for the last 20 years, my sister was an only child at home. So, to move from being an only child into a busy family, I can’t tell you how many conversations I’ve had with her
about, “Look, it is not all about you. It’s not your turn to be the important one right now. It’s somebody else’s turn to be the important one right now.” That’s been a whole other layer.

**Family functioning.** Family functioning (see Table 4.24) is the output of the family systems framework that considered overall functioning according to eight categories: i) affection, ii) self-esteem, iii) spirituality, iv) economics, v) daily care, vi) socialization, vii) recreation, and viii) education (Hutchison, 2010). These functions were understood as the activities and tasks in which a family engaged for members to meet their needs and wants (Turnbull et al., 2006). Family characteristics, interactions, and stage in the family life cycle (discussed in following section) influenced how the family attended to these functions. A transactional relationship between functions was also considered, where the benefits achieved in one function could positively affect other functions, and vice versa (e.g., difficulties related to one family function could negatively affect another function). For instance, economic challenges could negatively impact recreational and/or social activities (Turnbull et al., 2006).

<table>
<thead>
<tr>
<th>Domains</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
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</thead>
<tbody>
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<td><strong>A: Affection</strong></td>
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<tr>
<td>Positive</td>
<td>Physical and verbal affection between caregiver and atypical sibling, caregiver and spouse, caregiver and/or children, and children and atypical sibling</td>
<td>MFC, DFC, SF, MM, SM</td>
<td>12</td>
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<tr>
<td>Negative</td>
<td>Low physical and verbal affection between atypical sibling and caregiver, spouse and caregiver, and extended family and caregiver</td>
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Table 4.24. Continued.

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<th>Category</th>
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<th>D</th>
<th>FC</th>
<th>SF</th>
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<th>SM</th>
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<tbody>
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<td>B: Self-Esteem</td>
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<td>Positive</td>
<td>High feelings of self-worth among family members, including atypical sibling growing independence post-transition</td>
<td>MFC</td>
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<td>Negative</td>
<td>Low feelings of self-worth among family members, such as spouse feeling abandoned; child feeling abandoned; child overburdened with caregiving duties; spouse overburdened with caregiving duties</td>
<td>MFC</td>
<td>15</td>
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<tr>
<td>C: Spirituality</td>
<td>Identifying with formal faith-based activity, self-ascribed spiritual belief, and prayer as household spirituality</td>
<td>MFC</td>
<td>6</td>
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<tr>
<td>D: Daily Care</td>
<td>Meeting the physical and health needs of caregiver (through supports from spouse and children), atypical sibling (caregiver, spouse and children participating in setting appointments for atypical sibling, preparing meals, providing transportation, and bathing/grooming/toileting), and children (parents engaging in activities to ensure children feel supported and not ignored)</td>
<td>FMC</td>
<td>26</td>
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<tr>
<td>E: Socialization</td>
<td>Caregiver establishing new friends through social media and persons with shared experiences, and establishing social network for atypical sibling through volunteering, attending church, and participating in activities with children</td>
<td>MFC</td>
<td>9</td>
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<tr>
<td>Negative</td>
<td>Caregiver establishing new friends through social media and persons with shared experiences, and establishing a social network for atypical sibling through volunteering, attending church, and participating in activities with children</td>
<td>MFC</td>
<td>14</td>
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<td>F: Economics</td>
<td>Achieving economic stability through traditional employment, taking on additional work, formal supports, and unearned family resources from extended family members and family trust</td>
<td>MFC</td>
<td>11</td>
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<td>Negative</td>
<td>Economic struggles due to reduced work hours or unable to work due to caregiving demands, pride in not accepting government handouts, limited government resources, and no savings from extended family members</td>
<td>MFC</td>
<td>13</td>
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Table 4.24. Continued.

<table>
<thead>
<tr>
<th>G: Recreation</th>
<th>Positive</th>
<th>Negative</th>
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<tbody>
<tr>
<td>Described recreational activities involving family members, including exercise, vacation, engaging in local entertainment, going to the movies; getting a massage, attending church, attending the Opera, and participating in Special Olympics</td>
<td>MFC</td>
<td>15</td>
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<tr>
<td>Described difficulties being able to participate in recreational activities due to burden of caregiving and role captivity</td>
<td>MFC</td>
<td>13</td>
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</table>

<table>
<thead>
<tr>
<th>H: Education</th>
<th>Positive</th>
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<tbody>
<tr>
<td>Emphasizing importance of having completed education, children attending college, and ensuring children will attend college</td>
<td>MFC</td>
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</table>

**Affection.** Affection considered the physical and verbal exchange between members that defined positive and negative attachment and love within the family unit (Rousso, 1984; Turnbull, et al., 2006). One positive theme (20 references) and 1 negative theme (6 references) emerged for this theme.

**Positive**

*Theme: Physical and verbal affection within caregiver and atypical sibling subsystem, marital subsystem, parental subsystem, and children and atypical sibling subsystem.* Twenty references were presented by all caregivers emphasizing positive physical and verbal affection within the different familial subsystems. Caregivers described the expression of some level of affection from their siblings with DD to other immediate family members. One caregiver (MFC) described the support she received from her spouse that helped her manage the difficult moments related to caregiving.

*I truly married the right guy. I told him, at some point, after it was so stressful in the first probably four to five weeks, “If you want out, I don’t blame you. Just go. I don’t even like I won’t fight you on it, this is insane. Our lives right*
now are insane.” He’s like, “No, we’ll make it through, don’t worry about it, it will work out.”

**Negative**

*Theme: Low physical and verbal affection between atypical sibling and caregiver subsystem, marital subsystem, and extended family and caregiver subsystem.* Six references were provided by a small number of caregivers (MFC; SF) that described receiving low levels of affection from their atypical sibling, spouse and extended family. One caregiver (MFC) described how her father released himself from caregiving and forced the responsibility onto her at age 21 years, at a time she had to raise her own child with no spousal support.

*At the beginning [taking over caregiving role at age 21], I was very resentful of how it occurred? You know my dad made a comment that I asked for this responsibility. So, it was mine to take and I was not allowed to ask him for any help.*

**Self-Esteem.** Self-esteem was viewed according to feelings of strength and self-worth among family members and within the whole family (Turnbull et al., 2006). One positive theme (11 references) and 1 negative theme (15 references) were cited for this category.

**Positive**

*Theme: Atypical sibling’s developing skills, increasing self-worth, and growing independence.* Caregivers (MFC; DFC; SF; MM; SM) described a long-held belief that siblings with DD were capable of more than parents allowed. Caregivers described inspiring their siblings with DD towards new activities and developing new skills. In turn, this effort resulted in caregivers’ own increased self-esteem within their role alongside their atypical siblings’ growth.
and increased self-development. "I've allowed her to do what my parents wouldn't allow her to do. Now that she has her own space, she feels more independent and more adult."

**Negative**

**Theme:** Low feelings of self-worth among family members due to caregiver loss of freedom, caregiver resentment for feeling abandoned by extended family, spouse feeling abandoned, child feeling abandoned, child overburdened with caregiving duties, and spouse overburdened with caregiving duties. Caregivers provided 15 references citing examples of situations that diminished the self-esteem of family members. One caregiver (MFC) described feeling a loss of freedom that hampered self-worth.

 Mostly, I have gone through different stages because your life is totally different with this responsibility. I think I have gone through the stages of “what in the hell was I thinking?” I may be a little resentful because I do not have the freedom in my life that I used to have.

**Spirituality.** Spirituality referred to how persons found meaning within themselves, understood their connection to the universe, and made sense of all things sacred (Canda, 1999; Gaventa, 2001). One theme (6 references) was presented for this category.

**Theme:** Identifying with formal faith-based activity, self-ascribed spiritual belief, and prayer as household spirituality. Caregivers (MFC; DFC; SF) described different ways their families understood spirituality within the household. Though some discussed attending a Christian church as a means of social engagement for themselves and their atypical siblings, other caregivers described spirituality as prayer for and a relationship with a higher being, and
(in one case) Jesus. These efforts provided meaning and another source of strength for family members.

**Daily care.** One theme (26 references) resulted for how all caregivers, their spouses, and children engaged in daily care activities to meet the physical and health needs of all family members.

*Theme: Meeting the physical and health needs of family members through supports from spouse and children, atypical sibling receiving support from caregiver, spouse and children in setting appointments for atypical sibling, preparing meals, providing transportation, and bathing/grooming/toileting, and children receiving support from parents to engage in activities ensuring children felt supported and not ignored.* Caregivers explained how each immediate household member contributed to fulfilling or received support. Caregivers did not describe efforts towards supporting their spouses. The married male caregiver described the fear of losing his then-fiancée due to sharing caregiving responsibilities, ensuing burden of this shared responsibility, and limited intimacy within the marital dyad due to the extensive physical care required for his brother with DD.

**Socialization.** Socialization looked at how families achieved the socialization needs of its members through the joys and disappointments related to having friends (Turnbull et al., 2006). One positive theme (9 references) and 1 negative theme (14 references) emerged for this category.

*Positive*

*Theme: Caregiver establishing new friends through social media and persons with shared experiences and establishing a social network for atypical sibling through volunteering, attending church, and participating in activities with children.* Caregivers (MFC) described their
efforts for establishing friendships through social media as well as with other sibling caregivers. Caregivers (MFC; DFC; SM) also described efforts to ensure social participation of their atypical siblings. One male caregiver (SM) explained the increased social interaction of his sister after she moved into a group home. Another caregiver (DFC) discussed how her children were a means of socialization for her brother with DD.

*There are a lot of times when my son will take my brother and go out with his friends; they’ll go bowling or go watch a football game, or something like that. And, in that respect, my son has gotten other people involved in my brother’s life.*

**Negative Theme: Disappointments of friendship due to feeling abandoned by friends because of responsibilities of caregiving, perceived discomfort among friends of atypical sibling, and atypical sibling’s problem behaviors.** Caregivers (MFC; DFC; SF; MM; SM) described feeling disconnected from and abandoned by friends due to the responsibilities of caregiving. In turn, this outcome affected the whole household. One caregiver described pulling away from friends due to a discomfort with his brother with DD.

*It [co-residence] had a negative impact on friendships, definitely. While he [brother with DD] lived with us, it had a very isolating effect. We didn’t have the freedom to go out with people, especially friends that lived close by. But also, to a certain degree, I kind of isolated myself because people are a little awkward with the situation. They don’t know what they should do or shouldn’t do.*
**Economics.** Economics looked at the family’s economic resources to meet the financial needs of its members. One positive theme (11 references) and 1 negative theme (13 references) were cited for this category.

*Positive*

*Theme: Achieving economic stability through traditional employment, taking on additional work, formal supports, and unearned family resources from extended family members and a family trust.* Eleven references emerged where caregivers (MFC; DFC; SF; SM) described how economic stability was achieved for the household. Efforts included traditional employment, taking on an extra job, and achieving government supports. Two caregivers (SF; SM) each received income through unearned family resources, including one caregiver (SF) receiving financial support from her father and another (SM) through a family trust.

*Negative*

*Theme: Economic struggles due to reduced work hours or inability to work due to caregiving demands, pride in not accepting government handouts, limited government resources, and no savings from extended family members.* Thirteen references emerged for this theme where caregivers (MFC; MM) described impediments to achieving economic stability within the household. Caregivers (MFC; SF) discussed having to reduce their work to part-time or being unable to work at all. Many caregivers (MFC; MM) described the struggle related to attaining formal supports. One caregiver (MM) discussed how his mother's illness diminished the funds built by her to support his brother with DD.

*I am going to be in my fifties by the time I will have established a career, moved into that career and be making more money. But, I always assumed, because I work in IT, that I was going to work a career and get to a point where I*
had enough money between the savings we planned on having and the money I am making that my brother wouldn’t even need services. He didn’t grow up receiving services; that was not part of the plan. But then my mom got cancer and she passed. So, the savings accounts weren’t anywhere near where I thought they would be. My career was still young. I had just gotten out of my Master’s program a couple of years prior. Siblings in my position are considerably older than me and have a completely different set of issues.

**Recreation.** Recreation considered play and leisure time in which family members participated e.g., hobbies, sports, and/or games (Mahon, Mactavish, & Bockstael, 2000). All caregivers equally described both positive (15 references) and negative (4 references) aspects related to engaging in leisure activities as well as limitations to having recreational involvement.

*Positive*

Theme: Described recreational activities involving family members, including vacations, engaging in local entertainment, going to the movies, attending church, and participating in *Special Olympics*. Fifteen references were presented where caregivers described different activities in which family members engaged in some type of leisure activity.

*Negative*

Theme: Described difficulties being able to participate in recreational activities due to caregiving burden and role captivity, atypical sibling’s problem behaviors, and difficulties related to being unable to plan in advance. Though caregivers described types of recreational activities, they also discussed difficulties being able to engage in recreation due to the responsibilities of caregiving. One caregiver (DFC) discussed feeling captive to the role.
I think the most challenging thing is not having any spontaneity.

Sometimes I feel trapped; I have to plan so far in advance to do something out of work, things like that. It gets planned around whether my son can take care of my brother. Not a lot of people understand that.

**Education.** Emphasis on education can indicate opportunities for employment and quality of life (Hanson, 2004). There was a strong emphasis on education among families, including 1 positive theme (8 references) and 1 negative theme (1 reference).

**Positive**

Theme: Emphasis on education, including importance of having completed or completing higher education for caregiver, spouse, and children (attending and/or planning to attend college). Caregivers placed a strong emphasis on education, describing the importance of having completed, in the process of completing, or engaging their children in higher education. Almost all caregivers (n=9) had engaged in some level of undergraduate or graduate education. In addition, all caregivers’ children (18 years and over) but one was engaged in or had completed an undergraduate degree or higher. One caregiver discussed the energy she and her husband contributed to education.

*I go to work for fun, but I don't really hang out with friends right now. My husband and I are finishing up our masters. So that pretty much takes up on most of our time. I used to work in law enforcement, but I had to leave the sheriff’s office to take care of my sister. I got to the point that I had to be at home because my sister didn’t have as much companionship or funding as she does now.*

**Negative**
Theme: Inability to continue education due to caregiving duties. One caregiver (SF) discussed her frustration and disappointment for being unable to continue her higher education due to the limited instrumental supports from her extended family (i.e., father and sisters).

