TRANSITIONS AND HEALTH TRAJECTORIES OF PARENTS CARING FOR CHILDREN WITH INTELLECTUAL DISABILITIES

by

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STATEMENT OF DISSERTATION APPROVAL

The following faculty members served as the supervisory committee chair and members for the dissertation of Alison Lee Eldredge

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ABSTRACT

Little is known about transitions and lifetime health trajectories of parents caring for children with intellectual disabilities (ID). Parental health is important because of its far-reaching effects on parents themselves, their children, and society at large. The purpose of this qualitative study was to describe (1) how parents in mid- and later life (≥55 years of age) caring for children with mild to moderate ID narrate the transitions of this experience, and (2) parental perceptions of the influence of raising a child with ID on their health trajectories. Through a series of three in-depth, semistructured interviews, one of which included a lifeline illustration of their personal health trajectory, 6 couples and 6 additional mothers (*n*=18) shared their experiences raising children with ID and its relation to their life transitions overall.

Parents narrated unique stories of resilience containing individual variations in both the content and prominence of the following challenges: (1) discovering, receiving, and accepting my child's limitations and diagnosis of ID, (2) caring for my child's health issues, (3) managing behavioral issues, (4) facilitating attainment of early developmental milestones, (5) ensuring a good education for my child, and (6) increasing my child's autonomy. In response to these challenges, parents initially took action to provide for their children. Over time, they learned to reflect over their experiences and utilize additional coping mechanisms for support. As parents adapted, they gained skills and learned lessons greatly enriching their lives.

Parents could not link personal, physical health problems to their child’s disability; however, they reported receiving benefits to their emotional, social, and spiritual health. Many parents initially experienced negative feelings, but over their lifespan, these feelings were replaced with increased love and gratitude for their child. Marriages and families became stronger as families worked together. Most parents found strength and/or meaning in their religious and spiritual practices.

Based on the narratives of raising a child with ID, social actions can be undertaken to decrease risk factors and strengthen protective factors in order to maintain or improve parents’ resilience and consequently their overall health. Early and continued professional and interpersonal support and resources are crucial.

This dissertation is dedicated to my son, Teancum and daughter, Ruby.
May you always follow God’s plan for you.

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CHAPTER 1

INTRODUCTION AND STATEMENT OF PROBLEM

This narrative and life history study used narrative analysis techniques of Lieblich, Tuval-Mashiach, and Zilber (1998) to explore how older parents raising sons and daughters with mild to moderate intellectual disabilities (ID)[1] identify and narrate the transition of raising their child with ID, and the influence of the child on their health trajectories. In-depth interviews and lifeline drawings made by participants to depict critical events and transitions in their lives (Gramling & Carr, 2004) were used as data collection methods.

The results of this study lay the foundation for an understanding of the health trajectories of a specific population, and help build the science of health trajectory research. Once a thorough understanding is developed with additional studies, researchers

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[1] The term ID was selected for use in this study versus intellectual developmental disorder (IDD). A fact sheet about ID from the American Psychiatric Association (2013) explains that the DMS-5 changed the naming of mental retardation to intellectual disability (intellectual developmental disorder): IDD is a "parenthetical name...included in the text to reflect deficits in cognitive capacity beginning in the developmental period" (p. 1). Regier, Kuhl, and Kupfer (2013) state, "The joint naming convention reflects use of the term 'intellectual disability' in US law, in professional journals, and by some advocacy organizations, while the parenthetical term maintains language proposed for ICD-11" (p. 97).

may determine “how, when, and where to intervene” (Henly, Wyman, & Gaugler, 2011, p. S80) in supporting parents as they raise children with mild to moderate ID. Ultimately, this work may lay a foundation for understanding how to improve the health of parents caring for these children.

In this chapter, I provide an overview of the research study. The first section outlines the background and significance of the study, and is followed by the problem statement, purpose, research questions, and an overview of the research design. Next, I provide my assumptions about the study and information about myself, the researcher, as related to the study. The chapter concludes with definitions of key terms used in the study. Chapter 2 is comprised of a literature review providing a foundation for understanding transitions and health trajectories for parents of children with ID. Chapter 3 explains methods employed in the study. Chapter 4 describes results, and Chapter 5 discusses what was learned, and implications for future studies.

Background and Significance

Why study the transitions and health trajectories of older parents of children with mild to moderate ID? In essence, the number of people with ID is growing at a steady rate, and caregivers in general are experiencing increased expectations and responsibilities while resources and support are dwindling (Feinberg, Reinhard, Houser, & Choula, 2011). The health of parental caregivers potentially affects the parents themselves, as well as their dependent children and society at large. Without these parents, additional means of caring for children with ID would need to be secured.

This section begins with a description of the population, including information about the growing number of people with ID and the widespread effects of poor health among their parent caregivers. Following the population description, health trajectories and transitions are defined and their benefits in relationship to parental caregivers explained. At the conclusion, I present a recent call to action urging nurse researchers to study transitions and health trajectories.

Growing Number of People with ID

Recent reports suggest ID affects 1 in 10 families in the United States (Administration on Intellectual and Developmental Disabilities, n.d.) or 2-5 % of the US population (Kerr & Norlin, n.d.). This number continues to grow because of increased life expectancies "related to improvements in neonatal care, nutrition, and socioeconomic conditions" (Krahn, Hammond, & Turner, 2006, p. 70). People with ID are now living well into adulthood and beyond as a result of medical, pharmacological, and biotechnological advances (McKeever, 1999).

In addition to the increased number of people with ID and their longer lifespan, trends towards deinstitutionalization in the past half century and closure of long-term care facilities for this specific population add more responsibilities to parents (Feinberg et al., 2011; McKeever, 1999; McKeever, Scott, Chipman, Osterlund, & Eakin, 2006). In fact, the number of people with intellectual and developmental disabilities (IDD) living in public or private institutions in Utah has decreased from 25% in 1999 to 14% in 2009 (Smith, Lakin, Larson, & Salmi, 2011). In 2007, 70.2% of people with IDD in Utah lived in residential settings with 1-6 residents as compared with 4.9% in 1977 (Alba, Prouty, Scott, & Lakin, 2008). In 1998, 60% of people with ID in the United States lived with family caregivers, and this number continues to increase.

Although the number of people receiving residential and community services is increasing, government resources for serving parents and children are decreasing. Funding cuts exacerbate growing waiting lists, increasing the difficulty of obtaining services (Braddock, 1999; Feinberg et al., 2011). As a result, parents of children with ID are taking on added medical and caregiving responsibilities for their offspring (Heller, Stafford, Davis, Sedlezky, & Gaylord, 2010; McKeever, 1999).

Widespread Effects of Poor Health among Caregiving Parents

Family caregiving often comes at a high price for caregivers and their health (National Alliance for Caregiving, AARP, & Metropolitan Life Foundation, 2009; Schulz & Beach, 1999). Specifically, the increased workload and stress of parenting a child with ID results in negative physical, mental, emotional, and financial effects for parents (McKeever, 1999; Seltzer, Floyd, Song, Greenberg, & Hong, 2011; Yantzi, Rosenberg, & McKeever, 2007).

Research on the long-term impact of raising a child with ID on a parents' health is beginning to emerge. Seltzer, Floyd, Song, Greenberg, and Hong (2011) found health of parents of young adults with ID (*n*=220) to be similar to parents of young adults without disabilities (*n*=1,042) during midlife; however, at about the age of 60, parents of these young adults tended to experience poorer physical and mental health than the comparison group. The health differences were even greater among parents whose young adults co-resided with them.

Not only does the increased stress of raising a son or daughter with ID negatively compromise parental health, it affects their parenting behaviors and ultimately the child (Hastings, 2002; Seltzer et al., 2011). Specifically, higher levels of stress and caregiver burden generally increase the risk of abuse (Rodriguez & Green, 1997; Svensson, Eriksson, & Janson, 2013; Whipple & Webster-Stratton, 1991), and are associated with higher risk of placing a person in a long-term care facility and/or utilization of formal in-home services (Gaugler, Kane, Kane, Clay, & Newcomer, 2005; Lu & Wykle, 2007).

Conversely, parents with lower stress may be in a better position to help their children. For example, Merluzzi, Philip, Vacon, and Heitzmann (2011) reported lower stress levels and higher self-efficacy in caregiving tasks by caregivers of terminally ill family members who performed self-care behaviors. In addition, self-efficacy lowers stress, improves caregiver health, and decreases risk of burnout. Specifically, caregivers of family members with cancer or terminal illnesses who have increased self-efficacy are more successful in performing caregiving tasks and their dependents have greater health benefits and a higher level of well-being (Keefe et al., 2003; Merluzzi et al., 2011).

In addition to affecting parents and children, parental health influences society at large since family caregivers are one of the greatest assets to our society. In 2009, over 65.7 million adults served as family caregivers to an adult or child in the United States (National Alliance for Caregiving et al., 2009), saving the healthcare system about $450 billion dollars that year alone (Feinberg et al., 2011). Parents may benefit society as they work with their sons and daughters with ID to reverse existing health disparities among this population. They are in an ideal position to help their sons and daughters establish healthy lifestyle behaviors and make sure they receive adequate health services, some of the goals established by the United States Surgeon General (Leavitt, 2005). In addition, parents play an important role in encouraging and supporting their offspring to live in the community, an objective of Healthy People 2020 (Office of Disease Prevention and Health Promotion, 2014). However, how can parents effectively support their children and assist them in improving their health and well-being if their own health is deteriorating? The next section explains a first step in understanding parents' health, potentially leading to better outcomes for parents, their dependent children, and society.

Health Trajectories and Transitions

What is a health trajectory? Wyman and Henly (2011) defined a health trajectory as a pattern of health over time. The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organziation, 2011, para 1). Henly, Wyman, and Findorff (2011) emphasized that health is "experienced over time" (p. S7) and is not a static state. I would add, achieving a state of complete health is most likely unattainable; however, this state can be used as an ideal to work toward. Health trajectory graphs, therefore, are useful tools for describing and measuring individual changes to a person's physical, mental, and social well-being, which together reveal an overall picture of health.

Wyman and Henly (2011) differentiated health trajectories into five types. Table 1.1 lists the types of trajectories, as well as their definitions, and examples. Note that no specific examples for disability, end-of-life, and dying trajectories were provided by the authors.

Transitions, as defined by Meleis (2010), are changes in "lives, health, relationships, or environments" (p. 52), which include changes in a person's physical,

Table 1.1 Types of Health Trajectories Provided (Wyman & Henly, 2011)

Type	Definition	Examples
Developmental	Normal physiological changes and responses associated with typical stages of human development	Puberty Menopause Aging Pregnancy and childbirth Retirement Death of a family member Caring for a child with a chronic illness or disability
Acute illness	Abrupt onset of illness with short course and/or exacerbations of chronic conditions	Myocardial infarction Flare-up of multiple sclerosis
Chronic illness	Acute events resulting in irreversible damage and/or long-standing progressive diseases	Stroke, spinal cord injury, Schizophrenia, Parkinson's disease
Disability	"Pathways to disablement that have the potential for being arrested or reversed through rehabilitation and other forms of interventions" (p. S2).	
End-of-life and/ or dying	"Can occur across the life span and result from acute, chronic, and normal aging changes" (p. S2).	

mental, and/or social well-being. In this dissertation, transitions are the building blocks of parents' health trajectories; they are changes creating patterns. Without transitions, the health trajectory graph would be a flat line lacking deviation. Depending on the purpose of the health trajectory graph, the scope and magnitude can vary. An individual transition experience could be one of many in a health trajectory graph or that same experience could be the main focus made up of other, smaller transitions. For example, a divorce could be a single transition on a health trajectory graph representing a person's adult life or an entire graph could focus on the experience of the divorce with its accompanying transitions.

Over the past several decades, Meleis (2010) developed and refined a middle-range theory (connects general theories of social systems with empirically observable data (Merton, 1968)) and health transition model describing the nature, conditions, and patterns of response to transitions, and suggested the next step in transition research would be to define the “diversities and complexities in transition experiences through research with diverse populations in diverse types and patterns of transitions” (p. 64). This dissertation may add to the science as it describes a different type of transition among a population that has not been studied using the Meleis model. Her research is used as a framework in Chapter 2 for describing existing literature about parents raising children with ID, and is further discussed in Chapter 5 as I synthesize the findings from this study.

With a greater capacity to understand and describe transitions and health trajectories, a foundation will be set in this dissertation for professionals and others to understand the experience of these parents. This understanding may assist in creating timely, appropriate, evidence-based interventions in the parent-child caregiving process, and create an improved awareness of the impact transitions have on health trajectories in terms of function and quality of life for these parents.