I was told “Your mother would be very proud [for taking on the caregiving role] and your brother is blessed.” I don’t know if we ever appreciated what it took for my mom to raise my brother. It’s a bitter pill to swallow sometimes, and I feel under-appreciated. In Maryland, there’s a type of waiver program where I could actually get paid to be a caregiver because I’m a sibling. I want to stay home, go to school and finish my schooling. My brother is three full-time jobs and I’m not exaggerating. The stress that you are under. I want to complete my Bachelor of Science in Human Services, and I want to get back into the public school system as a behavior specialist. I was in the public school system for seven years before this.

Family life cycle (see Table 4.25). The family life cycle contains different developmental stages the family and its members must achieve before moving to the next stage (Turnbull et al., 2006). Transitions are periods of adjustment between stages where members master new skills and milestones and take on new roles to get ready for the next developmental stage (Carter & McGoldrick, 1999; (Poiner, Romito & Husney 2014). Transitions influence change to the family’s characteristics, interactions, and functioning; however, off-time [unexpected] transitions can occur that make transitioning to the next developmental stage
challenging, as well as create difficulties with relationships and future transitions, and emotional and stress-related problems (Poinier & Romito, 2014).

Table 4.25. Family Life Cycle.

<table>
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<tr>
<th>Stages in Adulthood (Categories)</th>
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<tbody>
<tr>
<td>Leaving home as a single adult</td>
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<tr>
<td>Coupling/marriage</td>
<td>2 (SF [n=1]; MM [n=1])</td>
<td>.20</td>
</tr>
<tr>
<td>Families and young children</td>
<td>1 (MFC [n=1])</td>
<td>.10</td>
</tr>
<tr>
<td>Families and adolescent children</td>
<td>2 (MFC [n=2])</td>
<td>.20</td>
</tr>
<tr>
<td>Launching adult children</td>
<td>3 (MFC [n=3]; DFC [n=1])</td>
<td>.40</td>
</tr>
<tr>
<td>Families in later life</td>
<td>1 (SM [n=1])</td>
<td>.10</td>
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</table>

In this dissertation, sibling caregivers each shared the experience of an off-time transition (i.e., planned/unplanned transition of a sibling with DD from parental to sibling co-residential care) within the developmental life stages of adulthood, including: coupling/marriage (SF [n=1], MM [n=1]), families and young children (MFC [n=1]), families and adolescent children (MFC [n=2]), launching adult children (MFC [n=3], DFC [n=1]), and families in later life (SM [n=1]) (Carter & McGoldrick, 1999; Turnbull et al., 2014).

Eighty percent of caregivers (MFC; DFC; MM) were married and/or had children. One caregiver (SM) was retired. This off-time transition influenced the dynamic of each household, including their characteristics, interaction, and functioning. From a life cycle orientation, seven caregivers assumed the caregiving role in middle adulthood (Hutchinson & Oltedal, 2014) where individuals are likely more focused on family. In this regard, there was likely a stronger willingness to take on caregiving. Two caregivers fell within the stage of early adulthood; though one caregiver had a child, both had been married for a shorter period of time. This stage assumed a greater emphasis on affirming the long term relationship and entrenching a professional life. For the married male caregiver, he described the difficulty of his brother’s physical disability as a central reason for sourcing his alternative residence. For the married female participant with a child in early adulthood, she discussed always knowing she would assume the caregiving role;
however, she described her husband’s difficulty adapting to the changing dynamic. Both instances may provide examples of a greater focus on building the relationship at this life stage. The single male caregiver fell within the life stage of old age and recognized his own ‘lived life’ as a reason for ensuring the security of his sister with DD in a group home (Hutchinson & Oltedal, 2014). When considering family life cycle and life stages, one caregiver (MFC) in middle adulthood provided the following narrative.

I am who I am, but the caregiving is relentless. It’s not like the big bird grows up and flies away. The baby bird is plateaued at best, and then will decline.

And there I meet what my mother must have met.

Summary

Family characteristics.

Family: definition, size and form. Though there is some variability with respect to the size and form of families, caregivers in this study shared similarities. When considering co-residence, all female caregivers co-resided with their siblings with DD. Both male caregivers formerly co-resided with their atypical siblings but sourced alternative residence, each three years prior to participating in this study. Regarding marital status and family form, six caregivers were married to opposite sex spouses at the time their sibling with DD transitioned to sibling co-residence. Only one female caregiver was married for a second time due to a spouse’s death; one caregiver divorced two years prior to transition and two were single. Since most caregivers remained married prior to and after the transition of their sibling with DD to co-residence, The marital dyad and spouses in general were considered a key support to the caregiver in his or her role. In addition, all married female caregivers and the divorced female caregiver had children,
emphasizing the importance of family and likely, the obligation and commitment they felt towards their role.

With respect to birth order, most siblings self-identified as being the oldest sibling and only 3 reported being the lone sibling (including both male participants). It is uncertain if male caregivers would have been expected to take on the caregiving role if there was another typical sibling of a different gender or birth order. For extended family, three female caregivers had parents but still took on the caregiving role. For one female caregiver, her mother was ill and physically unable to continue caregiving. Two female caregivers each had a physically able parent, one father who was married and one recently remarried. But the fathers absolved themselves of their caregiving duties, reflecting a patriarchal culture where women traditionally accept the caregiving role.

**Caregiver orientation and values.** Caregivers shared similar cultural features that reflect a Euro-American culture valuing self-reliance, individualism, and competition (Hanson, 2004). In this context, individualism and a systems-centered approach is emphasized over collectivism, that includes a stronger focus on individual rather than group goals. This value also considers a relationship-centered approach (i.e., where help is solicited from a macro level [i.e., federal/state community resources]) over relationships between persons to solve problems (Hutchison, 2010).

With respect to gender, most co-residential caregivers were female; both male caregivers formerly co-resided with but sourced alternative residence for their atypical siblings. This delineation reflects the gendered principle of caregiving (Hutchison, 2010). Age recognizes individuals’ experiences, responsibilities and future goals, as well as stage in the life cycle (Hutchison, 2010). Seven caregivers ranged in age from 40 to 65 years indicating that caregivers
took on their role in middle adulthood (Hutchinson & Oltedal, 2014). At this life stage, individuals may focus more so on family suggesting a stronger willingness to take on caregiving. Though two caregivers were in early adulthood (aged 35 years and 37 years respectively), the 35 year old caregiver (MM) was recently married, suggesting a greater focus on affirming his long term relationship, establishing a professional life, and a greater willingness to source alternative residence for his sibling with DD. The other 37 year old caregiver (MFC) reported how her spouse found co-residence with her brother with DD contributing to frustration for what is desired as a long lasting, supportive relationship. The 69 year old caregiver fell within the life stage of old age, and recognized his own ‘lived life’ as a reason for ensuring the security of his sister with DD in a group home (Hutchinson & Oltedal, 2014).

Most caregivers identified as Caucasian (n=9), and 1 identified as African American (n=1). However, given the similarity in age and each sharing the experience of growing up with a disabled family member, caregivers understood and identified with the misconception of disabled persons within the broader society (Hutchison, 2010). All caregivers spoke English as what was observed as their primary language. There was a similarity among caregivers regarding religions. Seven caregivers reported as Christian or Catholic. One reported as Quaker but explained she grew up Catholic and her husband was a non-practicing Jew. Two caregivers did not disclose their religion. However, there was no indication that caregivers did not share similarities regarding customs and beliefs, and holidays.

Eight caregivers worked, including six who were employed full-time, and two employed part-time. One part-time caregiver reported receiving a stipend from the state for caregiving. Two caregivers reported not working. In one case, the caregiver was supported by her living father. In the other case, the caregiver reported the benefits of receiving a stipend for her
caregiving duties. Income indicates the availability of resources as reflected by employment (Hutchison, 2010).

When considering geography, caregivers lived in states representing 4 of 5 regions throughout the United States, including the Northeast, Midwest, Southeast and Southwest. No caregivers lived in the Midwest. Nine caregivers reported former frustrations and struggles receiving financial and service supports for their siblings with DD. One caregiver, however, who lived in Arizona positively described the immediate availability of services for her brother and sister with DD, both who had transitioned to her home from Illinois (confirmed by two caregivers [MFC; SM] as having an underfunded system).

Finally, there was variability among caregivers regarding disability type. Both male caregivers described the physical challenges of providing care to their siblings with DD due, in part, to their siblings’ physical disabilities. These difficulties were identified as an integral component of their decision to find alternative residence for their atypical siblings.

Life management skills. Caregivers described different problem solving strategies as part of the immediate family’s cultural dynamic. When considering passive appraisal (i.e., setting aside worries), caregivers mostly described letting go of things they could not control. For caregivers with spouses and/or children, they discussed sharing responsibilities and decision-making with their spouses and children as a tool to manage worries. This finding infers a greater willingness to tackle changing dynamics when there are dependable family supports. Caregivers (SF; SM) with no familial supports such as a spouse or children described feeling challenges within their caregiving duties. Empathy as a form of reframing was also a strategy caregivers used towards themselves and with other family members, and between family members.
Few references emerged for spiritual supports as a vehicle for attaining comfort and guidance. Spiritual support, in this regard, was described as developing a relationship with a higher element outside of an organized religion. A number of references emerged that described how caregivers experienced social supports as a means of emotional and practical help. These included maintaining friendships with long-time friends, developing new friendships with other individuals who shared a similar experience, receiving direct support from family members (i.e., spouse and children), and in one case, receiving support from an aunt. There were many references observed for professional support. Professional support considered past and present efforts towards professional and agency supports described by caregivers. For two caregivers, spousal and family counseling was an opportunity for receiving professional assistance. Caregivers also identified different formal supports (e.g., day program services) for their atypical siblings.

*Family interaction.*

*Factors Influencing Family Processes.* When considering roles, caregivers assuming the parental role to their sibling with DD emerged as the most significant role shift within the family system. Caregivers with a spouse and/or children also described dividing roles suggesting responsibilities are covered across family members that can ease the burden on caregivers or other family members. Power distributions was described in terms of struggle that involved the caregiver and/or children asserting their power to establish control. This finding can assume that power and control are the means for some family members (i.e., caregiver and/or children) cope with and manage the quickly changing dynamic following the transition of the caregiver’s sibling with DD to co-residence. Communication exchange was reportedly mostly positive among caregivers with a spouse and/or children where members apprised each other of issues.
and solicited support. A small number of caregivers described a poor information exchange with extended family resulting in frustration and greater challenges in the caregiving role. One caregiver discussed her angry response to situational stress that may also represent frustration with caregiving challenges and lack of support. A small number of caregivers described establishing rules for their atypical siblings and young children (i.e., one preadolescent child and one pre-teen child) to set boundaries and establish household order.

Cohesion. Cohesion was viewed according to boundaries (emotional bonding between members), engagement and levels of independence among family members. Caregivers with a spouse and/or children mostly described open boundaries, positive emotional bonding, and feelings of positive and supportive engagement within the immediate family unit, indicating positive cohesion within the family unit. Immediate family members have a greater understanding of each other and may adapt more easily to transitions since they are more cohesive as a unit. Though a small number of references cited examples of disengagement within the immediate family unit, more examples referenced lack of engagement between the caregiver and extended family members, resulting in the caregiver feeling unsupported and captive to the caregiving role.

Level of Independence. Regarding level of independence, caregivers described the increased self-growth and growing independence of their siblings with DD following after transitioning to the sibling’s co-residence. However, they described a loss of independence among themselves, and in some cases, spouse and children as a result of the transition.

Adaptability. A large number of references described positive ways caregivers adapted to the new family unit demonstrating resilience among caregivers and family members for achieving stability and balance. A small number of references suggested difficulty immediately
following the transition that resulted in immediate challenges regarding uncertainty with the new changing dynamic among family members. Some caregivers also described problem behaviors among their siblings with DD to who were trying to cope with the changes and new environment.

**Family functioning.** Family functioning is composed of key categories representing outputs whose outcomes reflect the family’s interactions. A large number of references were cited for positive physical and verbal affection within families as a whole and between family members. This finding reflects the positive interaction and cohesion described by most caregivers with a spouse and/or children. A small number of challenges were described by caregivers related to low verbal and physical affection with their atypical sibling, spouse and extended family. Regarding self-esteem, most caregivers described increasing self-esteem related to the increasing independence of their siblings with DD; however, caregivers cited low levels of self-esteem for themselves and among family members due to a loss of freedom related to greater contribution to caregiving. Spirituality was represented as attending church, self-ascribed spiritual belief, and praying as a household. With respect to daily care, the atypical sibling required the greatest needs that were fulfilled by the caregiver and other family members, if available. Caregivers’ adolescent and pubescent children reflected needs in daily activities. In some cases, spousal distance may reflect a greater desire for feeling some fulfillment in daily activities; however, caregivers described the contributions of themselves and their older children to support the daily activities of family members.

Regarding socialization, caregivers described how caregiver burden, perceived discomfort among friends and atypical sibling’s problem behavior affected the socialization within the family unit. In one case, the caregiver discussed the adjustment of her young
adolescent daughter to the co-residence of her brother with DD. Most caregivers reported achieving economic stability through employment and receiving formal government supports. Though some caregivers described reduced work hours to fulfill caregiving duties, there was no appearance that co-residence restricted other family members from engaging in economic activity. Caregivers provided references describing efforts in which family members engaged in recreational activities together, but impediments to recreation followed the atypical sibling’s difficulty engaging in recreation and need to plan ahead. Finally, there was a strong positive emphasis within families related to education. Thus, among all caregivers, all children were planning, enrolled in, or had completed college.

**Family life cycle.** Families in this dissertation represent the life stages of early and middle adulthood, and retired age. As described, 80% of caregivers self-described as married and/or having children. One male caregiver was single and retired, and one female caregiver was single and not married. The off-time transition of the brother or sister with DD from parental to sibling co-residential care influenced the dynamic of each household resulted in shifts in familial characteristics, interaction, and functioning. For caregivers in middle adulthood (n=7; MFC; DFC), there was a greater focus on family. In this regard, there was an obligation, therefore there was a greater willingness to take on caregiving, in addition to the overall responsibility to this role. Two caregivers (MFC; MM) fell within the stage of early adulthood that recognizes how young couples are more focused on building their marital relationship. This stage assumed a greater emphasis on affirming the long term relationship and entrenching a professional life. It follows that the married female caregiver with a child described her husband’s lack of support representing his difficulty managing the transition and new family dynamic. For the married male caregiver, he described the difficulty of his brother’s physical disability as a central reason
for sourcing alternative residence. This caregiver described his former fear that the overall physical and financial difficulty of providing care to his brother could have ended the relationship to his then-fiancée. The single male caregiver fell within the life stage of old age and recognized his own ‘lived life’ as a reason for ensuring the security of his sister with DD in a group home (Hutchinson & Oltedal, 2014).