Future studies could examine the efficacy of interventions in improving overall health trajectories. Particularly challenging transitions for this population could be anticipated, thus providing time for preparation that may curtail or ease adverse effects of the event. Individuals who may be at greater risk for decreased psychological functioning or physical health could be screened (Henly, Wyman, & Findorff, 2011). Eventually, individually tailored interventions based on transition and health trajectory research may be developed and tested for effectiveness, with the ultimate goal of improving the health of parent caregivers.

Knowledge gained from this study may also add to the creation and refinement of theories about transitions and overall health trajectories. Transition theory could focus on identifying transition sequences, the relative impact transitions have on health, and the overall pattern of healthful and risky transitions. Finally, the findings may endorse changes in current policies to provide parents additional support as they care for their children with ID.

Call to Build Nursing Theory

In 2011, a supplement to the journal *Nursing Research* with a special focus on health trajectory research was issued. In it, Henly, Wyman, and Gaugler (2011) challenged nurses to build the science of health trajectories and issued several calls to action. This study sheds light on their first call, which aimed to improve the ability to describe, measure, and use health trajectory graphs to improve health for all populations across the lifespan. In addition, the first call sought to better understand life transitions by identifying "patterns of transition outcomes and factors associated with successful transitions at the individual, family, and systems level" (p. S80). This study uses and describes health trajectories to create a starting point for identifying and describing transitions among parents raising children with ID.

Problem Statement

Little is known about transitions and overall lifetime health trajectories of parents caring for offspring with mild to moderate ID. The health of these individuals is important because of its long reaching effects on parents, their children, and society at large. For example, parent caregivers may be experiencing poorer health as they age and assume growing responsibilities due to increased numbers and decreased mortality rates of people with ID, movement away from institutions into community care, and decreased amount of available funding and resources. Conversely, however, parent caregivers may also be exemplars of health as they overcome challenges and develop resilience. Knowing more about the transitions and health trajectories of these parents may be helpful "for knowing how, when, and where to intervene" (Henly, Wyman, & Gaugler, 2011, p. S80) in the parent and child caregiving process.

Statement of Purpose and Research Questions

The purpose of this study was to explore how parents caring for children with mild to moderate ID identify and narrate the transition of raising such a person, and describe the influence of this experience on parents' health trajectories. The results may be used to inform future research, and provide information for creating individually tailored interventions to support parents as they care for their children with ID, thus ultimately improving parental health. The health of their child may also benefit indirectly. In order to better understand the transitions and health trajectories, the following research questions guided the study:

Research Questions

1. How do parents caring for children with mild to moderate ID narrate the transition of raising such a person?
2. How does raising a child with ID influence parental health trajectories?

Research Design Overview

This narrative and life history study used in-depth interviews and lifelines to explore the transitions and health trajectories of parents aged 55 and above who were primarily responsible for the care and well-being of a son or daughter with a mild to moderate ID. Purposeful and snowball sampling were employed to select 6 fathers and 12 mothers to be interviewed three times each. Three approaches of narrative analysis from Lieblich et al. (1998) were used to analyze narrative data about the transitions parents experienced in their lives, particularly while raising a child with ID, and the influence of the said child on parental health trajectories.

Assumptions

Five assumptions influenced the creation of this research study. First, all human beings have the agency to choose for themselves who they want to become and the capacity to learn, grow, and make improvements in their lives; however, they may not have the resources or environment to support this trajectory. Second, every life contains transitions, because changes in “lives, health, relationships, and/or environment” (Meleis, 2010, p. 52) are unavoidable. These transitions are unique and complex among individuals. Third, caring for a son or daughter with ID is difficult and creates added stressors and variations in transitions that parents of children without ID do not experience. Parents who care for a child with ID are at higher risk for experiencing decreased health and well-being (Ha, Hong, Seltzer, & Greenberg, 2008; Seltzer et al., 2011). Fourth, parents can teach healthcare professionals about their experiences and health trajectories so they can collaborate to identify beneficial interventions as they pass through transitions. The final assumption is that parents of children with ID could benefit from nursing interventions that assist them in experiencing healthier transitions, thus leading to improved health outcomes.

The Researcher

As a co-creator with participants in this study, it is necessary to disclose my background and experience as it relates to this study. I acknowledge my life experiences and beliefs influenced the way I designed this study, collected and analyzed data, and interacted with participants. This section provides personal information pertinent to this study.

My nursing career began in 2002 when I graduated with a bachelor's degree in nursing. I worked in two inpatient units–rehab and ICU–before being employed in home health and hospice settings. In each place I worked, I interacted with a variety of family caregivers, and saw the triumphs and disappointments they faced while providing care.

After a few years of working as a clinical nurse, I returned to school for a master's degree in Community Health Nursing. The program focused on assessing the needs of populations at risk and developing and evaluating programs building on population assets and addressing shared needs. Following graduation, I worked for about a year as a teaching assistant before enrolling in a nursing Ph.D. program.

The doctoral program provided didactic and hands-on experience in research. The courses I took provided me with skills necessary to conduct independent research. One of the most influential experiences was working as a research assistant studying healthy lifestyle interventions suited to overweight and obese young adults with ID and their parents. Prior to this experience, my exposure to people with ID and their parents was fairly limited. I had always known people with disabilities, but had not interacted significantly with them in my family, school, or community. As part of my role on the research team, I participated in preparing the Institutional Review Board (IRB) application, screening and recruiting research participants, study implementation, curriculum evaluation, and data entry and analysis.

During the intervention, we challenged the young adults to go above and beyond what they and others thought they could do to care for their health. I loved watching them learn and excel as they worked on this challenge. Thinking about the young adults now makes me smile and chuckle a little. They were great! I remember one young man whose face would light up each time he saw me and he always wanted to give me a hug. He had paralysis in his arm and walked with a limp, which made exercise difficult, but that did not stop him. He was eager to try. I remember thinking I needed to encourage him to do more on his own, but his kind and appreciative personality made it hard to support his independence.

Once a week while the young adults were learning about health and exercising, we met with their parents to talk about improving health in their families. I was impressed by their dedication to attend classes and enthusiasm to learn. Parents enjoyed sharing ideas and experiences that worked, did not work, and appreciated the support. One group of parents even continued to meet together independently after classes ended.

As we began meeting, I immediately detected parental fatigue and burnout. They tried many things over the years to improve their young adult's health, but now it seemed like too much work. In addition, they complained their bodies were wearing down and could not do as much as they could years ago. They loved their young adult and wanted the best for them, but were tired from years of providing continual care. Many, however, seemed rejuvenated with the classes and appreciated the extra support.

As a result of this experience, I decided to focus my dissertation research on the health and well-being of parents of children with mild to moderate ID. Ultimately, I would like to develop programs for these parents building on their strengths and helping them reach their full potential as caregivers.

In preparation for this study, I selected a chair and four committee members, each with unique expertise, to guide me through the dissertation process. The chair of my committee, Dr. Lauren Clark, is an experienced qualitative researcher and was the Principal Investigator for the healthy lifestyle intervention studies for the young adults with ID. My second committee member was Dr. Marge Pett, a social worker with an extensive background in family counseling and research. She was a co-investigator for the parent healthy lifestyle intervention. Other committee members included Dr. Michael Caserta, Dr. Barbara Mandleco, and Dr. Pollie Price. Their respective areas of expertise include older adults and healthy aging, children and young adults with disabilities, as well as qualitative research and narrative analysis.

I began this study with over 5 years of marriage experience, so I knew some of the struggles of being married. I did not have children at the time, but had helped friends and neighbors with their children and worked with children of varying ages at church. Many of my friends with children shared with me some of their challenges and triumphs. A few months prior to receiving clearance from the IRB to do the study, I found out I was expecting my first child. I finished all of the interviews, except for one, before my son was born. The study was completed about the time of my son's second birthday and the birth of my second child. My son helped me understand a tiny portion of the disruptions and joys parents in this study experienced.

Although I am fairly new to research and working with people with ID, I felt my prior clinical experience, mentored research experience, educational background, and supportive environment assisted me in successfully carrying out this research study.

Definition of Key Terms

Key terms used throughout the dissertation listed in alphabetical order.

1. Child with ID: A study participant's biological, adopted, or step son or daughter to who has a mild to moderate form of ID. This term refers to the relationship, rather than the age of the person with ID. At the time of the study, the children were mainly young adults as they ranged in age from 16 to 54 years (Geiger & Castellino, 2011); however, the study focuses on the lifespan of the child. The terms person, son or daughter, and offspring are used synonymously with child.
2. Health: "State of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 2011, para 1).
3. Health trajectory: "Pattern of health over time" (Wyman & Henly, 2011, p. S1)

composed of a series of individual transition experiences.

4. ID: Intellectual disability. “Characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18” (Definition of Intellectual Disability, 2011, para 1). A major tool for measuring intellectual functioning is the IQ test. Test scores below or around 70-75 indicate limitations in intellectual functioning. Adaptive behavior can be measured with standardized tests and is comprised of three skill types: conceptual, social, and practical. No testing for ID was done; parents reported whether their child was officially diagnosed with ID, had “below-average in intelligence,” or “attended special education classes” (p. 482). These were criteria based on a study about health differences among parents raising children with ID performed by Seltzer et al. (2011).
5. Narrative: “Any prosaic discourse… [or] text that consists of complete sentences linked into a coherent and integrated statement” (Polkinghorne, 1995, p. 6). Narratives in the form of stories will be used.
6. Story: “Special type of discourse production… [where] events and actions are drawn together into an organized whole by means of a plot” (Polkinghorne, 1995, p. 7).
7. Stress: “A physiological response of the body to a perceived threat, either real or imagined” (Miodrag & Hodapp, 2010, p. 407)
8. Transition: “Change in lives, health, relationships, or environment” (Meleis, 2010, p. 52) including changes in a person’s physical, mental, and/or social well-being.

Transitions create the patterns in parents’ health trajectories. An individual transition experience could be one of many in a health trajectory graph or that same experience could be the main focus of a healthy trajectory graph and be divided into other, smaller transitions.

CHAPTER 2

REVIEW OF LITERATURE

The goal of this chapter is to provide background information for understanding the findings about the transitions and overall health trajectories of parents caring for children with mild to moderate ID presented in subsequent chapters. The discussion in this chapter focuses on individual transitions, the building blocks of health trajectories. The Meleis health transition model (Meleis, 2010), a well-known nursing transition model, was selected as a framework for presenting available, yet limited, information about parental transitions. A brief description of an alternative framework of resilience is presented at the end.

In studying the lives of parents of children with ID, it is important to remember the experience of raising such a child is unique for each parent, but some commonalities and patterns may exist. For example, one transition may be difficult for one person and have little or no effect on another.

The Meleis health transition model (Meleis, 2010) contains three parts—Nature of Transitions, Transition Conditions: Facilitators and Inhibitors, and Patterns of Response—leading to the development of nursing therapeutics/interventions (Figure 2.1). The chapter is divided into these three sections to explain each and provide information

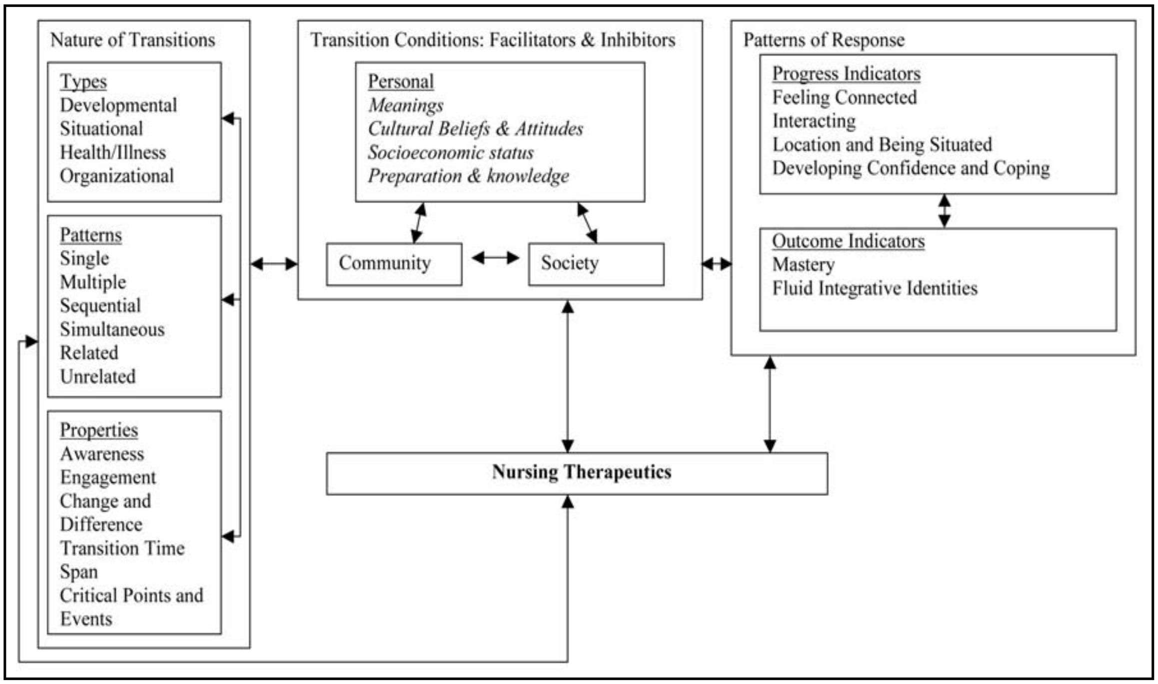

Figure 2.1. The Meleis Health Transition Model
Note. From *Transitions theory: Middle-range and situation-specific theories in nursing research and practice*, by A. I. Meleis, 2010, p. 56. Copyright 2010 by Springer Publishing Company. Reprinted with permission.

about parents caring for sons and daughters with ID.