Research Question 4.

*Does level of reciprocity between adult sibling caregivers and their siblings with DD mediate a more fluid transition from parent to sibling co-residential care?*

Reciprocity (see Table 4.26) is defined as the unconditional, mutual exchange of emotional and/or instrumental (i.e., tangible) support between two individuals. In the context of this study, reciprocity focuses on the emotional and instrumental exchange between the caregiver (i.e., participant) and his/her sibling with DD (i.e., care recipient). Features influencing this exchange can involve support from family and extended family members, and formal services to ease the challenges associated with caregiving. One theme emerged for emotional support, and 3 positive and 1 negative theme appeared for instrumental support.
Table 4.26. Reciprocity.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Support</td>
<td>Caregiver helping atypical sibling through the grieving process</td>
<td>MFC</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF</td>
<td></td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>Caregiver receiving supports from family (spouse and/or children participating in and sharing responsibilities) and extended family (financial resources) to help buffer limited reciprocal, instrumental supports from atypical sibling</td>
<td>MFC</td>
<td>12</td>
</tr>
<tr>
<td>Positive</td>
<td></td>
<td>DFC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SM</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caregiver receiving formal supports (i.e., government stipend for care provision; government waiver programs; formal caregiving; and, respite) to help ease limited reciprocal, instrumental supports from atypical sibling</td>
<td>MFC</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SM</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Atypical sibling contributing increased reciprocal, instrumental support than when living with parents</td>
<td>MFC</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DFC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF</td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>Caregiver burden due to expending higher reciprocal, instrumental supports to fulfill atypical sibling’s instrumental needs related to ADLs and IADLs</td>
<td>MFC</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DFC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SM</td>
<td></td>
</tr>
</tbody>
</table>

**Emotional support.** Theme: Caregiver helping atypical sibling through the grieving process. Three references resulted where participants (MFC; SF) described increased reciprocal, emotional support to help their atypical siblings manage the grief and loss of their parents. Though this effort was discussed as a positive motivation, this was a new and challenging experience for the participant and atypical sibling.

*When you have to get up at 5:30 to go to work and she woke you up at 1:00 because she misses mom, you’re tired. It is a little reminiscent of when you have a newborn in your house. So, you think to yourself, it’s okay. I can deal with this. Just keep going, just keep going. For the first year, there were lots of things*
like that because, I think, she was finding her way in a new situation. And, so was I. It was a little exhausting.

**Instrumental support.** Twenty-six positive and 19 negative references from all participants describing various aspects related to instrumental supports.

**Positive**

**Theme 1: Caregiver receiving supports from family (spouse and/or children participating in and sharing responsibilities) and extended family (financial resources) to help buffer limited reciprocal, instrumental supports from atypical sibling.** Participants (MFC; DFC; MM; SM) discussed instrumental support from family members that contributed to help buffer caregivers’ additional responsibilities for their siblings with DD. One participant (MFC) described the support she receives from her daughter.

*My daughter grocery shops. She starts dinner sometimes and picks my sister up. She is my sister’s primary caregiver in the morning and afternoon. For my husband, he has become a babysitter for her on the weekends if I'm not here. We are constantly tag teaming to see who’s going to go where and if my sister has to ride with us. But otherwise, nothing has changed. I still pay the bills and my son mows the grass.*

**Theme 2: Caregiver receiving formal supports (i.e., government stipend for care provision; government waiver programs; formal caregiving; and, respite) to help ease limited reciprocal, instrumental supports from atypical sibling.** Participants explained that any provision of services is a welcome relief. One participant (MFC) discussed the benefit of receiving formal caregiving services for her sibling with DD. “Having caregivers, we feel we can get far enough away from the situation and the day-to-day care that we don’t feel trapped in our own home”.

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Theme 3: Atypical sibling contributing increased reciprocal, instrumental support than when living with parents. Caregivers explained how they required greater instrumental responsibilities (i.e., contributions to daily care [ADLs]) from their siblings with DD than their parents. As described, this exchange resulted in siblings with DD realizing they had greater capabilities and provided a greater contribution to the household.

The laundry is about the most she does. She can also set the dinner table. We may push her more eventually. But, at this point, it’s still very new for her. It would take me standing there and saying “Okay, do this, do this, do this.” My mother never let her do the laundry. But, my mother was a little bit of laundry freak. My sister also washes her own clothes. And, if something gets stained because you put the wrong thing in there, then I’m sorry. If you left the tissue in your pocket and there was tissue all over your stuff, you won’t do that again.

Negative

Theme: Caregiver burden due to expending higher reciprocal, instrumental supports to fulfill atypical sibling’s needs related to ADLs and IADLs. All participants contributed a narrative for this theme resulting in 19 references. Participants’ narratives focused on increased activities of daily living and instrumental activities of daily living, including setting appointments for atypical sibling, meal preparation for/feeding atypical sibling, ensuring the safety of atypical sibling, providing transportation/ensuring physical mobility of atypical sibling, and bathing/grooming/toileting for atypical sibling. One participant (MM) explained his brother’s level of need.

My brother is a very gregarious guy. He’s a happy guy which is pretty much consistent with Angelman’s syndrome. But he is dependent on others for
pretty much all sorts of daily living activities. He’s unable to dress himself. He’s not toilet trained. And, he has barely enough fine motor skills to eat with a spoon. Everything has to be cut up for him. He has problems swallowing. He’s non-verbal and has limited mobility. His fine motor skills are so bad, in some instances, he’s even considered quadriplegic even though he can actually crawl himself around the house. He has no sense of danger, none whatsoever.

Summary. As described, reciprocity involves the emotional and instrumental exchange between the caregiver and his or her sibling with DD.

Emotional support. Emotional support in the context of reciprocity was presented among caregivers as the provision of greater support from the sibling caregiver to assist their atypical sibling with the grief and loss of parents through the transition. Though this effort was positively described, it was also considered a new and challenging experience for the caregiver and his/her atypical sibling.

Instrumental support. When considering instrumental support within a positive context, caregivers described believing their siblings with DD were capable of achieving more than their parents allowed. In this regard, caregivers discussed the success and growing independence of their atypical siblings by requiring a greater reciprocal contribution through more household responsibilities. Caregivers also explained that having additional supports through family (i.e., spouse and/or children sharing responsibilities) and extended family (i.e., financial resources) were believed to be strong contributors to helping them buffer the limited supports needed to help their atypical siblings. Within a negative view, caregivers discussed the
physical challenges by having to expend more energy into activities of daily living and instrumental activities of daily living.

**Research question 5.**

*Is there a difference between how typical siblings anticipate the co-residential caregiving role prior to the transition of their brother or sister with DD from parental to sibling care and the actual experience of the role following the transition?*

Table 4.27. Anticipating Caregiving Role Pre-Transition and Actual Experience Post-Transition.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipating Caregiving Role Pre-Transition</td>
<td>Always knew in early life of assuming/obligation to caregiving role</td>
<td>MFC MM SM</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Never knew</td>
<td>DFC SF</td>
<td>2</td>
</tr>
<tr>
<td>A: Role Adoption</td>
<td>Unawareness of how a caregiver takes on the parental role/role of authority figure, how atypical siblings are like children, atypical sibling's needs, loss of independence/feeling captive to the role, of the helplessness associated with caregiving</td>
<td>MFC DFC SF MM SM</td>
<td>22</td>
</tr>
<tr>
<td>B: Unaware of Aspects Related to Role</td>
<td>Discovering the challenges of the role, including realization that sole responsibility of atypical sibling rests with yourself as caregiver, caregiver's loss of self, caregiver experiencing diminished choices due to role responsibilities, caregiver's need to set boundaries/rules with atypical sibling, caregiver's need to plan/stress of always having to plan ahead, and caregiver's need to take on greater responsibilities</td>
<td>MFC DFC SF MM SM</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Society's seeming patronizing view of caregiving and persons with developmental disabilities</td>
<td>MFC DFC SF MM SM</td>
<td>6</td>
</tr>
<tr>
<td>Actual Experience Post-Transition</td>
<td>Ease of burden on caregiver after atypical sibling transitioned to group home/supported living</td>
<td>MFC DFC SF MM SM</td>
<td>2</td>
</tr>
<tr>
<td>A: What was Learned About the Role</td>
<td>Subthemes--affirmation from outsiders; self-pride in commitment to the role; taking pride in the positive development of their atypical sibling</td>
<td>MFC DFC SF MM SM</td>
<td>14</td>
</tr>
</tbody>
</table>
Anticipating the role pre-transition (see Table 4.27).

Two categories and 38 references emerged for how participants anticipated the caregiving role.

**Role Adoption.** Theme 1: Always knew in early life of assuming/obligation to caregiving role.

As described throughout, most participants (MFC; MM; SM) understood a commitment or obligation to the caregiving role. This understanding was underscored by a parental requirement or inner knowledge. One caregiver (MFC) described her obligation. “I've always grown up knowing that she would be my responsibility when my parents died. There was always a conversation that you know you're going to care for your sister. I don't even remember not knowing.”

Theme 2: Never knew. A small number of caregivers (DFC; SF) reported never knowing or considering taking on the caregiving role, but after the parent passed or, in one case, following a discussion with her siblings, the decision was made to take on the role. One caregiver explained, “The thought [of caregiving] never crossed my mind. But I never thought my mother pass away at such a young age.”

Unaware of aspects related to the role. One theme developed that described aspects of the caregiving role in which participants were unaware.

Theme: Unawareness of how a caregiver takes on the parental role/role of authority figure, how atypical siblings are like children, atypical sibling's needs, loss of independence/feeling captive to the role, of the helplessness associated with caregiving. Twenty-two references emerged for this theme. A key part of this theme was participants’ (MFC; DFC; SF; MM; SM) surprise at how much their siblings with DD were like children. Participants
believed this outcome was due in large part to the years of co-residence between the parent and atypical sibling that developed into a co-dependent relationship and resulted in stagnant personal growth of their sibling with DD. Participants described needing to adopt a parental or authority role to teach their siblings with DD more appropriate social skills. This finding indicates that participants likely believed they would maintain an emotional role pre-transition as this is the role in which they were more accustomed. One participant (MFC) described her efforts for setting boundaries.

*Because there were no boundaries set, my brother felt it was okay to do what he wanted because there were no consequences. Now, it’s not only have I upset my sister, but there’s also something I like that is being taken away. Putting those two things together helps him have a better understanding of what that is. Not that he really knows what a boundary is.*

**Actual experience post-transition (see Table 4.27).** Four themes and 35 references emerged related to how participants described their actual caregiving experience post-transition.

*Theme 1: Discovering the challenges of the role, including realization that sole responsibility of atypical sibling rests with yourself as caregiver, caregiver's loss of self, caregiver experiencing diminished choices due to role responsibilities, caregiver's need to set boundaries/rules with atypical sibling, caregiver's need to plan/stress of always having to plan ahead, and caregiver's need to take on greater responsibilities.* Fifteen references were made by all participants that described some aspect of realizing the actual unanticipated challenges related to caregiving. Both male participants reflected on the past challenges of caregiving as the main impetus for transitioning their atypical sibling to alternative living. One male participant
explained that the feeling of being solely responsible for their sibling with DD was met with feelings of a loss of independence.

I'm not really independent and in control because I'm not free to make all the choices I want to make. And, I'm forced into making some choices. Or, there's a layer of obligation that I can't walk away from. So, I'm not independent from that.

Theme 2: Society's seeming patronizing view of caregiving and persons with developmental disabilities. Six references were made where participants (MFC; DFC; SF; MM) described their perception of how society has a somewhat patronizing view of caregiving for persons with DD. One participant (DFC) explained it as a matter of obligation to a family member. “I've learned that I don’t like it when people tell me that I'm such a great person for doing this. I'm doing what my parents taught me to do.”

Theme 3: Ease of burden on caregiver after atypical sibling transitioned to group home/supported living. Both male participants (MM; SM) explained how the physical needs of their siblings with DD were highly burdensome resulting in the decision to transition them to alternative residence (i.e., supported living, and group home respectively). Though it appeared that both participants may have experienced some feelings of guilt for going against their parents’ wishes, each reported a significant reduction of burden related to caregiving in addition to a more active life for their siblings.

I would say for me the difference between the two situations is my wife and I have our life back. But I also think for him the difference is he has a world that is bigger now. He has more opportunities and his world is more about his needs and his life.
Summary. Anticipating the caregiving role pre-transition was considered according to caregivers’ views of role adoption and how they remained unaware of aspects related to caregiving. In this dissertation, most caregivers understood a commitment or obligation to the caregiving role and described always knowing they would take on this responsibility. A small number of caregivers stated they never knew, but after some thought, decided it was the right thing to do. Regarding aspects related to the role, caregivers described being unaware of: how their role shifted to becoming more of a parent to their siblings with DD, how their atypical siblings remained more like children, their atypical sibling’s needs, the degree of feeling captive to the caregiving role, the helplessness associated with caregiving.

When considering actual experience post-transition, caregivers described a number of role challenges related to responsibilities (i.e., increased responsibilities, having diminished choices due to responsibilities, and being solely responsible for caregiving). Other challenges included always having to plan ahead negating any spontaneity in recreation/leisure, and setting boundaries/rules. Caregivers also described their surprise regarding directly experiencing a patronizing societal view of caregiving and persons with DD. Both male caregivers discussed the ease of burden and increased independence for their siblings with DD once they transitioned to alternative housing. One married female participant with children had formerly placed her sister with DD in a group home. Though the experience was not successful and her sibling with DD returned back to co-residence, the caregiver described a feeling of freedom during the period her sister did not co-reside, but she also described greater mutual independence and reciprocity following her sister’s return to her home.
Other Emergent Factors

Grief and Loss (see Table 4.28)

Given that a major influential factor of this study was the effect on sibling caregivers following the transition of a sibling with DD from parental to sibling co-residential care, grief and loss of the parent emerged as a factor affecting sibling caregivers, siblings with DD, and the caregiver’s family members (i.e., children). Two categories appeared for grief and loss of the parent, including: A. Influential effect on family members of parent’s death, and B. Coping tools.

Table 4.28. Grief and Loss.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on Family Members of Parent’s Death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A: Effect on caregiver</td>
<td>No time to grieve following death of parent due to abruptness of atypical sibling’s transition and adjusting to changes within the household</td>
<td>MFC</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td>B: Effect on atypical sibling</td>
<td>Described post-transition outcomes of atypical sibling related to grief and loss include anxiety, behavioral issues, and confusion understanding parent's death</td>
<td>MFC</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DFC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>MM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SM</td>
<td></td>
</tr>
<tr>
<td>C: Effect on other family members (i.e., children)</td>
<td>Children feeling ignored by mother (caregiver) due to caregiver's new household responsibilities and obligations to atypical sibling</td>
<td>MFC</td>
<td>2</td>
</tr>
<tr>
<td>Coping Tools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caregiver helping atypical sibling with grief and loss by conveying idea that it is okay to speak/think about parent's death; openly discussing/bringing up parent's death; exposing atypical sibling to the reality of death</td>
<td>MFC</td>
<td>7</td>
</tr>
</tbody>
</table>

Influential effect on family members of parent’s death

Effect on caregiver. Theme: No time to grieve following death of parent due to abruptness of atypical sibling’s transition and adjusting to changes within the household. Five references were made for this theme. Participants (MFC; MM) discussed not having time to
grieve for their parent due to the abruptness in which the atypical sibling transitioned to co-residence. Participants inferred an anxiety when adjusting to the household changes leaving no time to grieve. One participant (MFC) explained that there were no ‘things’ in place to help sibling caregivers manage the changes.

*Trying to fill all that stuff out and trying to go through the grieving process was tough. Upon reflection, I wish I would’ve had more things in place that we didn’t have. But I also wish that there would’ve been someone to walk me through the process.*

**Effect on atypical sibling. Theme:** Described post-transition outcomes of atypical sibling related to grief and loss include anxiety, behavioral issues, and confusion understanding parent’s death. All participants described effects on their siblings with DD that they directly related to anxiety, behaviors (i.e., passive aggressive), and a confusion that follows the parent’s death. Most references inferred a lack of understanding about how to grieve. The divorced female participant explained, “You know, I worried about that too, the grieving. I don’t know if he really did grieve or not. That’s a hard thing to know.” The married male participant discussed the possible anxiety his brother felt.

*So, now that my mom is gone and my brother was just living with our stepdad all the time. And now, I’m living with my brother and in my own place. I feel my brother has a lot of anxiety from this and a lot of unprocessed stuff that he might never really be able to fully deal with due to his disability. I would definitely say that if I didn’t have that buffer, it would definitely have been worse.*

**Effect on children. Theme 3:** Children feeling ignored by mother (caregiver) due to caregiver’s new household responsibilities and obligations to atypical sibling. Two references
were made by participants indicating a realization among the sibling caregiver (i.e., child’s parent) a feeling among their children that they were not receiving a level of attention in which they typically received. Participants implied an overall exhaustion managing the change and being unable to provide this needed comfort to their child.

*My daughter was extremely close to my mom. Losing my mom was very hard on my daughter to begin with. But I also think she felt a bit of a separation anxiety between her and me. I can tell it’s because my attention is now divided.*

**Coping tools.** *Theme: Caregiver helping atypical sibling with grief and loss by conveying idea that it is okay to speak/think about parent's death; openly discussing/bringing up parent's death; exposing atypical sibling to the reality of death.* Seven references resulted for this theme. Participants (MFC; SF) described different coping tools focused on helping atypical siblings grieve their parent’s loss. These tools mostly involved communication and talking openly about the event.

*How she dealt with our parents not being here anymore, especially after mom died, was tough. There were times in the middle of the night where she came to the bottom of the stairs and hollered for me; needing me to come down and sit with her because she was crying. I would talk to her about our parents and got her settled back down so she could sleep. I think the hardest part was nighttime, when it was time to go to bed and she thinks about it more. She stays up later then we do.*

**Summary.** Grieving emerged as an unexpected factor that was considered according to its influential effect on family members of the parent’s death preceding the transition. Caregivers described having no time to grieve due to the abruptness of the atypical sibling’s transition and
needing to quickly adapt to household changes. Caregivers described the experience of their siblings with DD, including increased anxiety, behavioral issues and confusion understanding their parent’s death. Some caregivers discussed how their children felt ignored and being unable to provide comfort during the grieving process due to caregiver exhaustion from taking on new household responsibilities. Coping tools were described within the context of supporting atypical siblings manage their grief, including using ‘talk’ about their parent’s death as a means of exposing the reality of death.

**Future Planning (Table 4.29)**

Future planning among parents has received much attention in the literature on parents and their adult children with DD. The current literature shows that little more than 40% of parents have planned for the financial and emotional future of their child with DD (Lauderdale & Huston, 2012). It is unclear how many siblings have prepared for the future of their brother or sister with DD. Sixteen references and 4 themes emerged for how parents and sibling caregivers planned/not planned for the future of their family member with DD.

### Table 4.29. Future Planning.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Theme</th>
<th>Participant Type Providing References</th>
<th>Number of Participants Per Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A: Parents</td>
<td>General mention of plans (no details described or known)</td>
<td>MFC</td>
<td>2</td>
</tr>
<tr>
<td>B: Sibling Caregiver</td>
<td>Established special needs trust, plan outlined in estate, mentally started to plan, and searching for group home/alternative living situation</td>
<td>MFC, SM</td>
<td>6</td>
</tr>
<tr>
<td>No Planning</td>
<td>No formal discussion with parents, parent unfairly relinquished caregiving responsibility to typical child following parent's spouse's death with no future planning support, parents uncertain about what to do, caregiver uncertain about what to do, caregiver procrastinating due to fear of own mortality, and no plan in mind</td>
<td>MFC, DFC, SF, MM, SM</td>
<td>8</td>
</tr>
</tbody>
</table>
Planning

Parents. Theme: General mention of plans (no details described or known). Two participants (MFC) described that their parents had discussed a future plan for their sibling with DD, but provided no details indicating no details were described. This outcome can also indicate that the parents did not include their children in the future plans.

Sibling caregivers. Theme: Established special needs trust, plan outlined in estate, mentally started to plan, and searching for group home/alternative living situation. Six references emerged where participants (MFC; SM) discussed planning for the future of their siblings with DD. One participant discussed her plans that emphasized covering the different aspects to provide supports for the future of her sibling with DD.

*We do have some form of a plan. And actually, an independent living situation is part of that plan. That technically allows my brother to direct his own services. But due to the nature of his disability that isn’t entirely feasible without somebody like me, a caregiver, to give a voice here. We have also established a special needs trust.*

No planning.

Theme: No formal discussion with parents, parent unfairly relinquished caregiving responsibility to typical child following parent's spouse's death with no future planning support, parents uncertain about what to do, caregiver uncertain about what to do, caregiver procrastinating due to fear of own mortality, and no plan in mind. Eight references resulted from participants (MFC; DFC; SF; MM; SM) who described aspects related to how they and their parents did not plan for the future of their sibling with DD. There was a pattern among some participants related to the mortality of themselves and their parents as caregivers regarding
planning. In addition, participants shared a similar experience with parents that they were uncertain what to do, indicating a greater need of information for how to plan for the future of a sibling with DD. One participant referenced the issue of mortality, but her response infers an additional exhaustive responsibility that seemed too overwhelming.

*If I don't make plans, then nothing's going to happen. It's kind of a procrastination aspect. If I don't do it, it doesn't matter. And part of my mind cure is, well, if I am dead then I'm dead. She could go back to our dad. Sorry, I'm not going to be here; you guys figure it out. I know it is a selfish aspect on my part right now and it's something I'm working on.*

**Summary.** Planning was described in the context of future planning according to planning (i.e., planning for the future) and no planning. A small number of participants described their parents making future plans for their siblings with DD, but no details of what was planned was described by caregivers. A small number of caregivers discussed making future plans themselves, including establishing a special needs trust, mentally starting to plan, and searching for an alternative living environment. The majority of caregivers stated they had no formal discussion with parents regarding planning. The idea for not planning was presented in the context of parents unfairly relinquishing responsibility to the caregiver, parents fearing their own mortality, and uncertainty of what to plan for.
CHAPTER 5: DISCUSSION

This chapter summarizes the qualitative results obtained from the narratives of 10 adult sibling caregivers of a brother or sister with a developmental disability regarding their experiences related to well-being and family functioning following the planned or unplanned transition of their brother or sister with DD from parental to sibling co-residential care. Findings are considered within the context of co-residence and family systems. This chapter concludes with implications for social work practice and future research, and the strengths and limitations of the dissertation study.

Context of Transition

This dissertation looked at the post-transitional effect on adult sibling co-residential caregivers and, in this regard, considered type of transition (i.e., planned or unplanned) as an integral factor. Vanhoutteghem et al. (2014) proposed that transitions typically occur in crisis, no matter if planned or unplanned, following the ill-health or death of a caregiving parent. In this study, the issue of fluid and non-fluid transitions emerged from participants’ narratives. Fluid was viewed as the planned or unplanned transition occurring while the parent was still living and the adult sibling caregiver had time to prepare and adjust to the co-residential transition of their sibling with DD. Non-fluid considered the idea that the planned or unplanned transition occurred during a crisis (e.g., parent’s illness or death resulting in inability to continue caregiving) requiring the immediate co-residential transition of their sibling with DD with little or no time to prepare.
For most participants, the transition was planned, but only one participant described the planned transition as fluid. Two participants described experiencing a non-fluid transition and one participant explained her transition was fluid. These findings show that the majority of participants experienced a non-fluid transition. Vanhoutteghem et al. (2014) reported similar results where 8 participants out of 10 (6 planned and 2 unplanned) described the transition of their sibling with DD from parental to sibling co-residential care as non-fluid.

**Discussion of Research Questions**

This dissertation used a structural analysis (i.e., within-case analysis) to attain a response to research question 1 that looked at participants’ individual stories of transition and analyzed how participants described their stories to understand the meaning they ascribed to and identified with the caregiving role. A thematic narrative analysis (i.e., across-case analysis) was used to answer research questions 2 to 5 for analyzing all narratives regarding what participants described regarding the transitional effects on sibling co-residential caregivers as related to well-being, family functioning, reciprocity, and the anticipated and actual experience of caregiving.

**Research Question 1**

*How do typical adult siblings make meaning of their experience and identity as a caregiver following the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care?*

The most notable construct regarding the meaning of participants’ experiences and identity with the caregiving role included duty, responsibility, obligation and a commitment to family. This idea emerged from the narratives of six female participants and supported the finding that typical siblings feel obligated to take on the caregiving role (Dew et al., 2013). The notion also supports the idea that sisters are more involved in caregiving than brothers and
provide higher levels of emotional and instrumental support (Bigby, 1997; Greenberg et al., 1999; Orsmond & Seltzer, 2000; Pruchno, Patrick, & Burant, 1996; Seltzer et al., 1991; Seltzer et al., 2005; Zetlin, 1986). Furthermore, though most typical siblings anticipate future caregiving (Mass Mutual & Easter Seals, 2012), sisters expected to co-reside with their sibling with DD (Seltzer et al., 2005). One participant’s narrative implied a gendered, patriarchal identity associated with the role. This construct follows the gendered characteristic and female orientation of caregiving where women assume the role more frequently than men (Moen & Wethington, 1999).

One female participant described a deep bond with her sibling with DD and always knowing as a child she was committed to supporting her sibling. Connodis (2009) discussed this idea where level of involvement in childhood mirrored level of mutual support and cohesion in adulthood. Both male and female participants described honoring a commitment to parents as how they identified with the caregiving experience. Parents strongly influence a sibling’s decision to take on future caregiving (Heller & Kramer, 2009). Jewell and Stein (2002) found that siblings will provide support for their brother or sister with DD when expected to by parents. Some narratives described an emotional, physical and financial burden of caregiving. This construct supports earlier findings in which co-residence can result in reduced emotional, physical and material well-being (George & Gwyther, 1986; Sonik et al., 2016).

Two stories of transition described the parental relationship with their siblings with DD as co-dependent and enmeshed. This reflects a similar finding by Perkins and Haley (2013) of the existence of reciprocity in caregiving relationships whereby 25.3% of older parental caregivers reported receiving more emotionally than given and 22% reported receiving more tangible help from their adult child with DD than given, suggesting mutual co-dependency does
occur in some relationships. When considering issues related to familial challenges, 20% of typical sibling caregivers reported that having a sibling with DD negatively affected family cohesion, and about 75% of sibling caregivers believed their atypical sibling put some level of strain on their life (Mass Mutual & Easter Seals, 2012).

**Research Question 2**

*What is the effect on typical adult siblings’ well-being after assuming the caregiving role following the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care?*

Burke et al. (2015) found frustration among sibling caregivers regarding efforts to attain and retain disability services, as well as feeling isolated that was related to the caregiving experience. Holl and Morano (2014) also reported a need among sibling caregivers for greater knowledge regarding service availability and access. In this dissertation, study participants described frustration and disappointment navigating for and sourcing formal service supports immediately following their atypical sibling’s transition. This outcome related to dissatisfaction with the community and negative social well-being for its limited service availability. Some participants also described financial instability resulting in negative material well-being due to limited financial and service supports and reduced employment due to increased caregiving responsibilities. Taylor and Hodapp (2012) found that co-residence can result in negative material and social well-being for sibling caregivers. The authors suggested that since many persons with DD were unable to independently function without supervision, formal support services were needed because most caregivers did not have the financial means to provide continual, full-time care. With respect to formal remuneration for caregiving, Burke et al. (2015) found that anticipating caregivers were more ambivalent about paid caregiving compared to
current caregivers who were more positive about receiving a stipend. In this study, participants who received formal financial and service supports through services to their siblings with DD or payment for caregiving services demonstrated more positive social and material well-being.

Negative social, emotional and material well-being were observed in study participants who lived alone with their siblings with DD and/or with no immediate familial support from spouse or children, and those reporting limited financial and social support from extended family. This outcome was reflected in feelings of low self-esteem, low fulfillment and respect/status, resulting in feelings of isolation, role captivity, stress, depression and emotional exhaustion. Evidence suggests that low social support can result in diminished physical and mental health (Saxena, 2015). In addition, co-residence was also associated with reduced mental, financial and social well-being (George & Gwyther, 1986). A more recent study found that 20% of sibling caregivers reported strained interactions with extended family, 30% indicated limited physical, emotional and financial support from family and friends, and 45% reported caregiving to be financially stressful (Mass Mutual & Easter Seals, 2012). In addition, while 67% siblings who anticipated the caregiving role expected to receive physical, emotional and financial supports in the long term, only 58% reported actually getting this support (Mass Mutual & Easter Seals, 2012). In the current study, positive physical well-being was observed as engaging in physical activities such as types of physical exercise; however, participants described these activities as a means to have ‘alone time’ and counter the burden related to caregiving.