Nature of Transitions

The first part of the Meleis health transition model (Meleis, 2010), Nature of Transitions, appears to be the most developed, and is divided into Types, Patterns, and Properties of transitions. A review of literature focused on parents of children with ID yielded many examples of types of parental transitions, but little information about the patterns and properties of these transitions. As shown by Figure 2.1, Meleis (2010) suggests there are four basic types of transitions people experience during their lives—Developmental, Situational, Health/Illness, and Organizational. The first three transition types are covered in this section followed by a brief explanation and examples of transition patterns and properties. Meleis used organizational transitions to represent “changes in environments that pertained to nurses” (p. 4), so they are not applicable to these parents.

Developmental Transitions

Developmental transitions are the first type of transitions listed in the Meleis health transition model (Meleis, 2010). She describes the following examples of transitions that may make people vulnerable: “pregnancy, childbirth, parenthood, adolescence, menopause, aging, and death” (p. 52). Parents in this study who are over the age of 55 and raising young adults with ID are most likely not directly concerned with pregnancy, childbirth, and adolescence. However, they almost assuredly grapple with the other four areas—parenthood, menopause, aging, and death. Literature related to these four areas related to the study population was limited. Most studies focused on stressors involved in continually providing care for a dependent child with ID.

The remainder of this section focuses on the stressors of parents raising children with ID. It begins with a definition of stress and presents studies revealing higher levels of stress existing among parents of children with ID as compared to parents of children without ID. The section conclusion highlights several potential stressors these parents may encounter throughout their lives.

Higher Stress among Parents of Children with ID

Although much debate exists over the definition of stress, the phenomenon and its effects are becoming clearer (Miodrag & Hodapp, 2010). For the purposes of this study, stress is defined as “a physiological response of the body to a perceived threat, either real or imagined” (Miodrag & Hodapp, 2010, p. 407) . This definition is based on the work of Hans Selye (1965), who is known internationally for his contributions to the definition of the concept of stress. Selye explained that stressors, either pleasant or unpleasant, speed up the intensity of life and can increase “the wear and tear exerted upon the body” (p. 97). Thus, increased quantity and intensity of stressors wear out the body over time. According to the Mayo Clinic Staff (2013), life today is perceived as a series of nonstop threats activating the stress response on a continual basis. When acute stressors accumulate, they develop into a condition of chronic stress.

A handful of studies confirm higher stress levels among parents of young children with ID versus parents of similar children without disabilities (Dyson, 1996; Gallagher, Phillips, Drayson, & Carroll, 2009; Pelchat et al., 1999); however, most sample sizes are small. More recently, studies have examined stress among parents of young children with Autism Spectrum Disorder (ASD) compared to children without ASD. Research discussing stress levels of parents of older children with ID is limited. These studies are described in the section about health and illness.

An example of a study comparing stress levels among parents of children with a disability compared to parents of children with no apparent disability was performed by Pelchat et al. (1999). The authors compared 144 fathers and mothers of 72 6-month-old infants, and found significantly higher scores for parental stress, stress appraisal, and psychological distress among the parents of infants with a disability. Among these parents, mothers experienced more stress related to role restriction, felt more threatened and stressed by their parental role, and reported a greater level of psychological distress than fathers.

Another researcher, Dyson (1996), studied stress levels of parents of children between the ages of 7 to 14. She found a significant group difference between 19 parents of children with learning disabilities and 55 parents of children without learning disabilities. In fact, the mean parental stress level for parents of children with learning disabilities was 2 ½ times higher than the comparison group.

Gallagher, Phillips, Drayson, and Carroll (2009) compared 30 parents of children/adolescents from the ages of 3-19 with developmental disabilities and 29 parents of youth the same age without disabilities. These researchers focused on parents' antibody response to vaccination in order to determine stress levels and ability to fight viral and bacterial infections. Participants were also scored on standard measures of depression, perceived stress, social support, caregiver burden, and child problem behaviors. The antibody response of parents raising youth with disabilities was significantly diminished in relation to the comparison group, meaning they were experiencing higher levels of stress affecting their immune response.

Stress also affects parental sleep. For example, Gallagher, Phillips, and Carroll (2010) studied the sleep patterns of 67 parents of children between the ages of 3 to 19 years with developmental disabilities and 42 parents of youth the same age without disabilities. They found parents of youth with developmental disabilities reported and met criteria for poor sleep quality. They were also more likely to be poorer sleepers, and reported more parental stress, more child problem behavior, and less social support compared to the comparison group.

Stressors among Parents of Children with ID

In Chapter 1, I described the increasing responsibilities and expectations placed upon parents as a result of the changing trends in demographics and care of people with ID, who are living longer than ever before, and requiring parents to assume more of their care. The increase workload and stress negatively effects parents' health and well-being. The next section discusses additional parental stressors, including behavioral problems of children with ID, transitioning to adulthood, unmet expectations, stigma and stereotypes, finances, time, and traveling with/without a child with ID.

Behavioral Problems of Children with ID

Behavioral problems exhibited by children with ID can be extremely difficult for parents. In fact, Gallagher et al. (2009) found child behavioral problems appeared to be one of the main contributing factors to a diminished antibody response among parents of people with disabilities. Behavioral problems have also been linked to increased psychological distress (Pinquart & Sorensen, 2003), increased incidence of infectious illness (Dyck, Short, & Vitaliano, 1999), and the onset of cardiovascular disease (Mausbach, Patterson, Rabinowitz, Grant, & Schulz, 2007).

Transitioning to Adulthood

Another concern for these parents is that the children are now living longer and thus facing issues of adolescence and adulthood. These developmental stages are transformative and can be difficult for both parents and children regardless of intellectual capacity. In fact, Schneider, Wedgewood, Llewellyn, and McConnell (2006) claimed disability tends to compound major developmental challenges already faced by typically developing adolescents. They wrote “depending on their level of impairment, adolescents will differ in their ability to achieve many of the cognitive, communicative, social and behavioral milestones of their typically developing peers” (p. 927). This period is a time when people with ID “become more aware of their differences, develop feelings of inadequacy or become frustrated when they are unable to keep up with peers. This can be exacerbated by being stigmatized, teased or rejected by peers” (Schneider et al., 2006, p. 927). Physically, adolescents with ID continue to grow in size, thus creating a larger gap between their “physical size and intellectual capacity.…Becoming adult-sized may result in increased daily care needs for their families as they become more difficult to physically assist or lift, or harder to control and discipline” (Schneider et al., 2006, p. 927).

Another challenge for parents and young adults during this time period in the state of Utah is the loss of eligibility for state-funded education when young adults with ID turn 22 years old. The young people lose the relative structure and safety of a school environment, and parents resume full responsibility of their care. Some families are able to secure a form of adult services; however, even when services are available and funded through state programs, parents must either continue to advocate for and oversee their young adult’s day-to-day activities, safety, and health or delegate that responsibility to a guardian or care agency. Consequently, parents who maintain custody and/or guardianship of their son or daughter struggle with the developmental task of facilitating independence for the young adult with ID, as well as assuring the young adult’s health and safety during these transitional years (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009). Some young adults with ID get married and have children. When they give birth, the new parents often require additional support, most of which comes from their own parents (Weiber, Berglund, Tengland, & Eklund, 2011). Becoming a grandparent to a child born to a son or daughter with ID may be an additional responsibility resulting in further stress.

Unmet Expectations

People with ID do not generally meet the same developmental milestones or have the same accomplishments as those without ID. Parents exhibit many emotions initially and experience a feeling of loss extending across the lifespan (Patrick-Ott, 2011). They not only feel “sadness and sorrow, but also fear, helplessness, anger, frustration, and other feelings characteristic of grief” (Eakes, Burke, & Hainsworth, 1998, p. 179). Larson (1998) described a paradox of emotions and feelings experienced by mothers of children with disabilities. She suggested mothers felt tensions between “loving the child for who he or she was and wanting to erase the disability,” dealing with incurability while seeking solutions, and “maintaining hopefulness for the child’s future while being given negative information and battling their own fears” (p. 865). These are tensions between the parent’s initial expectations and the reality of the situation.

When these negative feelings reappear over time, they are known as chronic sorrow, a concept introduced in the early 1960s. Such feelings are initially very intense and often decrease as time goes by; however, each time a developmental milestone is not attained or a parent sees a child without a disability achieve a milestone, feelings of loss may return to varying degrees (Eakes et al., 1998).

Stigma and Stereotypes

Today, stigma surrounding people with disabilities can result in parents experiencing guilt, shame, and rejection. Traditionally, mothers are assigned responsibility for the outcomes–both good and bad–of their sons and daughters, and thus may often feel responsible or at fault for their child's disability or illness (McKeever & Miller, 2004; Risdal & Singer, 2004). For example, McKeever and Miller (2004) reviewed three qualitative studies in which the participants were 66 mothers of children with chronic illness or disability. They found mothers felt pressure to "conform to traditional ideologies of care" (p. 1184) in which they selflessly devoted themselves to caring for their children, and felt an expectation to modify or forfeit employment to provide care for their children. Based on these findings, McKeever and Miller claimed society expects mothers of children with disabilities to invest everything in providing care for their children; however, these efforts are devalued because their children remain "socially unproductive and burdensome to society" (p. 1182). Not meeting the standards of society may leave parents feeling guilty and lead to increased levels of stress.

Finances

Another stressor for parents is the added financial cost of raising a son or daughter with ID. Providing medical care, therapy, and ensuring needs are met is expensive. For example, in 2003, the average lifetime cost for one person with ID was estimated to be $1,014,000 greater than the cost of living for a person without a disability. In 2012, the annual lifetime cost of an individual with ASD was estimated to be $2.3 million, whereas caring for people without disabilities cost about $1.4 million per year (New research finds annual cost of autism has more than tripled to $126 billion in the U.S. and reached £34 billion in the U.K., 2012). The estimated “lifetime costs for all people with intellectual disabilities who were born in 2000 would total $51.2 billion” (Centers for Disease Control and Prevention, 2005). In addition to the high cost of raising a son or daughter with ID, caregivers often have a decreased financial earning potential because they must sometimes quit their jobs or seek part-time employment (Gordon, Rosenman, & Cuskelly, 2007; Gould, 2004; Johnson & Sasso, 2006; McKeever, 1999). Promotions and other career advancing opportunities are often sacrificed as well (Abel, 1995b; Gordon et al., 2007; McKeever, 1999).

Parish, Rose, and Swaine (2010) described the precarious financial situation among 753 households containing a child over the age of 5 with a developmental disability. By examining 2001 to 2004 panels of the Survey of Income and Program Participation (SIPP), which is administered by the U.S. Census Bureau and includes a nationally representative sample of uninstitutionalized civilians living in the U.S. They found elevated poverty levels across the lifespan of parents of sons and daughters’ with developmental disabilities. Poverty levels decreased somewhat during the parents’ midlife when income levels were higher, but increased again in their later years. Additionally, parents had few financial reserves in case of crisis.

In order to help ease the financial burden on people with disabilities, the U.S. government established various means-tested programs for eligible Americans with disabilities, including Supplemental Security Income (SSI), Medicaid, and food stamps. These safety nets are helpful, but often insufficient to cover all needs, thus resulting in continual financial strain on families. These programs may or may not benefit families caring for children with ID, since qualification is not determined by family but by individual applicant. Some programs are means-tested, while others depend on the severity of the condition. All have an application process, wait time, and are subject to bureaucracy and complex rules of eligibility. The complex application process and rigorous rules for documentation, recertification, and ongoing compliance may result in fewer people receiving needed benefits. In most cases, responsibility for obtaining these benefits rests upon parental caregivers.

Time Burden

Providing care for a son or daughter with ID requires time. Haverman, Berkum, Reijnders, and Heller (1997) found the fewer the adaptive skills of a child with ID, and the more behavioral and physical health problems the child has, the more time demands are placed on parents. These time demands may limit what parents are able to do. For example, mothers may have less time available to be employed outside of the home, significantly decreasing earning potential (Gould, 2004). In addition, time influences caregiver burden or overall stress (McManus et al., 2011).