It is reported that having a network of family and friends can reduce the interpersonal conflict and stress, and buffer the challenges related to caregiving (Coyle et al., 2014; Saxena, 2015). Although siblings become the expected caregiver to their sibling with DD, their spouses and children also provide support (Vanhoutteghem et al., 2014). Positive social and emotional
well-being were observed among study participants with a spouse and/or children. In the context of friendships, positive social and emotional well-being among participants was observed as maintaining friendships with only the closest friends. Participants also described establishing new friendships with other sibling caregivers in the community and through social media. This result supports the findings of Holl and Morano (2014) who suggested that sibling caregivers desired more information on connecting with other sibling caregivers.

**Research Question 3**

*How does the planned/unplanned transition of a sibling with DD from parental to sibling co-residential care affect sibling caregivers’ family functioning?*

There is little data looking at family systems and family functioning of sibling caregivers and their families following the transition of their siblings with DD from parental to sibling co-residential care.

**Family characteristics.** Regarding family characteristics (inputs), family size increased for all families in this dissertation due to the transition of their sibling with DD from parental to sibling co-residential care. Seven caregivers were married (MFC; MM), two were single (SF; SM), and one divorced (DFC). When considering gender, most sibling caregivers were female. This finding follows the current literature where women more so than men fulfill the caregiving role (Moen & Wethington, 1991). It also reflected the gendered patriarchal characteristic related to the caregiving role (Moen & Wethington, 1991).

In this dissertation, the male caregivers co-resided for 3 years with their siblings with DD but found alternative residence after this period. Findings show that it is more probable that sisters will co-reside with their atypical siblings when parents are no longer able (Burke, Taylor, Urbano, & Holdap, 2012; Seltzer et al., 2005). However, both male participants described
significant physical disabilities of their siblings with DD as a limiting factor regarding their ability to continue co-residential caregiving in the long term. Dew et al. (2013) found that increased physical disability in siblings with DD can affect level of involvement of typical siblings. For birth order, most sibling caregivers (MFC [n=4]; DFC; MM; SM) identified as the oldest sibling and three (DFC; MM; SM) reported as the lone sibling. This finding follows the current literature where siblings (typical sisters) older than their sibling with DD provide greater involvement and support (Pruchno et al., 1996; Seltzer et al., 1991).

Families shared similar cultural values of the Euro-American culture. In addition, 9 families identified as Caucasian and 1 as African American. Regarding religion, seven families reported being part of a Judeo-Christian culture, 1 reported as Quaker. At present, there was limited information looking at the influence of culture, race/ethnicity and religion on sibling caregivers within a co-residential context. However, families presented as following a traditionally Euro-American culture that valued self-reliance and individualism as well as soliciting formal macro supports from the broader community (Hanson, 2004). An unexpected outcome was the limited support received from extended family and friends. Llewellyn, McConnel, Gethng, Cant and Kendig (2010) found greater health among caregivers was associated with support from family and friends, and having a partner. Furthermore, having the support of friends and family can enhance a caregiver’s physical and emotional well-being (Saxena, 2015). These findings indicate that any type of support can help all family members manage the burden related to supporting a member with significant needs.

Six caregivers reported being employed full-time, 2 part-time, and 2 stated they did not work. Two caregivers described receiving a stipend. Though nobody can argue the benefits of employment as a positive means for material well-being, Burke et al. (2015) found that most
current caregivers felt positively about paid caregiving; however, anticipating caregivers were uncertain about paid caregiving. In this study, caregivers positively described the benefits of having a stipend recognizing its contribution to enhancing the family’s overall welfare.

**Family interaction.** Three-fourths of sibling caregivers discussed that having a sibling with DD was stressful to family life (Mass Mutual & Easter Seals, 2012). In addition, 20% stated that having a sibling with DD negatively influenced the cohesion among family members, and relationship with extended family. In this dissertation, caregivers described mostly open boundaries within all familial subsystems indicating strong emotional bonding among family members. Some caregivers described the need to set boundaries within the marital and typical-atypical sibling subsystems to assert authority and establish rules. Caregivers also described positive engagement through participating together in activities and providing each other protection and affection. This result demonstrated the availability of social support among family members. Positive level of independence was described in the context of sibling caregivers encouraging greater independence of their siblings with DD. In contrast, a loss of independence was experienced by all family members, described as caregivers feeling captive to the caregiving role, loss of freedom among all members, and young and adolescent children’s loss of independence for taking on additional responsibilities.

Presently, studies look at the effect on family members following the transition of their sibling with DD, including emotional outcomes (e.g., anxiety and isolation) experienced by all family members, as well as the impact of parents’ lack of planning for the future of their child with DD. Data on the interactional processes among family members and their related subsystems is limited. The Mass Mutual and Easter Seals’ study (2012) found that approximately 75% of typical sibling caregivers believed the relationship with their sibling with DD strained
family life, and 20% reported that having a sibling with DD negatively impacted cohesion in their family, relationship with parents, and interactions with extended family. These findings indicate potential challenges with respect to family interaction. This dissertation found that roles shifted among family members and its subsystems, including caregivers assuming a parental role, marital subsystem adopting a shared decision-making role, and adolescent and adult children taking on a proxy primary caregiving role at times when the sibling caregiver was unable. For power distribution, young and adolescent children struggled to assume power as a means of recognition of attaining attention. Positive communication was described in the context of members working together as a unit to keep each other apprised of duties/challenges and soliciting help. Negative communication emerged as a response to situational stress and ignored attempts from extended family to receive help. Rules involved setting boundaries and creating order to inspire atypical siblings towards greater independence and contribution to a healthier lifestyle and household affairs than when living with parents.

Assuming the parental role was considered one of the most significant role shifts among family members. Early findings showed higher levels of emotional than instrumental support among typical siblings at the point where parents were the primary caregivers (Krauss et al., 1992). As found, following the transition of their atypical sibling to co-residential care, sibling caregivers assumed a parental role indicating a shift from to greater instrumental support. As a result, caregivers discussed the need to establish new rules and boundaries as a means of spurring greater growth and development in their atypical siblings. This direction was also a conscious effort to eliminate the dependency their siblings with DD experienced when living with their parents. It is said that the increasing health challenges facing parental co-residential caregivers results in greater needs from and mutual dependence with their atypical siblings (Ryan, Taggart,
Truesdale-Kennedy & Slevin, 2014). This mutual interdependence is also described as a barrier to future planning (Williams & Robinson, 2001).

Regarding adaptability, caregivers described becoming more self-regulated, taking on new duties, sharing responsibilities with family members, increasing responsibilities and independence for atypical sibling, and encouraging greater respect between young and adolescent children and atypical sibling. Challenges included difficulty for atypical sibling to adapt to the new household. Some caregivers described the emergence of problem behaviors among atypical siblings due to the atypical sibling being unable to grieve the loss of parents and being forced to transition without choice.

**Family functioning (outputs).** Few studies have looked at sibling caregivers who co-reside with their sibling with DD resulting in limited data and presumptive factors about the functioning of caregivers’ families following the transition of a sibling with DD from parental to sibling co-residential care.

Regarding affection, findings in this dissertation show more positive family functioning in larger families (i.e., families with spouses and/or children) to manage the co-residential transition of a sibling with DD when there are more members to share roles and responsibilities rather than one member (e.g., sibling caregiver) to assume the lion’s share of responsibilities. Coyle et al. (2014) reported that challenges following the atypical sibling’s co-residential transition can include providing care to their sibling with DD and mediating the impact of these new responsibilities related to the new role. In addition, informal support, such as help from family members, can buffer the challenges related to living with a sibling with DD (Coyle et al., 2014). A study on sibling caregivers showed that 20% reported having a sibling with DD put a strain on interactions with parents and extended family members (Mass Mutual & Easter Seals, 2014).
2012). This finding supports the results of this dissertation where one sibling caregiver noted challenges within the marital dyad, and three sibling caregivers (MFC; SF) described negative interactions and cohesion with parents and extended family members. Positive physical and verbal affection was found among this study’s caregivers who were married and/or had children, likely indicating that higher levels of shared support available in larger families can result in greater positive emotional bonding, cohesion, and adaptability to mediate the many challenges related to the transition of and co-residence with a sibling with DD.

Positive self-esteem in the context of family functioning was described as the reward experienced among caregivers after seeing the growing independence of the atypical sibling post-transition. This was a common theme among this study’s participants, where caregivers recognized their atypical siblings’ greater abilities to perform regular household tasks than when residing with parents. As a result, sibling caregivers required increased effort of their siblings with DD. This outcome supports findings of Scelles (2002) where, in some cases, sibling guardians desired doing better than their parents. Also, current sibling caregivers reportedly experienced greater enjoyment seeing their atypical siblings become more independent (Burke et al., 2015). Negative self-esteem was related to the spouse and/or children feeling abandoned and neglected, as well as the spouse and/or children feeling overburdened with caregiving duties. This finding relates to caregiver reports that having a member with DD can put a strain on family life (Mass Mutual & Easter Seals, 2012). In addition, 74% of sibling caregivers studied reported challenges balancing their own needs with their family’s and atypical sibling’s needs indicating difficulty providing for the needs of all family members.

George and Gwyther (1986) suggested that co-residence was related to reduced caregiver well-being due to low financial resources, social participation and recreation. Thus, it can be
inferred that co-residence can negatively influence the financial resources, social participation, and recreation among families and their members. In this dissertation, most families described themselves as achieving positive economic stability due to both spouses participating in traditional employment, caregiver taking on additional work, having formal supports, and receiving additional funding through informal family supports. Negative economic stability, however, was related to reduced work hours among caregivers, limited government resources (i.e., formal supports), and having no savings through familial supports. Caregivers in the current study mostly described difficulty maintaining friendships and feeling abandoned by friends. Alternatively, spirituality was considered a means of emotional support as well as opportunities for socialization for some caregivers and their family members. Positive socialization involved establishing new friendships with persons with common through social media and participating with their atypical siblings in local activities. It was unclear the effects of co-residence on the socialization among family members. These results follow the current data where 45% of sibling caregivers surveyed reported financial strain from caregiving, and 30% reported receiving no financial or emotional support from family or friends (Mass Mutual & Easter Seals, 2012).

Regarding daily care, large families, including a spouse and/or children shared responsibilities to support their member with DD and the family as a whole. The atypical sibling required the greatest needs that were fulfilled by the caregiver and other family members, if available. Caregivers’ adolescent and pubescent children reflected needs in daily activities. In some cases, spousal distance may reflect a greater desire for feeling some fulfillment in daily activities. Caregivers positively described the contributions of themselves and their older children to support the daily activities of family members.
Regarding socialization, caregivers described how caregiver burden, perceived discomfort among friends, and atypical sibling’s problem behavior affected the socialization within the family unit. In one case, the caregiver discussed the adjustment of her young adolescent daughter to the co-residence of her brother with DD. Most caregivers reported achieving economic stability through employment and receiving formal government supports. Though some caregivers described reduced work hours to fulfill caregiving duties, there was no appearance that co-residence restricted other family members from engaging in economic activity. Caregivers provided references describing efforts in which family members engaged in recreational activities together; however, impediments to recreation followed the atypical sibling’s difficulty engaging in recreation and need to plan ahead. Finally, there was a strong positive emphasis within families related to the attainment of higher education. Thus, among all caregivers, all their children were planning, enrolled in, or had completed college.

**Family life cycle.** Life stage and circumstances can influence the co-residential transition of a sibling with DD (Burke et al., 2012; Davys et al., 2016). Saxena (2015) believed that lifetime experience with a sibling with DD can influence the decision to take on future caregiving. Saxena (2015) proposed factors related to life stages that can influence siblings’ willingness to take on the caregiving role. In early adulthood (i.e., ages 30 years to late 40s), siblings of persons with DD focus on jobs, relationships and marriage, and having children, but maintain a filial obligation to support their sibling with DD. In this study, participants within this life stage took on the caregiving role alongside marital and employment obligations. Saxena (2015) also proposed that middle-age is met with reduced emotional and physical well-being, and heightened stress and interpersonal conflict that may negatively influence the ability to take on the caregiving role. It is suggested that having a network of friends and family for
social/emotional support can reverse this trend (Saxena, 2015). All caregivers in this dissertation within the life stage of middle adulthood were female (MFC; DF; SF), and the majority felt an obligation and duty to assume the role. Only the divorced and single female caregivers had not planned assuming this responsibility. But some of the caregivers (MFC; SF) within this life stage reported reduced economic and physical well-being, and there were claims of reduced support from extended family and friends. For caregivers in later adulthood (i.e., 60 years of age and older), it is proposed that physical and cognitive changes can hamper the ability to perform caregiving duties. In this study, the single male caregiver who met this criterion reported physical difficulties that influenced his decision to source alternative housing (Saxena, 2015). The proposed ideas of Saxena (2015) did not include caregiving in the context of co-residence.

**Research Question 4**

*Does level of reciprocity between adult sibling caregivers and their siblings with DD mediate a more fluid transition from parent to sibling co-residential care?*

Reciprocity was described as the emotional and/or instrumental exchange between the caregiver and his or her sibling with DD. Earlier data found that typical adult siblings mostly provide higher levels of emotional than instrumental support to their siblings with DD when not assuming the caregiving role (Grant, 1989; Krauss & Erickson, 1988; Krausset al., 1992). In this study, caregivers described a shift from a prior emotional support to their siblings with DD towards a more instrumental role providing for the care of their atypical siblings.

Emotional support was represented in the context of providing emotional support to help their siblings with DD cope with the loss of parents and transition into the new household. Though typical siblings framed this experience as positive, they also described this effort as challenging. At this point, there is little data from a social work orientation looking at grief and
loss as related to emotional reciprocity between caregivers and transitioning atypical siblings. Though caregivers may feel an initial sense of personal benefit and greater purpose for providing emotional support to their sibling with DD, the lack of reciprocal support combined with the additional physical duties of caregiving can become overwhelming.