Traveling with and without Child with ID

Going anywhere with or without a person with a disability, especially in their younger years, can be taxing. The challenge increases if there are additional medical needs or behavioral concerns. The thought of moving medical equipment and supplies or finding someone competent and willing to care for the person while parents are not home can be daunting. In addition, while parents are out with their son or daughter, behavioral issues can be disruptive. In fact, Yantzi et al. (2007) found these factors may lead parents to isolate themselves because staying home may simply be easier.

These caregiving responsibilities extend throughout the lifespan of parents, requiring them to continually balance their own physical, social, and emotional needs while supporting their children (Thorin, Yovanoff, & Irvin, 1996). It is no wonder that with all of these added stressors parents of children with ID had significantly worse physical and mental health than the general population (Seltzer et al., 2011).

Situational Transitions

Situational transitions, the second type of transition, are “triggered by events that require spatial or geographic changes… and/or relationship changes” (Meleis, 2010, p. 85), such as discharge from hospitals, relocation to rehabilitation or elder care homes, immigration, homelessness, addition or loss of a family member through birth or death, changing professional roles, widowhood, and family caregiving. These transitions are specific to individuals and vary tremendously in scope and magnitude from person to person. Many examples of situational transitions may pertain to parents in this study. For example, a parent could lose his or her job, get divorced, move, or add an additional family member.

I was unable to locate any studies exploring situational transitions in the lives of parents of children with ID. Most articles were specific to children or young adults with ID and occasionally included information about the impact of the transition on parents. The most common transitions discussed were related to preparing people with ID to transition within and out of the school system (Bull, 2008; Kraemer & Blacher, 2001; Wehman, Kregel, & Barcus, 1985).

Health and Illness Transitions

Research on health and illness among parents of children with ID discusses the effects of increased stressors in parents' lives, including the negative effects excessive stress has on various body systems, including the brain (Lupien, McEwen, Gunnar, & Heim, 2009), heart (Low, Salomon, & Matthews, 2009), and immune system (Gallagher et al., 2009). In addition, the Mayo Clinic (2013) suggests increased stress impacts the body, mood, and behavior, resulting in headaches, chest pain, fatigue, anxiety, restlessness, overeating, and social withdrawal in people who experience high levels of stress.

The higher levels of stress associated with raising offspring with ID could explain why these parents' physical and mental health is poorer than parents who raise offspring without ID (Mayo Clinic Staff, 2013). For example, Ha, Hong, Seltzer, and Greenberg (2008) examined data from the MIDUS (Midlife in the United States) study, a nationally representative probability sample of English-speaking, uninstitutionalized adults between the ages of 25 and 74. They compared data from a sample of 162 parents of children with developmental disabilities and 133 parents of children with mental health disabilities to a comparison group of 1,393 parents of typically developing children. Parents of children with disabilities had higher levels of negative affect and a greater number of somatic symptoms than the comparison group. In addition, parents of children with developmental disabilities showed poorer psychological well-being than either group. They also found the effects of raising a young person with a disability on parents' well-being attenuated with parental age. Raising a greater number of children with developmental disabilities was also associated with significantly higher levels of negative affect and marginally greater somatic symptoms. The study found no significant gender differences in health between parents raising a child with disabilities and the comparison group. On the positive side, parents of children with developmental disabilities who were older when their children were diagnosed and/or whose children had a longer duration of disability had lower levels of negative affect and better psychological well-being than the younger parents of children with developmental disabilities.

Seltzer, Floyd, Song, Greenber, and Hong (2011) compared "parental patterns of attainment, social participation, psychological functioning, and health in midlife and early old age" (p. 479) in 220 parents of adult children with intellectual and developmental disabilities and 1,042 parents of adult children without disabilities. The group comprised of parents of adult children with disabilities was further divided into those who co-resided with their adult child and those whose adult child lived elsewhere. Similar findings across variables in these three groups were reported at midlife; however, as parents reached early old age (mid-60s), parents of adult children with disabilities tended to experience poorer physical and mental health. Differences also were found at this time between the two groups of parents of people with disabilities. Parents whose offspring co-resided with them tended to still be married to their first spouse and have poorer health than the other two groups; people with Down syndrome were more commonly found residing at home. Parents with adult children who lived outside the home tended to be divorced, and their health was more similar to the comparison group, though the adult child's diagnosis varied. All results mentioned were significant except for diagnosis type, which was not examined.

Risdal and Singer (2004) performed a meta-analysis of six studies to evaluate the impact of children with developmental disabilities on marriage. The overall weighted effect size for marital adjustment between parents of children with developmental disabilities and parents of typically developing children was negligible (*d*=.21). Although the difference between groups was small, a positive effect size indicated the presence of a disability was positively correlated to marital strain. The six studies analyzed showed an average increase of 5.97% in divorce rates among couples raising children with developmental disabilities.

In discussing parental health and stress, it is important to remember variability exists over time and among parents of offspring with ID. Some parents are able to adapt better than others. In fact, Ha, Hong, Seltzer, and Greenberg (2008) noted little is known about factors affecting specific parents who have poor health or parents who demonstrate greater resiliency. However, they found type of disability, family resources, "perceptions and beliefs regarding the disability, and the social context of the family" (Ha et al., 2008; Pelchat et al., 1999, p. 378) influenced parents' ability to adapt. Although differences exist among parents, some patterns may be present.

Patterns and Properties of Transitions

Patterns of transitions include the timing and relationship among transitions. Specifically, transitions can occur one at a time, in multiples, sequentially, and/or simultaneously. Some transitions are related to each other, while others are not (Meleis, 2010). For example, a parent may be diagnosed with diabetes and learn about the death of a sister in the same week, or a parent may become employed after staying home for a long period of time and find that his or her child's behavior problems escalate. Therefore, mapping patterns of transitions by looking at health trajectory graphs may help determine when interventions would be most appropriate and necessary.

Transitions are also made up of several interrelated and essential properties (Meleis, 2010), including levels of awareness, engagement, change and difference, time span, and critical points and events. Levels of awareness may vary and influence levels of engagement in the transition process, and is depicted as "perception, knowledge, and recognition of a transition experience" (p. 57). If a person is not aware of a transition occurring, he or she will likely not make any changes. Awareness makes a person more apt to be actively involved or engaged in the transition.

The next property is engagement, activities people actively participate in as a result of a transition in their lives. Some examples of engagement may include the following for parents raising children with ID: learning about Down syndrome, talking to other mothers of a child with Down syndrome, and preparing for a child's graduation from high school.

The final concepts, change and difference, are arguably somewhat vague and few examples were found in the literature. Meleis (2010) said the terms are similar, but not interchangeable or synonymous with transition. She differentiated between a change and a transition by saying, “all transitions involve change, whereas not all change is related to transition” (p. 57). A change may occur, but a person may judge it as insignificant or may not be willing or ready to adjust to it. In this case, no transition occurs and the person continues as before. Meleis further explained, “a change may be related to critical or disequilibrating events, to disruptions in relationships and routines, or to ideas, perceptions, and identities” (p. 58). Some examples of changes leading to a transition include receiving a diagnosis of ID in a young person, starting school, losing a job, or the passing of a loved one. If a change results in a transition, the person “adapt[s] to new roles and situations, come[s] to terms with the [change], and eventually result[s] in new meanings and a sense of mastery over an extended period of time when… the ‘whole picture’” (p. 57) is understood. Thus, “transitions are both the result of change and result in change” (p. 58).

A difference is “exemplified by unmet or divergent expectations, feeling different, being perceived as different, or seeing the world and others in different ways” (Meleis, 2010, p. 58). An example could be a person diagnosed with cancer and undergoing treatments. The person may feel different than peers because of the diagnosis. The chemotherapy treatments could result in hair loss and fatigue, thus subsequently resulting in differences of appearance and expectations. If these differences affect the person, a transition will occur.

Another property of transitions explained by Meleis (2010) is that transitions occur over time. Establishing beginning and end points may be difficult, because some transitions can be dormant for a time and resurface later. The parents of the son or daughter with ASD may think they have adapted to the change of raising person with ASD, but may then go to a high school graduation of another young person and still feel sad about the diagnosis and unmet expectations, demonstrating they still have work to do in adapting to the ASD diagnosis.

The final property of transitions is critical points and events. According to Meleis (2010), critical points and events occur when awareness of change or difference heightens or engagement in the transition experience increases. Critical points related to raising a person with ID would most likely be diagnosis, early interventions, school years, and transitioning into the community (Abrams & Goodman, 1998; Bianco et al., 2009; Bull, 2008; Calhoun, Calhoun, & Rose, 1989). However, critical points over the lifespan of parents have not been identified.

Transition Conditions: Facilitators and Inhibitors

This section describes the middle part of the Meleis health transition model (Meleis, 2010): conditions, defined as personal, community, and societal factors facilitating and inhibiting transitions. Community and societal factors are discussed together and include a brief historical overview of disability and ID in order to provide insight into the cultural beliefs and attitudes prevalent today. Little information supporting concepts in this and the final part of the model was discussed in the literature.

Personal Factors

The first transition condition, personal factors, includes meanings, cultural beliefs and attitudes, preparation and knowledge, and socioeconomic status. First, the meaning assigned to a particular event may facilitate or hinder healthy transitions (Meleis, 2010). For example, parents may associate parenting with happiness or drudgery. This association or meaning may change from minute to minute, day to day, or year to year. Different parents can vary in their meanings of parenting, and each unique meaning creates a different transition experience. Some meanings facilitate a healthy transition, while others inhibit the transition.

Meleis (2010) also suggests that culture influences beliefs and attitudes, and attaches stigma to different events by acting as a facilitator or an inhibitor to an emotional response. For example, parents of offspring with ID may often believe they are the cause of the disability (McKeever & Miller, 2004). This belief may result in grief or depression, and hinder a healthy transition. Conversely, a belief about the importance of self-care may facilitate a healthy transition.

Meleis (2010) claimed low socioeconomic status often negatively affects healthy transitions. She suggests low socioeconomic status increased the likelihood of negative psychological symptoms. According to Emerson (2003), who studied economic status and psychological impact among 245 mothers of children with ID and 9, 841 mothers of children without ID, families raising children with ID were more often economically disadvantaged than their counterpart.

Additional factors facilitating a transition are being prepared and having knowledge (Meleis, 2010). For example, a parent could prepare his or her youth for graduation from the public school system by discussing and visiting different vocational and volunteer sites. This knowledge and preparation will help the transition to be smoother and less difficult (Bull, 2008).

The notion of being prepared could also include a person’s coping skills. These skills can be taught prior to the transition, and provide parents with tools and resources to use throughout the transition process. Several studies discovered relationships between personality types, coping skills, and well-being (Kim, Greenberg, Seltzer, & Krauss, 2003; Seltzer, Greenberg, Floyd, & Hong, 2004). For example, Glidden, Billings, and Jobe (2006) studied parents of children with developmental disabilities and found some coping strategies were related to higher levels of subjective well-being. Thus, teaching parents effective coping strategies may help them achieve successful transitions.

Community and Society Factors

The community in which a person resides can inhibit or facilitate transitions (Meleis, 2010). Specifically, Wodehouse (2009) studied the helpfulness of community services for parents of people with developmental disabilities and behavior problems, and discovered parents had the following complaints about community services: information was difficult to obtain and commonly haphazard, providers lacked understanding of their situations and blamed them for their children’s behaviors, respite was limited and often not a true break, and obtaining helpful specialty services for behavior problems was difficult. The author concluded that many excellent resources could be found in communities, but for various reasons, they were not helpful or accessible to parents. In other words, the authors believed community resources should have been facilitators, but instead were inhibitors, and recommended forming partnerships between parents and care providers to make resources more helpful.

Along with community factors, societal beliefs can also inhibit or facilitate transitions (Meleis, 2010). These beliefs are formed over time, so a brief history of disability and ID with regard to society is included.

References to disability and ID are found very early in the history of mankind with a variety of rationales. The first reference to ID occurred in the Egyptian Papyrus of Thebes in 1552 B.C. (Harbour & Maulik, 2010). Ancient Greeks and Romans felt children with ID "were born because the Gods had been angered" (p. 1). Similarly, others viewed disability as an "immutable condition caused by supernatural agency" (Longmore, 2003, p. 42). Conversely, others felt people with severe ID were "capable of receiving divine revelation" (Harbour & Maulik, 2010, p. 1). For the most part, however, people generally view disability negatively throughout history and hypothesized about its causes.