Ryan et al. (2014) described the relationship between caregivers and adults with ID as mutually supportive. Perkins and Haley (2013) found increased disadvantage of tangible reciprocity (i.e., instrumental support) among parental caregivers and their children with DD was associated with increased depressive symptomatology, poorer mental health, and a decreased desires to find alternative residential placement for their adult child with ID, yet some caregivers reported receiving more tangible help from the adult child with DD than they gave – suggesting mutual dependence (Perkins & Haley, 2013). Within the structural analysis of this study, three participants also characterized the former relationship between their caregiving parent and sibling with DD as co-dependent. In the context of reciprocity, sibling caregivers discussed requiring greater household responsibilities of their siblings with DD based on a belief that their siblings were capable of more than parents allowed. Burke et al. (2015) described sibling caregivers’ enjoyment seeing their siblings become more independent, but caregivers also explained that having additional informal and formal supports through family (i.e., spouse and/or children sharing responsibilities), extended family (i.e., financial resources), and community resources (e.g., day program and respite services) were believed strong contributors to helping buffer the limited supports needed to help their atypical siblings. As reported by participants in this study, most caregivers’ parents had not organized any formal services for their siblings with DD.
Research Question 5

*Is there a difference between how typical siblings anticipate the co-residential caregiving role prior to the transition of their brother or sister with DD from parental to sibling care and the actual experience of the role following the transition?*

Level of involvement in childhood reflected level of cohesion, contact and mutual support in adulthood (Connodis, 2009; Dew et al., 2013). Caregivers in this dissertation described a sense of obligation and always knowing they would be responsible for their atypical sibling in adulthood. Though a small number of caregivers discussed never knowing they would assume the role, caregivers also discussed a lack of awareness for how they anticipated the role with respect to how their atypical siblings remained like children, a helplessness associated with caregiving, feeling captive to the caregiving role, and how taking on caregiving results in a shift from being a sibling to adopting a parent role.

Participants in this study discussed parents’ limited willingness to transition their children with DD towards formal residential services. Given the extensive waiting lists and poor funding availability through formal supports, if residential services are not achieved prior to a parent’s illness or death, it is likely that co-residential caregiving will fall to a sibling. In this study, two married female caregivers with children successfully secured alternative residential services while the parent was still the primary caregiver. In both cases, however, the parent withdrew their adult child with DD from the residence due to being unable to live without their child with DD. This outcome exposes the potential co-dependence that existed within the parental-atypical sibling dyad. In addition, some caregivers discussed how their parents wanted the sibling to assume the caregiving role. Jewell and Stein (2002) found that typical siblings will provide care support to their sibling with DD when parents expect it. Parents also expect the same level of
involvement and care that can place additional burden on the typical sibling who is balancing his
or her own familial commitments (Davys et al., 2011). Despite this expectation, many sibling
caregivers discussed successful efforts to stimulate greater independence and growth for their
atypical siblings.

While caregivers described a number of challenges regarding their actual experience
post-transition (i.e., increased responsibilities, having diminished choices due to responsibilities,
and being solely responsible for caregiving), other challenges included setting boundaries/rules,
and always having to plan ahead negating any spontaneity in recreation/leisure. Caregivers also
expressed feeling patronized as a martyr for taking on the role reflecting a discomfort with how
society views caregiving and persons with DD. Both male caregivers described the increased
independence for their siblings with DD and the obvious independence for themselves once they
transitioned their atypical siblings to alternative housing.

Other Emergent Factors

Grieving

Grieving for the loss of the parent was considered according to its influential effect on the
sibling caregiver, children, and sibling with DD during and following the co-residential transition
of the atypical brother or sister. The death or incapacity of a parent who has provided a lifetime
of support, in addition to the loss of home and supportive networks, can be troubling for a person
with DD (Llewellyn et al., 2004). In many cases, the abrupt transition of a person with DD
leaves little opportunity to grieve and process the loss. Persons with DD rarely have children
and/or marry, and may not have immediate family members to depend on for support as they age
(Dew et al., 2008).
In this study, caregivers described having little grieving time for themselves when the planned or unplanned transition is non-fluid and results from a crisis. As a result, all family members were required to quickly adapt to household changes due to the addition of a new member with DD. In this study, caregivers described their siblings with DD as having increased anxiety, behavioral issues, and confusion understanding their parent’s death. Some caregivers discussed how their own children felt ignored and being unable to provide comfort during the grieving process due to taking on new household responsibilities. This report may indicate feelings of guilt among caregivers for being unable to fulfill their traditional duties for other family members. Only one sibling caregiver (MM) with no children, however, discussed the post-transitional effect on his then-fiancée. This caregiver fell within the life stage of early adulthood and was beginning his career and relationship. He discussed concerns of potentially losing the relationship. He praised his partner for her continued support who he described as having no real responsibility to his commitment. Vanhoutteghem et al. (2014) found that while spouses and children participated in providing support, family members were relatively unprepared for the transition. Vanhoutten and colleagues also found that siblings-in-law were not asked about their opinions and believed they had no alternative but to support the decision. In this dissertation, sibling caregivers described using exposure as a coping tool for grief that involved discussing and bringing up their parent’s death. This can also be considered a way of managing grief collectively.

**Planning**

Much attention has been given to planning among parents for the future of their adult child with DD. Less than 40% of families have made future plans for their member with DD due, in part, to uncertainty and difficulty facing their own mortality (Lauderdale & Huston, 2012).
But parents of children with DD are often overwhelmed and may forgo their atypical child’s future needs because present needs such as providing direct, informal care may seem more important (Lauderdale et al., 2010). Parents may also be indecisive about future plans due to the unavailability of workable solutions (Perkins, 2009).

Planning was described in the context of future planning according to planning (i.e., planning for the future) and no planning. A small number of participants described their parents making future plans for their siblings with DD. However, no details of what was planned was described by caregivers. Some caregivers discussed making future plans themselves, including establishing a special needs trust, mentally starting to plan, and searching for an alternative living environment. These results are similar to data that shows 64% of current sibling caregivers were aware of specialized service supports but 29% did not take advantage of the services themselves due to the challenges of balancing their own needs with the needs of their immediate families (Mass Mutual & Easter Seals, 2012). Caregivers also stated they had no formal discussion with parents regarding planning for the future. The idea for not planning was described as parents unfairly relinquishing caregiving responsibility to the sibling, parents fearing their own mortality, and uncertainty about what to plan.

**Implications for Social Work Practice and Future Research**

The transition of a sibling with DD from parental to sibling co-residential care has a significant effect on the sibling caregiver’s wellbeing as well as family functioning. At this point, sibling co-residential caregivers remain not well known or understood given the limited data available for considering implications and future research related to social work practice.
Practice Implications

Social work practitioners in the community and within healthcare settings must become aware of and identify families of a member with DD in which a typical sibling may assume the caregiving role following the transition of a sibling with DD from parental to sibling co-residential care. To support this vulnerable group, social workers must consider the following key areas: informal supports, formal supports, and future planning.

Informal Supports

Family and extended family members. In this dissertation, sibling caregivers with a spouse and/or children demonstrated high social and emotional wellbeing regarding positive familial supports; however, some caregivers with pre-adolescent and adolescent children described a sense of guilt for being unable to provide their children the same attention level as given prior to the transition of their sibling with DD. This post-transitional outcome was due to the unanticipated needs of and care provision to their co-residing sibling with DD. In addition, though most sibling caregivers described their spouses as supportive, one caregiver reported her husband had little involvement to support her caregiving responsibilities and another described how her husband would inappropriately involve himself in situations related to her sibling with DD. Furthermore, some sibling caregivers (i.e., MFC; SF) further described a lack of support from extended family, including their siblings with no disability who averted responsibility to support their sibling caregiver as well as limited parental support from two siblings whose fathers were still living. Social workers can provide counseling supports to sibling caregivers and their families to manage the changing family characteristics (e.g., increased family size) and changes in the interaction between family members. Changing interactions may involve role and power shifts and shifts in individual responsibilities. To manage these changes, social workers
can help families adopt positive, open communication skills that lead to stronger cohesion, proper boundaries, and greater ability of family members to adapt and manage the changing dynamic. Promoting open communication and cohesion can also result in greater affection within families and more positive overall functioning.

**Social support networks.** Many sibling caregivers in this study reported that the responsibilities and burden associated with the caregiving role resulted in little time to maintain past friends, as well as engage in recreational and leisure activities. Thus, many caregivers maintaining only the closest friendships but losing much of their social network. In turn, sibling caregivers identified new friendships with siblings in common through local activities or making connections with stakeholder groups through social media. Social workers recognize the importance of human relationships and must establish or seek out opportunities for sibling caregivers to network and provide social supports to each other. These efforts can include local outings with other sibling caregivers, as well as seeking out online sibling groups through social media.

Social workers can assist future sibling caregivers by identifying local community groups as well as groups on social media. Advocating for state agencies to establish supporting networks is another avenue to help siblings connect.

The transition of the sibling with DD to sibling co-residence care was described as influential on young and adolescent children. Caregivers inferred a sense of guilt for their inability to manage the challenges of their transitioning siblings with DD and be more attentive to their children. Considering that caregivers reported a drop in recreational and leisure activities, social workers can advocate for respite services that would allow caregivers, spouses and children to engage in such activities.
Counseling to manage the grief and loss of the parent. For most individuals in this study, whether planned or unplanned, the transition of the sibling with DD from parental to sibling co-residential care was non-fluid leaving little time to adapt to the changes within the family. Sibling caregivers in this study discussed challenges, including behavioral challenges among siblings with DD and caregivers’ children, related to not being able to mourn the loss of the parent/grandparent that resulted in the transition. In addition, sibling caregivers suggested requiring their siblings with DD to take on new responsibilities from when they lived with their parent. With this in mind, social workers can provide grief and loss counseling to help family members manage the loss of the parent. This effort can ease the transition of a sibling with DD by establishing greater communication among members that in more positive cohesion. Social workers can also provide family counseling to help members manage the new dynamic by improving communication among family members, establishing boundaries, and following strategies to adapt to the new changes.

Formal Supports and Services

Waiver supports and services for siblings with DD. As discussed in this dissertation, limited formal supports and funding resulted in increased physical and financial burden, and isolation among caregivers. Consequently, sibling caregivers experienced declines in social and emotional wellbeing. In some cases, however, managing the addition of their sibling with DD required a reduction in work hours that caused a decline in material wellbeing. Results of the dissertation suggest some parental co-residential caregivers may have refused, not sought out or not received formal services. Thus, at the point where the parent died or became ill and the brother or sister with DD transitioned to the sibling’s co-residential care, there are not likely to be formal services. Many sibling caregivers discussed the challenges of providing support to
their siblings with DD directly following the transition from parental to sibling care. In part, these challenges were due to the lack of formal services, including limited immediate access to waiver supports services (e.g., respite care, day program services, and stipends for paid caregiving). Combined with the additional household responsibilities for supporting their siblings with DD, siblings described the difficulties associated with getting access to needed waiver support services, including long waiting lists and challenges navigating the system, searching for services. It is important for social workers to look at availability of formal services within the community such as waiver services, respite care, and stipends for informal caregiving to help buffer the potential burden of caregiving on emotional, physical and material well-being. This is a critical component for families where the transition to sibling co-residential care is non-fluid and may occur during crisis. Social workers must advocate for formal supports for sibling caregivers. This role can also include becoming familiar with types of formal supports available and advocating for greater access. It is critical that social workers identify the formal service supports needed for the siblings with DD to help sibling caregivers and their families cope with the changes. Given that caregivers described a growing independence among atypical siblings post-transition, social workers can advocate for and inspire families towards this direction. Although some siblings may choose to remain as the primary caregiver providing co-residence, both male caregivers who sought out alternative living arrangements described decreased physical and financial burden. In addition, these caregivers identified how their siblings with DD were living life in a manner they believed would not occur if they co-resided together.

**Future Planning**

The current study found that parents rarely involved their sibling children (typical and atypical) in future planning, and most sibling caregivers had not planned themselves for the
future of their sibling with DD despite the challenges related to parents not planning. Social workers must advocate for and encourage sibling caregivers to plan for the future of their sibling with DD. These efforts can include establishing a special needs trust for the financial future of their sibling with DD, as well as obtaining formal service supports that include residential habilitation services.

**Future Research**

When considering future research, few quantitative data are available regarding sibling co-residential caregivers of a brother or sister with DD. A descriptive study can help identify the scope of this group. At this point, there is confusion regarding the full range of needs to support sibling caregivers from a clinical and practical orientation. While this dissertation identifies some insight regarding sibling caregivers’ well-being and family functioning, the results are based on the small number of caregivers through a qualitative lens and within the context of a post-transitional effect. More study is needed that involves a mixed methods approach, including quality of life surveys of all family members and observations that indicate the well-being and functioning of family members. Caregivers in this study described an enmeshed, co-dependent relationship between their parent and atypical sibling in the context of limiting their positive development. Since the inclusion criteria required looking at sibling caregivers who had assumed the role within five years, the long term effect of this living arrangement on the sibling caregiver, his/her spouse, and/or children is unknown. Although sibling caregivers described success in reciprocal efforts towards increased instrumental responsibilities of their atypical sibling, it is not certain if aging and its related declines in physical health resulted in the typical-atypical sibling relationship becoming more like the parental-atypical sibling dyad. The potential effect of this outcome was described as dysfunctional within families. Though the data looked at anticipating
and current caregivers, future research can also include a quasi- or experimental study comparing the well-being and family functioning of current and former co-residential caregivers. Finally, having strong social support from family members and friends and engaging in recreational activities are instrumental in reducing social isolation and role captivity among caregivers. Future research can identify how siblings who are not typically visible in the community source these resources. More research is needed to assess ways siblings can establish connections with other siblings. As identified in this study, and within the literature, having strong social support can mitigate the feelings of isolation and captivity associated with caregiving. Finding out how some sibling caregivers cultivate their social resources can help others establish more supportive connections.

Limitations and Strengths

The study presents several limitations. This study is not generalizable to the larger sibling caregiver population, as it is limited for its non-representative sample. For this limitation, the results of this study should be interpreted and applied with caution. Future research should include more diverse groups of the sample regarding, for example, race/ethnicity, socioeconomic status, and the region. This study included geography as a demographic feature regarding the location of participants, but the difficulty in sourcing participants for this dissertation limited the chance of looking at geography and its relationship to this phenomenon.

All efforts were made to ensure the validity and trustworthiness of the data, but the researcher may have been biased based on responses by caregivers. Likewise, there was the potential for social desirability bias among participants where they provided responses they believed would be favorably interpreted by the researcher (Creswell, 2009). These responses could influence how the researcher constructed themes from the data. It is also important to
acknowledge that phone interviews do not allow the researcher to observe body language, which can be a critical component in qualitative research.

When considering the structural analysis of data, only 7 out of 10 participants responded to the researcher regarding their interview. For the thematic narrative analysis, a co-coder for all interviews could have resulted in greater validity regarding identified themes in this dissertation. One interview was co-coded, and another interview was coded by a Professor of Business not related to this field. Neuendorf (2002) proposed that all interviews should be co-coded. In addition, the author suggested that for validity, a consensus of 80% is acceptable and multiple suggestions are necessary for inter-rater reliability.

Despite the limitations, this study had many strengths. Currently, there is limited data regarding siblings as primary caregivers in the context of co-residence. This study also used two approaches for narrative analysis: structural analysis and thematic narrative analysis. The former approach examined how participants told their stories of transition, and constructs were developed to create the meaning of the experience of sibling co-residential caregivers. The latter analysis was used to scrutinize themes across participants to attain a shared view of ideas. The outcome of this study can result in identifying ideas for establishing future quantitative study.

Conclusion

The goal of this dissertation study was to explore the life stories of sibling co-residential caregivers regarding the planned or unplanned transition of their siblings with DD from parental to sibling co-residential care. Areas of focus included the meaning ascribed to and experience of caregiving, effects of this phenomenon on well-being of sibling co-residential caregivers, family functioning of sibling co-residential caregivers, reciprocity between the caregiver and atypical
sibling, as well as how sibling caregivers anticipated the role and experienced the post-transition. Currently, there is scant data providing a comprehensive understanding of this phenomenon.

When considering demographics, participants in this dissertation were representative of gender and birth order relative to caregivers in general, but a large deficit was the lack of diversity in the study sample. More research is needed to look at the role of culture. Considering the context of transition, the initial approach was to look at the influential effect of transition type (i.e., whether the transition was planned or unplanned). While sifting through interviews it became obvious that the process of transition (i.e., whether the transition was fluid or non-fluid [occurred in crisis]) played a greater role for its impact on the well-being and functioning of the caregiver and his or her family. Caregivers experiencing a non-fluid transition described various difficulties, including the lack of formal support from the community and from extended family. This outcome exposed the need for social workers to advocate for greater resources and provide clinical support to help families manage the transition. In addition, the lack of opportunity for family members to grieve the loss of the parent emerged as a significant issue that exposed the need for interventions to manage through the transition process.

The structural analysis of transition stories revealed constructs regarding how caregivers identified with and gave meaning to caregiving. For the most part, caregivers felt a deep obligation, commitment, and responsibility to the role but two stories described the parental-atypical sibling relationship as enmeshed and co-dependent. This perception may have altered the approach of caregivers, inspiring greater independence for instrumental reciprocal support from their siblings with DD.

The thematic narrative review provided responses to the areas of well-being, family functioning, reciprocity, and how caregivers anticipated and actually experienced the role.
well-being, greater positive social and emotional well-being was observed among participants with a spouse and/or children. This finding follows the current recommendation that strongly emphasizes the need for formal and informal supports from the community and immediate family members to help buffer the difficulties associated with caregiving. High physical well-being, such as recreation and leisure, was also observed among caregivers with larger families, indicating that having additional support likely provided greater opportunities to engage in healthy activities. Alternatively, sibling caregivers who lived alone with their siblings with DD demonstrated higher negative emotional and social well-being. Findings showed caregivers felt abandoned by their extended family members indicating more effort was needed to assess ways of soliciting greater support from their social network. Results for material well-being were mixed and not relative to family size. Overall, caregivers did not describe material well-being as a significant issue. For one caregiver, however, negative well-being was attributed to having to take on additional work due to pride in not seeking available government funding. One caregiver described reducing her hours to part-time work due to the demands of caregiving. Another caregiver described not working due to caregiving demands and depending on her father to cover material expenses.

With respect to family functioning, strong emotional bonding was mostly observed for the interactions among family members, yet caregivers emphasized the need to set boundaries within the typical-atypical sibling dyad. This finding can relate to the adjustment of the atypical sibling to his or her new familial dynamic. When considering level of independence, caregivers described encouraging greater development of their sibling with DD, resulting in greater independence and growing self-esteem. Alternatively, caregivers described reduced independence and self-esteem among family members due to the loss of freedom and role
captivity related to the additional responsibilities. Caregivers also described increased loss of independence for their young and adolescent children who were required to take on greater household responsibilities. For larger families, roles and responsibilities were described as being shared among family members. In small families, however, increased burden on the caregiver was observed, especially when the atypical sibling was not able to provide a reciprocal level of support. Rules were explained according to caregivers establishing boundaries with their siblings with DD.

For overall functioning, caregivers described great physical and verbal affection towards each other. But they also described increased efforts among members towards daily activities. Caregivers also discussed an overall reduction in socialization, recreation and leisure activities.

Regarding reciprocity between the sibling and sibling with DD, the outcome of the transition was a shift in the sibling caregiver from providing emotional to instrumental support. Emotional support was framed in the context of providing emotional support to help their siblings with DD manage the grief and loss of parents as well as transition into the new household. Caregivers described this experience as challenging. Recognizing the former relationship between their parent and atypical sibling as co-dependent, caregivers discussed greater instrumental reciprocal responsibilities for their siblings with DD. This effort was based on a belief that their atypical siblings were capable of more than parents allowed. Caregivers heralded this outcome as a great achievement describing the personal growth and independence of their sibling with DD. Indirectly, it was observed that any increased effort from their atypical sibling enhanced their relationship and helped to ease the caregiving burden.

Caregivers in this dissertation described always knowing they would assume the role, but many also discussed a lack of awareness for how they anticipated the role. They described not
knowing how their atypical siblings remained like children, a level of helplessness associated with caregiving, feeling captive to and isolated in the caregiving role, and how taking on caregiving resulted in a shift from sibling to becoming the parent. When considering their current experience, sibling caregivers mentioned a number of challenges including increased caregiving responsibilities, having diminished choices in many aspects of life due to their caregiving responsibility, and being solely responsible for caregiving. Other challenges included the need to set boundaries/rules, and always having to plan ahead negating any spontaneity in recreation/leisure. But caregivers described feeling patronized as a martyr for taking on the role, reflecting a discomfort with how society viewed caregiving and persons with DD. Both male caregivers described the increased independence for their siblings with DD and the obvious independence for themselves once they transitioned their atypical siblings to alternative housing.

For social workers and social work researchers, a major implication is the lack of preparation and planning for the transition. It appears that a family’s adaptability may have been easier given some level of anticipatory guidance with respect to resource availability and counseling to help families cope with the increased demands and responsibilities related to having a new member with DD. This effort can significantly reduce the impact on caregivers and their families.

It is also important for social workers in the community and in health services familiarize themselves with existence of this group and understand the resources needed for support. Further research is needed to initially attain a descriptive view of this population. Lastly, it goes without mention that social work values prescribe advocating for at-risk populations. Social workers must advocate for resources and best practice interventions to help sibling co-residential caregivers and their families achieve a fluid transition to their new roles.
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APPENDIX A: DEFINITIONS OF TERMS

Quality of Life

Felce and Perry (1995) constructed a quality of life model categorized according to three domains: 1) objective life conditions (objective determination of physical, material, social, and emotional well-being, and development and activity), 2) subjective feeling of well-being (satisfaction with physical, material, social, and emotional well-being, and development and activity), and 3) personal values and aspirations (importance of satisfaction with physical, material, social, and emotional well-being, and development and activity). Each domain is organized around five sub-domains: 1) physical well-being, which refers to health, fitness, mobility, and personal safety, 2) emotional well-being that considers the individual’s positive affect, status/respect, satisfaction, fulfillment, faith/belief, and self-esteem, 3) social well-being that looks at interpersonal relationships (family/household life, relatives, friends and social life) and community involvement (activities and events, acceptance and support), 4) material well-being, which refers to finance/income (stability/tenure, security), housing quality (stability/tenure), neighborhood (security), privacy, transport, possessions, and meals/food, and 5) development and activity which looks at competence/independence (choice/control, productivity/contribution), job (productivity/contribution), homelife/housework (productivity/contribution), leisure/hobbies (productivity/contribution), and education (productivity/contribution) (Felce & Perry, 1995).
Figure A-1. Quality of life model (Overall Well Being).

Figure 3 illustrates the quality of life model (also defined as overall general well-being), which shows the dynamic interaction of the domains and sub-domains. It follows that a change in satisfaction (subjective feeling of well-being) can result in a reassessment of one’s personal values and lifestyle. Likewise, a change in personal values can precipitate a change in satisfaction and an objective circumstance. Similarly, a change in some objective aspect of life can alter satisfaction, one’s personal values or both (Felce & Perry, 1995). Though each domain can affect one another, they can also change independently due to external influences. These influences may include one’s developmental history, employment, genetic, social and material backgrounds, peer influences,
age and maturation, and political, social, and economic factors (Felce & Perry, 1995). Considering the effect of external influences, Felce and Perry (1995) highlight the importance of measuring all three domains together to fully comprehend a person’s quality of life and overall well-being.

**Caregiving**

For this study, caregiving is defined as providing assistance and support without monetary reward to a family member or friend that cannot manage without help due to disability or ill-health. Care provision through informal supports (i.e., assistance and support from a family member or friend) is considered one of the most crucial sources of long-term care to persons who are elderly or have a disability (Braddock, Hemp, & Rizzolo, 2008; Reinhard, Given, Petlick, & Bemis, 2008). Duties can involve providing assistance with daily activities, such as eating, getting in and out of bed, bathing, dressing, and using the toilet (Thompson, 2004). But additional responsibilities may include getting groceries, administering medications, making meals, and housework (Thompson, 2004). A principal benefit of family caregiving is the opportunity of keeping the family together, and allowing care recipients to stay in their home and the community (Redfoot, Feinberg, & Houser, 2013; Perkins, Lynn & Haley, 2007).

Care provision to a family member with DD differs from other types of caregiving due to the extensive (often lifelong) duration of the caregiving role (Haley & Perkins, 2004). Given this duration, providing care to a person with DD (depending on level of physical and mental disability) can be extremely taxing on the individual caregiver and significantly impact his or her quality of life.

In families where there is no disability, caregiving is generally understood in the context of *sandwich caregiving*. Sandwich caregiving describes adults (baby boomers born between 1946 and 1964) who inherit caregiving responsibilities for one or both aging parents while also
having parenting responsibilities for their own children (Chisholm, 1999). *Compound caregiving*, however, refers to parents who maintain caregiving duties for their child with DD, and subsequently take on additional caregiving responsibilities for another family member (Perkins, 2010). For a typical sibling, assuming caregiving responsibilities is a complex function considering the breadth and potential immediacy of the new role. As a sibling caregiver, a typical sibling must mediate the responsibilities of managing his or her own family, work responsibilities, support the physical, mental and financial needs of his or her sibling with DD, and in some cases, have additional compound duties to care for an ailing parent.

**Developmental and Intellectual Disabilities**

As defined under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, a developmental disability is considered a severe, chronic disability of an individual that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before the individual attains age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more areas of the following major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and,
5. reflects the individual’s need for a combination of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and individually planned and coordinated.

It should be noted that any person, from birth to age 9, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental
disability without meeting three or more of the above described criteria if he or she has a high probability of meeting those criteria in later life (ADD, 2013). Developmental disabilities include intellectual disabilities, autism, epilepsy, and cerebral palsy. According to the Center for Disease Control, over 17% of children, aged three to 17 years, have a developmental disability (Center for Disease Control [CDC], 2011--http://www.cdc.gov/features/dsdev_disabilities/).

**Intellectual Disability**

Intellectual disability (ID) is defined as a neurodevelopmental disorder involving limitations in adaptive and intellectual functioning (American Psychiatric Association[APA], 2013; Tasse, 2013). While prior measure primarily focused on intelligence level to diagnose ID (assessed intelligence quotient [IQ] of 70 or below; APA, 2000), the current standard mostly considers adaptive functioning (i.e., levels of support) (Tasse, 2013). The following criteria is needed for an ID diagnosis:

1. **Criterion A:** deficits in intellectual functioning (e.g., reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, learning from experience, and practical understanding),
2. **Criterion B:** adaptive impairments (AI) in one or more activities of daily living (i.e., communication, social participation, independent living, and across multiple environments, such as home, school work, and recreation) measured according to three domains:
   i. Conceptual: language, reading, writing, math, reasoning, knowledge, and memory needed to solve problems,
   ii. Social: awareness of others’ experiences, empathy, interpersonal communication skills, friendship abilities, social judgment, and self-regulation, and
iii. Practical: self-management across life settings, including personal care, job responsibilities, money management, recreation, managing one’s behavior, and organizing school and work tasks, and

3. Criterion C: onset of intellectual and adaptive limitations during the developmental period (e.g., individual development from birth to 18 years of age) (Tasse, 2013).

ID is also assessed at four degrees of severity (also known as levels of impairment or intellectual functioning [i.e., mild, moderate, severe, and profound]) (APA, 2013). Degrees of severity are determined through IQ level (typically, at two or more standard deviations [SD] of intellectual functioning from the population mean on standardized IQ measures) and extent of adaptive impairment. Levels of ID are defined as follows: mild ID (IQ within 55-70; <2 SDs, and 2 or more domains in AI), (b) moderate ID (IQ level within 35-54; <3 SDs, and 2 or more domains in AI), (c) severe ID (IQ level within 20-34; <4 SDs, and all 3 domains in AI), and (d) profound ID (IQ below 20; <5 SDs, and all 3 domains of AI) (APA, 2000).