At times, people with disabilities were deprived of basic human rights and blamed for evils in society due to fear, curiosity, and/or hatred (Longmore, 2003). The Bible states people who were lame, blind, crippled, mute, contagious, or mad were not allowed to participate in temple rituals (Stiker, 1999). Ancient Greek and Roman infants with severe ID were often allowed to die of exposure (Harbour & Maulik, 2010).

Attempts to cure people of physical disabilities are listed throughout history, but were rarely successful. For example, Longmore (2003) described some treatments professionals used on the physically disabled to try to "fix" their infirmities. For example, paralyzed limbs were amputated. In addition, medical experiments were performed on deaf students to restore hearing. These experiments included "bleeding, blistering, leeching, fracturing the skull just behind the ear with a hammer, or piercing the eardrum, inserting a probe through the nose in the Eustachian tube and working it back and forth, all inflicting excruciating pain, all with no effect" (p. 46).

When efforts to cure people with disabilities were not effective, society began segregating and institutionalizing people with disabilities in order to provide them with efficient care and keep them away from people without disabilities (Harbour & Maulik, 2010). In addition, in the early 1900s, researchers began learning more about genetics and encouraged sterilization of people with disabilities in order to stop them from reproducing (Pham & Lerner, 2001). In fact, by 1944, sterilization laws were adopted in 30 states. Between 1907 and 1944, 42,000 people in the U.S., mostly women, were involuntarily sterilized "in an attempt to eliminate the presumed genetic sources of diseases including feeblemindedness" (Harbour & Maulik, 2010, p. 3)

Nazi atrocities, additional genetic research, civil rights movements, and feminism led to disapproval of sterilization in the 1940s (Harbour & Maulik, 2010; Pham & Lerner, 2001), but 22,000 more people were sterilized between 1943 and 1963 (Harbour & Maulik, 2010; Pham & Lerner, 2001). In 1978, guidelines were established forbidding the use of federal funds for sterilizing incompetent or institutionalized people. Today, laws make involuntary sterilization difficult.

The 20th century also brought increased rights and services to people with disabilities. Political changes for the disabled community started in 1918 when the first federal vocational rehabilitation legislation was established for disabled veterans. In 1920, the policy was extended to disabled civilians. The U.S. elected their first president with a disability, Franklin D. Roosevelt, in 1933; however, he hid his paralysis and cheerfully created a public image for himself masking any signs of dependency on others (Longmore, 2003).

From that time onward, victories for people with disabilities continued to rise. Several organizations were formed and legislation specifically enacted. In 1935, the League of Physically Handicapped was started, and the Social Security Act was enacted. The National Association of Parents and Friends of Mentally Retarded Children was formed in 1950. In 1952, legislation was enacted in 46 of 48 states to educate people with ID. President John F. Kennedy established the President's Panel on Mental Retardation in the early 1960s, and "President Johnson's War on Poverty and establishment of Project Head Start sought to address some of the environmental causes of intellectual disability" (Harbour & Maulik, 2010, p. 5).

In 1973, Rehabilitation Act 504 was enacted to protect the disabled from discrimination in federally-funded programs. In 1975, "The Education for All Handicapped Children Act secured a free public education for children with ID" (Harbour & Maulik, 2010, p. 5). The Americans with Disabilities Act was passed in 1990, increasing equal access to school, work, public transportation, and public places for people with disabilities (Longmore, 2003). "In 1994, the United Nations passed the *Standard Rules on Equalization of Opportunities for Persons with Disabilities*, providing international standards for programs, policies and laws for those with disabilities" (Harbour & Maulik, 2010, p. 5).

A history of disability would not be complete without some mention of their tireless caregivers. Most people with disabilities require varying levels of care throughout their life. Looking back on the history of caregiving illuminates some conditions currently surrounding transitions for parents of people with ID. Women have been the primary caregivers for families, friends, and neighbors. When a person was sick or had a disability, a woman (mother, step-mother, grandmother, daughter, or sister) often assumed responsibility for the care. Women throughout time sacrificed sleep, time, health, energy, school, and career opportunities to care for those in need (Abel, 1995a).

Today, responsibilities of caregivers constantly change as the number of people needing care and the severity of diseases increase (Scharlach, 2008). At the turn of the century, 22.4 million families were caring for adults, and 4.4 million families were caring for children (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2003). In 2009, over 65.7 million adults served as family caregivers to an adult or child in the U.S. (National Alliance for Caregiving et al., 2009). This number continues to climb as the numbers of older people and people with disabilities increase (Administration on Aging & Department of Health and Human Services; Krahn et al., 2006). Even more caregivers are needed because many long-term care facilities have closed. In addition, less care is being provided in hospitals, so family caregivers are required to perform complex caregiving tasks for ill family members. In fact, today, many women and an increasing number of men are giving time and physical and emotional energy to care recipients (Scharlach, 2008).

Patterns of Response

Patterns of response is the last area of the Meleis health transition model (Meleis, 2010). Meleis said patterns, characterized by certain progress indicators and outcomes, mark the end of a healthy and successful transition leading to improved well-being.

Progress Indicators

Few details are provided by Meleis (2010) to explain the four progress indicators: feeling connected, interacting, location and being situated, and developing confidence and coping. An example of feeling connected may include a parent feeling a deeper connection with his or her family and friends, or forming a special bond with healthcare professionals following a difficult transition.

Being situated could include accepting the place a person resides following the transition, and could be physical or symbolic. Being situated could mean the person is able to comfortably switch back and forth from talking about life before and after the transition (Meleis, 2010). For example, parents may talk about situations and life experiences before and after their child was diagnosed with ID. Developing confidence and coping skills are further indicators a healthy transition is taking place, and may be seen in parents who understand the transition process, increase resource utilization, and develop strategies for managing transitions.

A possible concept tying the four progress indicators together for the parents is integrating the child's disability into the parents' lives. Boström, Broberg, and Hwang (2010) defined such integration as the merging of the disability into the background of their life so they were no longer preoccupied with it. These authors used semistructured interviews to elicit narratives from 17 parents about their perceptions and subjective experiences of raising a child with ID. Parents ranged from 24 to 43 years-of-age with a mean age of 32. At the time, the children in the study were between the ages of 5 months and 5 years old. The authors described the range of integration parents displayed while describing their experiences of raising children with ID. The parents ranged from being preoccupied by the diagnosis (thoughts about the diagnosis played a dominant role in everyday life) to accepting and integrating it into their lives (the disability merged with the background). The authors noted struggling with thoughts of the diagnosis and having it be a central element in their everyday lives produced negative emotions. They found most parents provided a balanced description of the diagnosis and were preoccupied with the diagnosis and its consequences; however, some parents had already integrated it into their lives despite the short time period since the diagnosis. The authors also suggested positive parental emotions may have been protective factors promoting parents' ability to cope.

Integration did not mean the diagnosis was simply ignored because there were certain factors affecting a person's ability to achieve integration. For example, Boström, et al. (2010) described the range of emotional expressions exhibited by parents regarding their child and his or her ID, and their experiences with the disability. The authors claimed most parents gave balanced and affectionate descriptions of their children characterized by the following four elements. First, the parents described their child positively and with love and affection. Second, they shared positive and negative characteristics of their child with an emphasis on the positive. Third, parents described "well-functioning routines and parent-child interactions" (p. 96), and fourth, they spoke of "the child as an individual person" (p. 96). The concept of integration may provide greater understanding of the positive possibilities in parents' lives. In contrast, a few parents in their study spoke of their child in a distant or hostile manner or idealized them. In other words, their descriptions were overly negative or positive.

Lutz and Bowers (2005) also described disability as being integrated into a person's life, but their focus was on people with disabilities themselves instead of the caregivers. They discovered people with disabilities perceived their disability "as a multifaceted, complex experience that is integrated into and, ultimately, becomes part of their lives" (p. 1042). The authors went on to describe three categories of disability-related factors influencing a person's ability to integrate disability into their lives. These were "the fundamental effects of the disabling condition, others' perceptions of disability and its influence, and the need for and use of multiple resources from multiple sources" (p. 1042). Time and experience allowed people to adapt and become comfortable with their disability. They were able to learn more about it, shift expectations, and find new opportunities. The more these factors hindered their ability to live their lives, the more difficult it was to adapt to the disability. Therefore, integration of the disability could be a way parents manifest a reformation of their identity.

Another study that does not specifically discuss integration could also be used as a progress indicator. Grant, Nolan, and Keady (2003) mapped the lives of parents with children with ID, and described six caregiving stages. Their first and second stages include preparation for caregiving responsibilities and becoming aware of the disability. Next parents accept the realities of the disability and work through it. Their final stages are reaching the end of the caregiver journey and starting a new beginning. Towards the end, parents often report increased reciprocal relationships between with their children with ID, as well as a "heightened sense of caregiving enrichment" (p. 348). If parents 'let go' of their children during this stage, there can be a new beginning for parents and their children. However, many parents continue to care about their child and maintain varying degrees of involvement.

Outcome Indicators

Meleis (2010) identified two outcome indicators resulting from healthy transitions. The first is “mastery of the skills and behaviors needed to manage their new situations or environments” (p. 63). An example could be a parent mastering the skill of communication with their child with ID.

The second outcome is a reformation of parental identity that is fluid in nature and changes with taking on the identity of “parent of a child with ID.” Little research has been performed regarding identity among parents of children with ID, and there appears to be variability in parents’ ability to accept the identity of being a parent of a child with ID. In addition, different events in time may trigger parents to question their identity.

Todd and Jones (2005), for example, found some mothers struggled with their own identity during their child’s adolescent years. They interviewed 30 mothers (34 to 56 years of age) of adolescent children with ID about their experiences of parenting during the middle years of life. Mothers described their identity as ordinary and maternal in nature during the early years of caring for their children. However, their child’s disability had a larger impact on the mother’s identity during the child’s adolescence as the responsibilities of the disability prolonged their maternal role. One group of mothers strongly treasured their role as mother and wished others could see the same value and respect for motherhood. The second group “feared becoming engulfed by their maternal role and that something of value to them was threatened” (p. 399), and clung to aspirations of the past and questioned if and how those would happen.

Another author, Morgan (2010), described how 17 parents (56 to 82 years of age) of offspring with ID identified themselves as special parents, which further allowed them to take on the identity of long-term caregivers.

Alternative Framework: Resilience Theory

An alternative framework for explaining the transitions of parents raising children with mild to moderate ID is the resilience theory. Waite and Richardson (2004) defined resilience as “the process and experience of being disrupted by change, opportunities, stressors, and adversity and, after some introspection, ultimately accessing gifts and strengths…to grow stronger through the disruption” (p. 178). Resilience is not a static trait (Greeff & Nolting, 2013; Haan, Hawley, & Deal, 2002; Luthar, Cicchetti, & Becker, 2000) or “a quality… that is always present in every situation….Rather, resilience is defined by the context, the population, the risk, the promotive factor, and the outcome” (Fergus & Zimmerman, 2005, p. 404). In this study, resilience was depicted similarly.

The Resiliency Model by Richardson and Waite (2002) describes the process of adapting to stressors, adversity, or life events. Figure 2.2 graphically depicts the process. According to the model, individuals begin in a state of homeostasis during which they feel comfortable with their life situation. Then, life events and resilient prompts occur resulting in a disruption or “a risk or adversity that carries a significant threat for the development of a negative outcome” (Windle, 2011, p. 158).

Following the disruption, individuals generally reintegrate in one of four ways. First, they reintegrate dysfunctionally by “resort[ing] to substances, destructive behaviors, or other means to deal with the life prompts” (Richardson, 2002, p. 312). Second, they reintegrate with loss by “giv[ing] up some motivation, hope, or drive because of demands from life prompts” (p. 312). Third, they reintegrate back to their

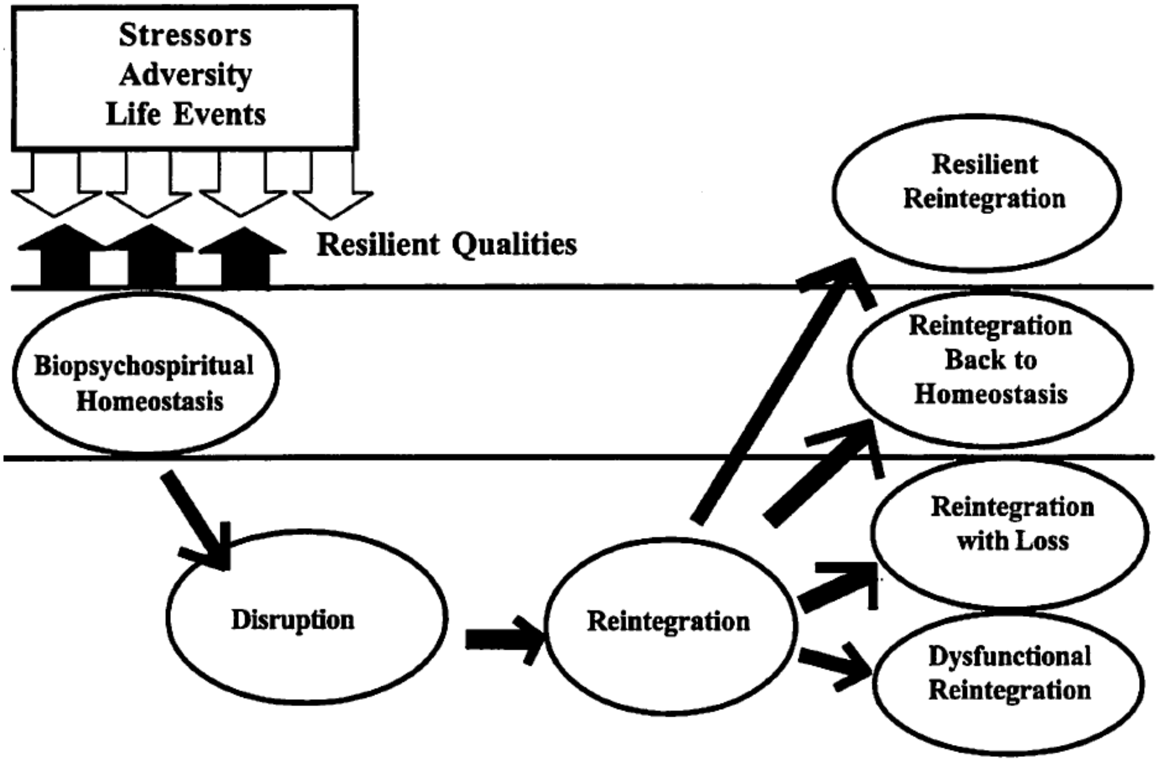

Figure 2.2 The Resiliency Model.
Note. From "Mental health promotion through resilience and resiliency education," by G. E. Richardson & P. J. Waite, 2002, *International Journal of Emergency Mental Health, 4*(1), p. 67. Copyright 2002 by Routledge. Reprinted with permission.

comfort zone not having changed from the event. Fourth, they reintegrate resiliently, learning from the event and growing as a result of the process. Resilience and reintegrating resiliently are used synonymously in this study.

Other literature added to this model provide clarity and understanding. For example, Windle (2011) described a process of "negotiating, adapting to, or managing [the] significant source of stress or trauma" (p. 163), which is another way of describing reintegration. Luthar, Cicchetti, and Becker (2000) described reintegration process as a process of balancing risk and protective factors. Risk factors, as defined by Bekhet et al. (2012), are "factors that predispose people to physical and mental health problems because they affect how a person adapts to stress (p. 651)." One goal of resilience, therefore, is to maintain or promote improved health. Protective factors, also known as compensatory factors or assets, are defined by Bekhet et al. (2012) as "factors that promote resilience by diminishing effects of risk and decreasing the negative reaction to it, thereby allowing [people such as] caregivers to achieve positive outcomes" (p. 651). Examples of protective factors in family members of children with ASD include social support, locus of control, and religious beliefs and spirituality (Bekhet et al., 2012). In studying resilience in families of young children with ID, Gerstein, Crnic, Blacher, and Baker (2009) found "marital quality was a clear compensatory factor" (p. 992) for parents.

Resilient reintegration is the ideal culmination of the resilience process. Richardson (2002) described it as "growth, knowledge, self-understanding and increased strength of resilient qualities" (p. 310). Bekhet et al. (2012) described this phase with indicators of resilience—"predictors of resilience" (p. 652)—and outcomes of resilience—"positive health outcomes" (p. 653). The resilience indicators found in their literature review discussing family members of children with ASD included self-efficacy, acceptance, sense of coherence, optimism, positive family functioning, and enrichment. Positive health outcomes included less depression, better marital quality, greater psychological well-being, and greater life satisfaction.

Chapter Summary

This chapter presented the well-known Meleis health transition model (Meleis, 2010) and concluded with a brief summary about resilience theory. Information about the transitions parents of children with ID experience was incorporated throughout. A fair amount of literature (Risdal & Singer, 2004; Schneider et al., 2006; Seltzer et al., 2011; Yantzi et al., 2007) is available to describe the different types of transitions parents of children with ID potentially could experience. However, little information about the other parts of the Meleis health transition model (Meleis, 2010) was found, thus affirming the need for more research.

Lacking a scientific basis to differentiate transitions for parents caring for children with ID, healthcare professionals are unable to understand parents' experiences or respond with precision to different kinds or magnitudes of transitions in a systematic, evidence-based way. This study will provide researchers and healthcare providers with information that may be helpful in beginning to create and test interventions to better support parents through transitions encountered over a lifetime. Theories about transitions and health trajectories can be developed and refined. Policies can then be created to give parents more support as they care for their sons and daughters and are called on to assist in eliminating health disparities among this population.

CHAPTER 3

METHOD

The purpose of this study was to explore how parents narrate the transition of raising a child with mild to moderate ID, and how that person influences parents' overall health trajectories. The methods of the study are reviewed in this chapter, beginning with the research design. Discussion of the research design includes information about participants, demographics, and the methods of narrative and life history data collection. The study protocol then outlines steps undertaken in the study and describes individual interviews. A description of data analysis follows, including narrative analysis and a step-by-step guide used in analysis. The chapter concludes with potential risks and benefits to participants and issues of study trustworthiness.

Research Design and Method

A qualitative method was selected for this study in order to explore in depth an underdeveloped phenomenon—transitions and health trajectories of parents raising children with mild to moderate ID—from their own perspective. Because parents of children with mild to moderate ID know the most about their own lives, transitions, and health, I wanted to explore their experiences in an open manner, thus allowing them freedom of expression in discussing aspects of their lives and experiences they felt were most important. The qualitative data collection of narrative in the form of life history allowed participants to share life experiences in their own words with little guidance.

Through a series of three in-depth, semistructured interviews, parents shared their life stories. The first interview dealt with the experience of raising a child with ID from the beginning. Guiding questions were used to elicit additional memories from different time periods (e.g., elementary school or junior high school). The second interview consisted of a series of follow-up questions regarding experiences shared in the first interview; some questions were derived from the Meleis health transition model a priori (Meleis, 2010). In the third interview, parents explained their lives using the lifeline drawings they created as a visual guide. Questions similar to those asked in the second interview were used. See Appendices A and B for interview questions asked. This section describes the research participants and provides greater detail about the data collection methods and study protocol.

Research Participants

A sample of up to 20 research subjects was approved by the Institutional Review Board (IRB) at the University of Utah, although only 18 were needed to constitute a complete dataset. Purposeful and snowball sampling were employed to select 18 parents (6 fathers and 12 mothers) who met five inclusion criteria. See Table 3.1 for a list of inclusion criteria. Following the table is a description of the inclusion criteria and demographic information. The goal of the sample size was to allow for a rich, full exploration of the topic with a diverse sample (Coyne, 1997). This sample size provided enough information to describe parental health trajectories and transitions in depth, but

Table 3.1 Inclusion Criteria

#	Inclusion Criteria
1	≥55 years-of-age
2	Adoptive or birth parent of a child with a mild to moderate ID
3	Parent reports primary responsibility for the care and well-being of his or her child with ID for the majority of the child's life
4	Speaks English
5	Able to draw and explain a lifeline drawing

did not produce so much information that analysis glossed over details (Sandelowski, 1995). There was no subject attrition.

First, parents aged 55 and above were selected. According to Seltzer, Floyd, Song, Greenberg, and Hong (2011), the health of parents of children with ID remains similar to parents of typically developing children until about the age of 60. At and following this age, several negative effects, including an increased amount of depression, greater obesity and functional impairments, poorer health-related quality of life, and less frequent visits with friends and family are noted.

The second criterion was the parental relationship. Originally, I required either the participant or his or her spouse/partner to be the birth parent. Participants could be married or partnered. Adoptive parents were to be excluded from participation as I had imagined their experiences to be different and suitable for a separate study. This criterion was explained to each participant prior to enrollment in the study; however, upon beginning one interview, the mother informed me she adopted her son shortly after birth from an agency, and knew the child had Down syndrome prior to adoption. Despite the variation from the inclusion criteria, I continued with the interview to test my assumption that her experience could be different than birth parents. I did not believe the interview would put her at risk. This participant did not receive additional support or resources, and never mentioned contacting the birth mother. In these regards, her experience seemed similar to other participants'. Following her interview, a deviation report and an amendment to the original proposal allowing adoptive parents to participate was sent to and approved by the IRB.

As part of the second criterion, the children of the parents participating in the study were required to have a mild to moderate form of ID as reported by the parents. No testing for ID was done; instead I relied on parents to tell me whether their child was officially diagnosed with ID, had "below-average intelligence," or "attended special education classes" (p. 482). These criteria were designed to be similar to those used in a study about health differences among parents raising children with ID by Seltzer et al. (2011).

Participants were raising children with ASD, Down syndrome, or brain damage. Asperger's disorder falls along the ASD continuum; however, I chose to keep this diagnosis separate as participant parents referred to their daughter as having Asperger's disorder, and their experience was distinctly different from other parents. These parents, as well as all other parents, told me their child had below-average intelligence and attended special education classes.

Third, parents were required to self-report being primarily responsible for the care and well-being of their child with ID for the majority of the child's life. One indicator of this primary caregiving relationship was that the child resided with the parent for the majority of his or her life and spent minimal time in a long-term care facility and/or group home. According to Seltzer el al. (2011), the parents of children with ID who co-reside with them tend to experience more physical and mental health problems than parents of children with ID whose children live elsewhere or do not co-reside with them. Lastly, participants were required to speak English and have the ability to draw and explain a lifeline diagram.

Demographics

Participants included 18 birth or adoptive parents ages 55 and over caring for children with mild to moderate ID. See Table 3.2 for more details. Prior to the study, I knew 11 of the 18 participants; 5 participated in *We Can Too!* and the others were acquaintances. All participants were currently married; however, 4 had been previously divorced and this was a second or third marriage. Only half the husbands were interviewed, so there were 12 mothers and 6 fathers. See the section titled Study Protocol for more details about sample selection. All parents reported raising 1 child with a mild to moderate ID except for 1 mother who was raising 2; the older child had Down syndrome and the younger ASD. Parents were raising 13 children with ID. Functional level of the children was not measured. As described by parents, 2 sons, 1 with ASD and the other with Down syndrome, seemed to be more severely affected, both physically and in terms of communication limitations, than the 11 other children. The daughter with Asperger's disorder seemed to function at a higher level than the other children, as she graduated from college, was married and divorced, and had four children.

All participants' children with ID were currently living with their parents, except a deceased son who lived with parents until his death. One son with Down syndrome

Table 3.2. Characteristics of Participants

Child		Parent			
Gender/age	Diagnosis	Mother/Father	Age	Education	Employment
1. Female/ 54	Brain damage	Mother: Anita Father deceased	79	High school	Homemaker
2. Male/ 28	Down syndrome	Mother: Betty Father: Bernard	69 69	College degree Graduate degree	Homemaker 31-40 hours/wk
3. Male/ 25	ASD	Mother: Catherine Father: Clifford	59 60	College degree Partial college	31-40 hours/wk Retired
4. Male/ 38	Down syndrome	Mother: Dorothy Father declined	60	Partial college	21-30 hours/wk
5. Male/ 27	Down syndrome	Mother: Evelyn Father: Eddie	64 63	Partial college Graduate degree	Retired 41-50 hours/wk
6. Male/ 29	Down syndrome	*Mother: Gail Father not interviewed	72	Graduate degree	Retired
7. Male/ 22	Down syndrome	Mother: Helen Father not interviewed	57	Partial college	Homemaker
8. Male/ 16	ASD	Same as child #7 Same as child #7			
9. Male/ 20	ASD	*Grandmother: Jean Grandfather deceased	66	College degree	31-40 hours/wk
10. Male/ 34	Down syndrome	Mother: Kathleen Father: Kenneth	75 78	Graduate degree Graduate degree	Retired Retired
11. Male/ 30	Down syndrome	Mother: Linda Father not interviewed	59	Partial college	Retired
12. Male/ deceased	Brain damage	Mother: Martha Father: Martin	64 58	College degree Partial college	41-50 hours/wk 41-50 hours/wk
13. Female/ 43	Asperger's disorder	Mother: Nancy Father: Norman	66 71	Graduate degree Graduate degree	1-5 hours/wk Retired

All names are pseudonyms
*Indicated child adopted.

lived in a basement apartment in his parents' home. The daughter with Asperger's disorder lived away from parents for approximately 10 years while attending college and living with her spouse. Her parents visited her regularly while she was in college to help her with homework. She moved in with her parents for about a year while she was married, and was ordered by the court to again live with her parents following her divorce. She currently has custody of her daughter and relies heavily on her parents for assistance.