While the terms ‘developmental disability’ and ‘intellectual disability’ are frequently used synonymously, there are important differences (Perkins, 2009). Most notably, intellectual disability specifically refers to a subgroup of the population with developmental disabilities, whose functional impairments result from cognitive and intellectual limitations. Hence, an individual may have a developmental disability, but not always an intellectual disability. For instance, a person with epilepsy is considered to have a developmental disability but may also have normative intellectual functioning. However, persons diagnosed with an intellectual disability will always have a developmental disability.
APPENDIX B: EMAIL AND ADVERTIZEMENT FLIER SCRIPTS

Email Script

“I am a Doctoral student in social work at the University of South Florida. I am engaging in a study looking at the effects on siblings who become the primary caregiver to and co-resides with their brother or sister with a developmental disability after transitioning from the parent’s co-residential care. The purpose of this study is to understand the effects on the sibling caregiver’s well-being and family functioning following this transition. The benefits of this study will be to help social workers learn more about this experience assist sibling caregivers to more fluidly manage this transition. I ask if you would like to participate in this study. By choosing to participate, you will be required to answer a series of questions in one, possibly two, phone interviews, no longer than two hours for the first interview and one hour for the second, about your experience of the transition itself and after the transition. The student will present his assessment to you prior to its presentation/publication to verify the accuracy of his examination. If you would like to engage in this study, please email rglaesse@mail.usf.edu with the following subject line: Want to Participate in Study.”

Advertisement-Flier Script

Doctoral student in social work at the University of South Florida seeking study participants for research on the effects on siblings who become primary caregiver to and co-reside with brother or sister with developmental disability after transitioning from the parent’s co-residential care. The study purpose is to understand the effects on sibling caregiver’s well-being and family functioning. The study benefits are helping social workers learn more about this experience to assist sibling caregivers to more fluidly manage the transition. By choosing to participate, you will be required to answer a series of questions in one, possibly two, phone interviews, no longer than two hours for the first interview and one hour for the second, about your experience of the transition itself and after the transition. Prior to presentation/publication of findings, you will be provided with the assessment of your interview discussion to verify its accuracy. If you would like to participate, please email rglaesse@mail.usf.edu.
APPENDIX C: PARTICIPANT CONSENT

Persons with Developmental Disabilities Transitioning from Parental to Sibling Co-Residential Care: Effects on Family Functioning

You are being asked to participate in a research study looking at what takes place after your brother or sister with a developmental disability transitions from your parents’ home to your home. To participate, you must be:

- 21 years or older,
- the primary caregiver to a brother or sister with an intellectual/developmental disability,
- receive no formal support from a parent due to illness or death,
- live together with your brother or sister.

This study is being conducted as part of a dissertation research project to understand how the transition of a brother or sister with a developmental disability from living with a parental caregiver to living with a sibling caregiver can be achieved with limited disruption. You will be asked questions relating to your story.

This research is being conducted by Richard Glaesser, Doctoral Candidate, School of Social Work, University of South Florida.

By signing this consent form, you agree and consent to participating in this confidential research study. Also, you will receive a copy of this consent form for your records. If you participate in this study, you will be interviewed for approximately two hours to provide your story about the transition of your sibling with an intellectual and/or developmental disability from your parents to your care.

Please be aware that when interviewed you may discontinue your participation at any time. There are no known risks for taking part in this study. Your participation is voluntary and anonymous, and there are no rewards or incentives for participating. Furthermore, all information you provide will be kept confidential and your name will be kept confidential. If you have any questions, please contact Richard (Rick) Glaesser at rглаesse@mail.usf.edu, or at (727) 301-9697.

Thank you for agreeing to participate in this important study.

__________________________________________  __________________
Participant’s signature                        Date
APPENDIX D: IRB APPROVAL

10/25/2015

Richard Glaesser
USF School of Social Work
13301 Bruce B. Downs Blvd., MHC1400
Tampa, FL 33612

RE: Expedited Approval for Initial Review
IRB#: Pro00013759
Title: Transitions of Persons with Developmental Disabilities from Parental to Sibling Co-Residential Care: Effects on Sibling Well-Being and Family Functioning

Study Approval Period: 10/25/2015 to 10/25/2016

Dear Mr. Glaesser,

On 10/25/2015, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within, including those outlined below:

Approved Item(s):
Protocol Document(s):
USF IRB Protocol

Consent/Assent Document(s):
Verbal Consent Form

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:
APPENDIX E: INFORMED CONSENT LETTER

Script for Obtaining Verbal Informed Consent Pro00013759

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. We are asking you to take part in a research study that is called: Transitions of Persons with Developmental Disabilities from Parental to Sibling Co-Residential Care: Effects on Sibling Well-Being and Family Functioning

The person who is in charge of this research study is Richard Glaesser. This person is called the Principal Investigator.

You are being asked to participate because you are a sibling with no disability to a brother or sister with a developmental disability, primary caregiver who co-resides with your brother or sister, 30 to 60 years, have experienced the transition for up to five years, and English-speaking. The purpose of this study is to understand the effects following the transition of a brother or sister with a developmental disability from living with a parental caregiver to living with a sibling who becomes the primary caregiver. This exploration will look at the well-being and family functioning of the primary sibling caregiver.

If you take part in this study, you will be asked to participate in a phone interview and answer questions relating to your story. The interview will last approximately two hours. Once completed, the Principal Investigator will transcribe your story and analyze your story to look at elements relating to well-being and family functioning. The Principal Investigator may request one more phone interview, not lasting longer than two hours, to ensure he gathers all of the information. After the Principal Investigator completes his overall review, he will send his review back to you to verify the accuracy of his analysis. It is asked that you complete your verification within 72 hours.

You have the alternative to choose not to participate in this research study.

You should only take part in this study if you want to volunteer and should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.
This research is considered to be minimal risk.

We will not pay you for the time you volunteer while being in this study.

We must keep your study records as confidential as possible. We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The Principal Investigator and Advising Professors
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety. These include:
  - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
  - The Department of Health and Human Services (DHHS).

If you have any questions about this study, you can contact the investigator Richard Glaesser at 727-301-9697. If you have question about your rights as a research participant please contact the USF IRB at 813-974-5638.

Would you like to participate in this study?
APPENDIX F: INTERVIEW GUIDE

I am interested in learning about your experiences after your (brother or sister) came to live with you. I have some general questions I would like to ask you, but I don’t want you to feel limited to these questions. Feel free to share with me as much as you are comfortable with. I am hoping to understand things from your point of view.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Questions</th>
</tr>
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| General                                        | Tell me a little bit about your family. (Look for: spouse, children, age)  
Do you and your family go to church?                                                                                   |
| Planned or unplanned transition of sibling with DD | How long has your brother/sister lived with you?  
Explain the story of how your brother/sister came to live with you.  
Did you know you would take on the caregiving role?  
Did you plan for this with your parents?  
Did you make plans for your brother/sister if you are no longer able to provide care? |
| Disability type/level of atypical brother/sister | Can you tell me about your brother or sister?  
What is his/her disability?  
Are there certain aspects of __________ behavior/disability that have been more difficult to deal with?  
Can you tell me about the resources available to you and__________? Have you used them? |
| Caregiving role                                 | Is caregiving different than what you expected?  
What have you have learned from this experience?  
What is different about your relationship now with your brother/sister with DD from when you weren’t living together?  
Has the relationship with your spouse changed?  
How did he/she have to readapt?  
Has the relationship with your children changed?  
How did they have to readapt?  
What makes you feel good about caregiving? |
| **What are the difficulties of caregiving?** | What about friends and other family? |
| Quality of life (Physical, Emotional, Social, and Material Well-Being, and Development and Activity (Choice, Control, and Productivity)) | How do you take care of your health? How do you stay positive? What do you do to have fun? Who do you hang out with? Has becoming a caregiver affected your work? Has caregiving affected your income? Do you feel independent and in-control? Do you feel productive? Are you religious? |
| Overall family functioning | Overall, what has changed in your family since brother/sister came to live with you? How have the responsibilities within the family changed? Who does what? Who makes the decisions? Has having your brother/sister made you and your family stronger? How does your spouse/partner help out? How do you children help out? |
| Reciprocity | Does your brother/sister with DD help out? In what way? If there are things your brother/sister cannot do physically, what are other ways you believe he is helping? |
| Demographics (if necessary) | What is your age? What is your spouse’s age? # of children under 18? Gender of children? # of children over 18? Gender of children? Race/ethnicity (White [non-Hisp], Black [non-Hisp], Hispanic/Latino, Asian, American Indian/Alaska Native, Hawaiian/Pacific Islander)? Highest level of schooling (< highschool grad, highschool grad, post HS grad, college grad, post-grad degree)? |
| Anything else? | Is there anything else you would like to add? |
APPENDIX G: MUTUAL CONFIDENTIAL DISCLOSURE AGREEMENT

Vanan Online Services

MUTUAL CONFIDENTIAL DISCLOSURE AGREEMENT

This Agreement is dated the 11th November 2017 and effective upon the date of first disclosure or the date of this Agreement, whichever occurs first, between and among Richard Glaesser (hereinafter "Client") and Vanan Translation. (Hereinafter "Company") (Vanan Translation and Company each are referred to herein as a “Party” and are collectively referred to herein as the “Parties”).

WHEREAS, Company has agreed to provide transcription to Richard Glaesser, is during the course of which the Parties to this Agreement may wish to disclose to each other in oral and written form or in other medium, certain non-public confidential and proprietary information.

NOW, THEREFORE, in consideration of the mutual covenants and agreements contained herein and intending to be legally bound, the parties hereby agree as follows:

1. In connection with the Services, it may be necessary or desirable for a Party to disclose to the other certain non-public Confidential Information. For purposes of this Agreement, "Confidential Information” shall mean all non-public, confidential and proprietary information relating to the Parties, their respective clients and the Services, which has been or will be disclosed by a Party orally or as set forth in writing, or contained in some other tangible form.

2. The receiving Party hereby agrees to hold in strict confidence and to use all reasonable efforts to maintain the secrecy of any and all Confidential Information disclosed by the disclosing Party under the terms of this Agreement and may not disclose Confidential Information without the express, written prior consent of the disclosing Party, with the exception of the following:

   (A) Information that the receiving Party can establish by prior record was already known to them or was in their possession at the time of disclosure and was not acquired, directly or indirectly, from the disclosing Party;

   (B) Information that the receiving Party obtains from a third party; provided however, that such information was not obtained by said third party, directly or indirectly, from the disclosing Party under an obligation of confidentiality toward the disclosing Party;

Vanan Online Services
www.vananservices.com;
US Ph: 866-221-3843
3. The receiving Party may disclose Confidential Information if compelled to do so by a court, administrative agency or other tribunal of competent jurisdiction, provided however, that in such case the receiving Party shall, immediately upon receiving notice that disclosure may be required, give written notice by facsimile and overnight mail to the providing Party so that the providing Party may seek a protective order or other remedy from said court or tribunal. In any event, the receiving Party shall disclose only that portion of the Confidential Information which, in the opinion of their legal counsel, is legally required to be disclosed and will exercise reasonable efforts to ensure that any such information so disclosed will be accorded confidential treatment by said court or tribunal through protective orders, filings under seal and other appropriate means.

4. The receiving Party shall not use the Confidential Information for any purpose other than in connection with the Services. The receiving Party will only disclose Confidential Information to their directors, officers, employees or agents, as applicable.

5. The receiving Party shall take all reasonable steps, including, but not limited to, those steps taken to protect their own information, data or other tangible or intangible property that they regard as proprietary or confidential, to ensure that the Confidential Information is not disclosed or duplicated for the use of any third party, and shall take all reasonable steps to prevent their directors, officers, employees and agents (as applicable) who have access to the Confidential Information from disclosing or making unauthorized use of any Confidential Information, or from committing any acts or omissions that may result in a violation of this Agreement.

6. Title to, and all rights emanating from the ownership of, all Confidential Information disclosed under this Agreement, or any material created with or derived from the Confidential Information, shall remain vested in the disclosing Party. Nothing herein shall be construed as granting any license or other right to use the Confidential Information other than as specifically agreed upon by the Parties.

7. Upon written request of the disclosing Party, the receiving Party shall return promptly to the disclosing Party all materials and documents, as well as any data or other media (including computer data and electronic information), together with any copies thereof, or destroy same and, upon request of the disclosing Party, provide a certificate of destruction.

All obligations established hereunder shall expire six (6) months from the date of disclosure.

Vanan Online Services
www.vananservices.com;
US Ph: 866-221-3843
9. The receiving Party agrees that the disclosure of Confidential Information without the express consent of the disclosing Party will cause irreparable harm to the disclosing Party, and that any breach or threatened breach of this Agreement by the receiving Party will entitle the disclosing Party to injunctive relief, in addition to any other legal remedies available, in any court of competent jurisdiction.

10. This Agreement shall be construed under and governed by the substantive laws of California, without giving effect to the conflicts of laws provision thereof. Any disputes arising between the Parties relating to this Agreement shall be subject to the exclusive jurisdiction and venue of the federal and state courts located in the City and State of California, and the Parties hereby waive any objection that they may have now or hereafter to the laying of venue of any proceedings in said courts and to any claim that such proceedings have been brought in an inconvenient forum, and further irrevocably agree that a judgment or order in any such proceedings shall be conclusive and binding upon each of them and may be enforced in the courts of any other jurisdiction.

11. This Agreement constitutes the entire agreement among the Parties as to the subject matter contained herein, shall supersede any other prior or contemporaneous arrangements as to the Confidential Information, whether written or oral, and may be modified in writing only.

IN WITNESS WHEREOF, the Parties hereto have executed this Agreement as of the day and year first above written.

http://vananservices.com/ — Vanan Online Services (P) Ltd.

By: Saravanan Nagaraj
Designation: CEO

By: [Signature]
Name: [Signature]
Designation: [Signature]
ABOUT THE AUTHOR

Originally from Toronto, Canada, Richard S. Glaesser received his Bachelor of Arts (General) in Economics from the University of Toronto (1990), Bachelor of Arts (Honors) in Economics and Political Science from the University of Toronto (2006), Master of Social Work from the University of South Florida (2009), and PhD in Social Work from the University of South Florida (2018).

Following a career that began in 1990 as a political aide, Dr. Glaesser worked as a public affairs consultant and policy analyst prior to his transition to the United States in 2001. In the United States, he worked for eight years as an economic analyst in continuing medical education and moved to social work practice thereafter in senior management roles for an agency providing day and residential services to adults with intellectual disabilities. From there, he worked for four years as graduate faculty instructor teaching social welfare policy, research methods and clinical evaluation at Saint Leo University. Currently, Dr. Glaesser is Director of Quality Enhancement overseeing the evaluation of programs and services for adults with developmental disabilities at Sunrise Community, Inc.

His research interests include all aspects regarding programs and services related to improving the lives of persons with intellectual and developmental disabilities.