Two parents were adoptive parents. The first adopted her son from an agency at birth knowing beforehand that he had Down syndrome. The second adopted her grandson with ASD when he was about 10 years old. She claimed to have taken the most active caregiving role in his life, and prior to adoption, watched him during the day most of the week.

One participant spoke English as a second language; however, she was English proficient. I believe all participants were capable of creating lifeline drawings on the provided butcher paper; however, 4 were not prepared at the third interview with their lifelines. Therefore, I created lifeline drawings in a word processing document with them during the interview so we would have material to discuss.

Data Collection Methods

Data were collected from three different sources: digital recordings and transcripts of narrative interviews with an emphasis on life histories, lifeline drawings created by participants, and a study journal. The study journal is comprised of my meticulous notes type written during the interviews as well as other notes recorded with regard to the study. The lifeline drawings were photographed and later returned to participants.

Narrative

Polkinghorne (1995) defined narrative as “any prosaic discourse… [or] text that consists of complete sentences linked into a coherent and integrated statement” (p. 6). It “draws together diverse events, happenings, and actions of human lives into thematically unified goal-directed processes” (p. 5). Riessman (1993) pointed out that some researchers define narrative broadly to the point of including almost anything, whereas other scholars use much more restrictive criteria. Narrative can be found everywhere; some examples include autobiographies, diaries, health records, paintings, comics, news items, and fables (Riessman, 2008). Clandinin and Connelly (2000) wrote, “life is filled with narrative fragments, enacted in storied moments of time and space, and reflected upon and understood in terms of narrative unities and discontinuities” (p. 17).

Elliott (2009) described three key features of narratives. First, narratives are chronological. They organize and connect events to form a whole. The events within a narrative highlight individual lives within a social context. Polkinghorne (1995) also added that narratives are not temporally linear, but told with a coherence unified by a plot or theme. The segment of time discussed in a narrative can range from being boundless to short episodes lasting under an hour, and is presumed to move from the past to the present in a unilinear direction. Riessman (2008) suggested narratives are stories containing a beginning, middle, and end with a plot and characters. This chronological ordering of events and narrative structure may be a part of the analysis process.

Second, narratives are meaningful. Elliott (2009) suggested narratives convey the meaning of events, behaviors, and experiences from the teller's point of view, thus creating greater understanding of the participant. They also provide a place for a teller to share his or her feelings and point out significant events. Narratives offer ”insight about the world and/or people's experiences of it” (p. 3). Of course, meaning can change over time as people have experiences and develop new ideas. Crotty (2003) pointed out that people act differently according to the meaning they assign to certain phenomena and adapt and modify that meaning to meet their needs. In fact, creating meaning may occur for participants as they present the narrative.

Third, narratives are inherently social. They are produced for specific audiences and told differently to diverse audiences. I acknowledge participants tailored their stories to me—a White, middle class, pregnant female student. Some initially participated, I believe, to help a student in need. All tried hard to understand my questions and share information they thought would be helpful. During interviews, participants may have been leery to be overly negative about their experiences because I was pregnant. One mother acknowledged she tamed her language because she knew my religious background. Also, the manner in which I asked questions and listened shaped both the manner and matter of their narratives. For example, letting parents know I was interested in what they said encouraged them to share more information.

Riessman (2008) suggested that narratives serve many functions for individuals and groups; they allow people to tell their stories and help make sense of events and experiences occurring in their lives, especially those that are challenging and/or traumatic (Riessman, 1993). People tell themselves and others who they are and who they are not by stories they tell. A major purpose of narrative is to construct identities. The participants in this study may have crafted stories about their experiences raising a child with ID to convince themselves and others they were successful at raising a child with ID.

Lieblich et al. (1998) further explained “narratives provide us with access to people’s identity and personality” (p. 7). They continued,

> Stories imitate life and present an inner reality to the outside world; at the same time, however, they shape and construct the narrator’s personality and reality. The story is one’s identity, a story created, told revised, and retold throughout life. We know or discover ourselves, and reveal ourselves to others, by the stories we tell. (p. 7)

Evidence of culture is also seen in stories, as are gender inequalities, racial oppression, and other practices of power. Finally, narratives allow individuals to “remember, argue, justify, persuade, engage, entertain, and even mislead an audience” (p. 8). Thus, narratives, collected through interviews, were helpful in developing a deeper understanding of the lives, transitions, and health of parents through their own perspectives.

Life History

Mandelbaum (1973) defined life history as “the account of a life, completed or ongoing” (p. 177). As parents shared their life histories through creating and narrating visual lifeline diagrams, we became collaborative partners in exploring, discovering, understanding, and constructing an account of their lives (Haglund, 2004). Through this process, I was able to “examine changes over time” (Haglund, 2004, p. 1309) in the parents. Some changes occurred quickly, while others spanned months, years, and even an entire lifetime.

Lifeline Drawings

Gramling and Carr (2004) presented the lifeline drawing as a way for participants to share life histories. They claimed lifeline drawings helped guide participant stories and jogged their memory of past events. These investigators provided participants in their study with various art supplies, and asked them "to draw a chronological display of their lives. The display was to consist of a line, horizontal or vertical, filled with events the participants considered significant in their lives from birth to the present" (p. 208). Participants were able to talk with one another as they created their lifeline drawings.

For the purposes of my study, I utilized lifeline drawings but modified the method. Participants were asked to create their lifeline drawings individually and on their own time, thereby allowing them additional time to think about and create a more meaningful product. The procedures are outlined in the study protocol section and the initial and revised interview guides in Appendices A and B.

Study Protocol

Upon approval of the IRB, recruitment flyers were distributed widely via e-mail and hard copy to acquaintances, colleagues, contacts in the disability community, and participants from *We Can Too!* I attended a meeting hosted by a community-based service agency for parents of children with ID, and left 20+ flyers (Appendix C) with the instructor who said he would distribute them among his clients. I also recruited at Murray Greenhouse, a nonprofit organization teaching independent living and employment skills to people with disabilities. I followed up with people who contacted me with interest in participating in the study within 24-48 hours. The first participants were people I knew.

My goal was to interview 20 participants; however, after 18 interviews, I felt confident data were sufficient in scope and depth to sufficiently answer my research questions.

While contacting potential participants, I used the recruitment script (Appendix D) to determine eligibility. If the person was eligible and willing to participate, I scheduled a first interview. The consent form (Appendix E) was sent via e-mail when possible to allow participants time to read it prior to the interview. If a person was unsure about participating, I asked whether he or she would like me to e-mail the consent form and follow up at a designated time. If the potential participant was uninterested, he or she was thanked and asked for potential referrals to the study. Four additional parents met inclusion criteria, but did not want to be involved in the study.

Participants were interviewed in the order in which they were recruited or according to their availability. Originally, I wanted to finish interviewing one participant before moving to the next in order to keep individual stories together. Quickly, I learned this was unrealistic and interviewed participants when they were available.

All individuals who expressed interest in the study were screened for eligibility. Initially, all who met inclusion criteria were enrolled. The purpose of the recruitment strategy was to discover a core shared narrative about the experience of raising children with ID, not necessarily to find a heterogeneous group of parents (Sandelowski, 1995). Once 5-10 participants were enrolled, interest in the study heightened, so I decided to be more selective about which participants I consented to include in the study. Periodically, I stopped recruiting altogether, so I could complete interviews. There were some commonalities among participants' stories, so I chose participants from my recruitment pool I thought may have a slightly different perspective. For example, characteristics such as older age, living in a rural location, various ethnicities and religions, and having children with different diagnoses were considered for participation in the study.

Some mothers participated without their husbands, so an attempt was made to recruit fathers without participant wives to compare the genders separately. However, recruitment was typically initiated and supported by the wife, so this plan was not followed and some wives and their husbands participated together. The wives wanted to participate with their husbands. As part of the process of being selective about participants, three husbands of participants were not recruited. Prior interviews had shown the fathers' stories to be fairly similar to their wives'. Interestingly, no parents who were currently divorced volunteered to participate; some had been remarried and were still married to the mother or father of the child with ID. Once the 18 participants had been interviewed, I felt comfortable declaring the data were saturated with rich stories containing similar characteristics that would permit me to answer study research questions (Sandelowski, 1995).

Once participants were enrolled, I planned to do the three individual interviews fairly close together to increase continuity between sessions. The ideal was to schedule them no more than 1 week apart. On the other hand, I wanted at least a day or 2 between interviews to provide time to review notes from the previous interviews and prepare questions and comments for upcoming interviews. In the end, interviews were generally conducted 1 to 2 weeks apart; however, some were conducted months apart due to scheduling conflicts. As a result of changes in the initial interview guide, interviews did not build on one another. As a result, I believe additional time between interviews did not affect information shared by participants.

Individual participants were interviewed three times with some exceptions. One couple was interviewed only twice out of convenience for all of us, with interviews two and three being condensed into a single session. One participant was interviewed four times to allow time for assistance in creating her lifeline drawing. When scheduling interviews, I requested they be held at times and in places as free from distractions as possible. Fathers and mothers were interviewed separately with one exception. A husband who did not participate in the study sat next to his wife and listened to the interview. He seemed interested in what we discussed and made two or three comments during the interviews requesting she elaborate on certain points he believed she was being modest about. I do not believe having him present affected her responses. They seemed comfortable in one another's presence, and she was not afraid to speak her mind. Interviews were mostly conducted at participants' homes. Other places included a nearby park, private rooms in public buildings, and my home. I suggested various locations, and we decided together which would be the most convenient and conducive for the interviews. Information about the interview settings was recorded in my study journal.

All interviews were digitally recorded. My goal was to keep the interviews between 60 and 90 minutes in duration. The limit of 90 minutes is recommended as an ideal amount of time for a qualitative interview (Elliott, 2009; Hermanowicz, 2002). In addition, Elliott (2009) suggested giving participants a timeframe for the interview to help them gauge the amount of detail to present. I explained this timeframe during the consent process and reminded them at the beginning of each interview. Parents were instructed to include enough details in their lifeline drawings so they could explain them in approximately 45 minutes.

Interview #1

Beginning with my first telephone or in-person encounter with participants, I made an effort to build rapport with participants and create a safe environment for sharing personal and sensitive information. I used several suggestions from Dickson-Swift, James, and Liamputtong (2008) for this purpose. First, I recognized I would be asking participants to share sensitive and personal information, which can be difficult. When I visited parents' homes for interviews, I asked questions about them and their surroundings in an effort to become acquainted. Showing an active interest in their lives and actively listening was also helpful. I encouraged a feeling of teamwork as we jointly created narratives. We were both able to learn from one another. Being willing to self-disclose my personal information when asked and appropriate promoted safety and understanding. For example, when participants discovered we belonged to the same church, they spoke to me as a fellow member. Throughout the entire process, I tried to treat participants with respect and care.

I began the first interview by verbally going over the consent document and answering any questions participants might have. Then, I went through the online demographic form (Appendix F) and filled in their answers myself. I thought going over the demographic form together would be a good way to foster conversation and possibly elicit stories related to participants' situation and health; however, that was not the case. After these items were completed, we started the interview about experiences raising a child with ID.

In creating the questions for the interview guide (Appendices A and B), I incorporated suggestions from Elliott (2009), Riessman (1993), and Mishler (1986). I did my best to make the questions simple and clear (Elliott, 2009). The questions were open-ended and focused on encouraging participants to share their stories (Riessman, 1993; Roulston, 2010). Riessman suggested using questions such as, "'Can you tell me more about that?,' and 'What was the experience like for you?'" (p. 55). Riessman (1993) recommended using 5-7 broad questions in the interview guide and several probing questions to help participants if they get stuck.

I planned to start with small talk before asking the first question on the interview guide, but often it was not necessary. Participants seemed comfortable sharing their experiences. I wanted the interview to be as unstructured as possible, thereby allowing participants more freedom to share what they felt relevant and important (Mishler, 1986). After performing several interviews, I decided parents needed more direction and probes than I anticipated. Therefore, I clarified, expanded, reordered, and added questions to the guide. Before leaving, I scheduled the next interview and asked participants if they knew anyone else who may be eligible and willing to participate, especially a spouse. I reminded them about the lifeline drawing and asked them if they had any questions.

Study Journal

During interviews, I took detailed notes about what was said by participants and compiled them into a study journal on my laptop. Notes were not taken, however, when participants explained their lifeline drawings on the butcher paper during the third interview. I wanted to give participants my full attention, and often stood or sat on the floor next to the drawing, making note-taking difficult on the computer. Following each interview, I improved readability of the notes by adding headings, clarifying ideas, and fixing punctuation. Occasionally, questions would arise, and I asked participants about them in subsequent interviews.

These notes were reviewed with each participant prior to beginning each interview to check the accuracy of my records. Partway through the study, I started e-mailing notes to participants who used email instead of summarizing them at the beginning of each interview. This allowed participants to have and read their own copies at leisure. It also decreased total interview time as a courtesy to participants. Generally, most participants did not read the notes and wanted to proceed with the interviews; however, some added details or clarified their stories.

The study journal also included descriptions of the interview setting, my overall thoughts and impressions of the interview, study procedures and progress, and reflexivity. Thoughts and impressions about the coding process and the study as a whole (Saldaña, 2009) were recorded. All data obtained—audio and written—were saved to the hard drive of a password protected computer in my home office, and backed up to a secure network at the University of Utah and an encrypted flash drive.

Interview #2

Interview #2 began with a member check using notes from my study journal. I summarized the main points from the previous interview and asked for any corrections to the information. Initially, this interview was to be used for participants to finish telling their stories; however, the additional time was not needed. Instead, I asked specific questions about how their child affected their overall health and well-being. Then, parents identified and described the main transitions, turning points, disruptions, and changes experienced while raising their child with ID and answered questions guided by the Meleis health transition model (Meleis, 2010). Additional follow-up questions were asked as needed. Both the initial and revised versions of the interview guide are located in Appendices A and B. I reminded participants about the lifeline drawing and answered their questions. Some had partially completed drawings and wanted feedback. The interview concluded with determining a schedule for the final interview.

Interviews #3

Interview #3 also began with a member check. This last interview focused on the parents' lives, as they spent approximately 45 minutes explaining their lifeline drawings (Appendices A and B). The lifeline drawings began with the parent's birth and continued until the present. After participants explained their drawings, I asked them the same questions I asked in Interview #2; however, this time they reflected on their entire life, not just the time spent living with the child with ID. In conclusion, I asked them to summarize their overall lifetime health and provide advice to others about raising a child with ID. I asked some general questions about the interview process, thanked them for their service, and told them I would send notes from Interview #3 by email. I requested permission to photograph their lifeline drawings with a digital camera and keep them in my office for analysis. I informed participants I would contact them to make arrangements for returning the drawings, and provide periodic updates until analysis was completed. That concluded our interviews. Returning the lifeline drawings was the final in-person contact I had with research participants.

Data Analysis

Narratives can be analyzed different ways. Lieblich et al. (1998) developed a classification system for “reading, interpreting, and analyzing life stories and other narrative materials” (p. 12). Elliott (2009) and Riessman (2008) more recently developed similar classification systems based on Mishler’s (1995) framework, which classified narrative types using different functions of language. The categories of the different types of narratives are essentially the same, but the naming is slightly different. I used the methods of Lieblich et al., but added some of Riessman and Elliott’s explanations for clarity.

Lieblich et al. (1998) described two main independent dimensions for analysis of narrative materials: holistic and categorical; and content and form. The two dimensions are combined to create four different types of analysis: holistic-content, holistic-form, categorical-content, and categorical-form.

Researchers using a holistic approach seek to keep the narrative together and analyze it as one entity. Sections may be interpreted as they correspond with the whole story. Categorical analysis separates the text into shorter sections and places it into categories (Lieblich et al., 1998).

Content and form is the second dimension (Lieblich et al., 1998). Content focuses on the event—what happened, why, who was involved, and/or the meaning. Elliott (2009) and Riessman (2008) called this type of analysis thematic and categorized it as being concerned with the content or actual events and experiences participants share (Elliott, 2009; Riessman, 2008). According to Elliott (2009), the content of narrative has two functions. First, it describes the participants’ past experiences and puts them into chronological order. The second function is to clearly describe what the events and experiences mean in participants' lives. Content analysis is the most straightforward and common narrative analysis, often used in nursing and other health occupations studies to "uncover and thematically categorize patients' experiences of illness" (Riessman, 2008, p. 53).

Polkinghorne (1995) labeled content analysis the paradigmatic type because it examines "the data to identify particulars as instances of general notions or concepts" (p. 13). It takes a whole narrative and breaks it into concepts and themes derived either from a previous theory or inductively from the data, and requires analyzing several stories in order to make a good comparison. "The strength of paradigmatic analysis is the capacity to develop general knowledge about a collection of stories" (Polkinghorne, 1995, p. 14).

In contrast, form analysis provides a description of the plot structure, sequencing of events, narrative style, etc. Structural analysis, another name for form analysis, focuses on the way the story is put together. Researchers analyze how the story is organized, the genre, the plot development in a progressive or regressive direction, and story coherence (Elliott, 2009; Riessman, 2008). For this study, I used categorical-content, holistic-content, and holistic-form (Lieblich et al., 1998) to answer the two research questions.

Data Analysis: Step-by-Step

In this study, analysis began after the first interview and continued throughout and after the interview process. Notes from my study journal and lifeline drawings were used as major sources of data. They provided a condensed version of the interviews, which I believed accurately represented parents' responses and painted an overall picture of the interviews. Notes also helped me initially avoid getting bogged down by details of what participants said (Gibbs, 2007). As part of analysis, I reviewed the notes and used them to purposely select key segments from interviews to be transcribed by either myself or a professional transcription service. About 68% of the first interviews were transcribed verbatim in their entirety as this interview related most to the research questions. Small portions of remaining data were transcribed as needed to add clarity to the analysis.

Data were analyzed using a verbatim transcription style (Gibbs, 2007). I was concerned about content and themes so did not focus on microlevel linguistic analysis such as pause length, false starts to words, or filler words. Body language and other emotions, such as laughing or crying, were usually not included. During interviews, two mothers became teary, and both referred to their emotions when speaking.

Following transcription, original files were saved and backed up. Each file from the transcription service was checked and compared with the audio file to ensure accuracy. Data were then de-identified replacing participant names, family members, and friends with pseudonyms from lists of popular baby names. Other identifying information, such as cities and schools, were changed or generalized to prevent recognition. After checking and de-identifying, I began analyzing data to answer research questions. The next sections describe the procedures used to answer each question.

Research Question #1

The first research question asked how parents caring for children with mild to moderate ID narrated the transition of raising a child with ID using an inductive, holistic-content analysis technique (Lieblich et al., 1998). Data were analyzed over the lifetime of the participants, thus making analysis holistic. The focus was on including events and their impact on parents' lives.

I began by thoroughly reading and rereading notes from my study journal, listening to portions of interviews, and examining lifeline drawings to glean a better understanding of this transition. I wrote about my initial and global impressions. Key interview segments that helped me to better understand the transition of raising a child with ID and its effects on parents' health trajectories were transcribed. My intent was to discover themes and patterns in how the story unfolded. I considered the amount of space devoted to the theme in the transcription and details provided or omitted (Lieblich et al., 1998). I marked themes and patterns, reading separately for each. Then, I followed them and noted conclusions. Once completed for each participant, I read through all themes looking for similarities. Concept maps were drawn for each participant to assist me in determining story patterns. The analysis culminated with one overall story depicting a collective description of the main transition parents' experienced while raising a child with ID.

Research Question #2

The second question about the overall lifetime health of parents and the influence of the child with ID on their health was answered using two methods: text and graphs. Textually, a deductive, categorical-content analysis technique was used utilizing data from Interviews #2 and #3. Parents were asked to describe how this child affected their health in Interview #2 and to talk about their overall health in Interview #3. The categories included physical, emotional, social, and spiritual health from the definition of health from the World Health Organization (2011).

Graphically, I created health trajectory graphs for each participant and made overall comparisons. Prior to creating the graphs, I used a deductive categorical-content analysis to identify parents' transitions in the lifelines, interview notes in my study journal, and transcripts. I used the existing definition of transition from Meleis (2010). The transitions for each participant were then sorted into the Transition Matrix for further examination. See Table 3.3. The first column is the participant's ID. The second through fourth columns represent three time periods in the participants' lives. "Growing Up"

Table 3.3 Example of a Transition Matrix

ID	Growing Up	Adult	Later Life	Main Events
101	Loved to play ball. WWII. Family moved to UT for 2 years. Stayed w/ cousins to finish junior high. Moved to CA. Met future husband 2 wks later. Went to all proms in HS. Graduated HS	Worked at insurance company. Married. 1st child born. Moved to NE. 2nd son born, Moved to CA. Bought 1st home. Daughter (dtr)- born, diagnosed @ 3 mo w/ hydrocephalus, 6 mo-shunt placed. Bought 1st car. Son born. Moved. Kennedy shot. Hysterectomy. Dtr- potty trained, started school (age 7). Moved to UT. Mom moved in. Dtr- started work at training company (age 26). Worked for dr's service for 8 mo. Worked as secretary for 2-3 yrs. Cruise. Worked at furniture store. Visited DC. 1st g-kids born.	Husband passed away. Went to HI. Worked at LDS temple. Son- moved in w/ family. Hip surgery. Son's wife took off w/ kids, divorce took 2 yrs. Mom died. Stopped working at temple. Surgery for macular hole. Became mom without power to g-kids. Back surgery. Son- serious car accident. Son- diagnosed w/ head & neck cancer. Hip surgery. Son- stroke & moved in. Diagnosed w/ diabetes. Son- hernia rupture, 8 days in coma. Financial difficulties. PE, anemia, 2 blood transfusions	Dtr- diagnosed @ 3 mo w/ hydrocephalus. Husband passed away. Son's divorce & raising his children. Personal & family health problems.
Summary of all participant responses				

started with birth and ended with graduation from high school. The division between "Adult" and "Later Life" was somewhat blurred. It was about the time when parents retired and their other children left home. The columns were filled in for each participant.

The "Main Events" column contains events from the three time periods I thought impacted participants' lives the most. These events were not confirmed with participants. While considering this, I recalled the language, detail, frequency, and emotion used by participants in interviews. To help me make decisions, I also used interview notes from my study journal to see which transitions parents identified as main transitions in their lives during the second and third interviews. Participants were not asked to verify main transitions as this was my interpretation of their stories. A summary of each column was created at the bottom to provide an overall understanding of the main events in particular time periods of all participants' lives.

Using a holistic-form approach, I created a health trajectory graph for each participant using their major transitions. The graphs span the participant's life from birth to the present, thus making it holistic. Being more concerned with the sequencing of events than the way in which the story was put together, the analysis is categorized as one of form rather than content.

The health trajectory graphs are marked by time along the x axis and overall health and well-being on the y axis. I used the broad WHO (Frequently asked questions, 2011) definition of health, which includes physical, mental [emotional], and social health. I also included spiritual health.

The slope of the line depicts the parents' level of health over time. The larger the slope in a positive direction, the closer the person comes to reaching a state of complete health and well-being. No human being could ever reach this ideal state, but potentially could come close. A negative slope represents participant movement further away from this state of health. Transitions are changes making up pattern in the health trajectory. Without any transitions, there would be a horizontal line with no slope. The slope angle was subjectively determined by the way parents' described their transitions. Large and significant transitions typically had the most change in slope and spanned more of the graph.

Once the individual graphs were completed, I compared them to determine similarities and differences. In particular I compared transition types, numbers, sizes, and placements between individuals, males and females, and diagnosis of child. I was not concerned with the content of the story at this time, but rather how the plot axis was developed in the stories (Lieblich et al., 1998).

Issues of Study Trustworthiness

Riessman (1993) suggested four approaches for validating narrative analysis: persuasiveness, correspondence, coherence, and pragmatism. She emphasized, however, there is no canon of validation fitting all research projects, and each approach has limitations. In the discussion that follows, each approach is described, along with a summary of measures taken to increase study trustworthiness.

The first approach for increasing trustworthiness is to create a persuasive interpretation of the data. Riessman (2008) defined a persuasive interpretation of the data as "plausible, reasonable and convincing" (p. 191). I diversified the sample by selecting parents with characteristics I believed were somewhat different than those already recruited in order to obtain different points of view regarding the experience of raising a child with ID. I clearly organized the steps I took to analyze the data in Chapter 3 and study findings in Chapter 4. Direct quotes were utilized in Chapter 4 to explain findings and stay close to data.

The next approach, correspondence, examines whether or not the "narrative matches accounts from other sources" (Riessman, 2008, p. 187). This can be done by completing member checks to assure correct data interpretation (Riessman, 1993). After each interview, I shared with participants a summary of my study journal from the previous interview to assure accuracy of information. Using multiple forms of data collection—narrative, lifeline drawings, and a study journal—strengthened the correspondence by triangulating data (Gramling & Carr, 2004). Furthermore, working with my committee to discuss data findings increased correspondence and rigor.

Third, coherence examines whether a story hangs together, and is consistent and persuasive. With the assistance of my committee, I created a coherent story describing the collective experience of raising a child with ID. Health trajectory graphs were also used to describe parents' health over time. Finally, pragmatic use is the degree to which the study is used as a basis for other studies. Again, with feedback from my committee, I outlined the steps taken to collect and analyze data as clearly as possible to help future researchers. My study journal also increased trustworthiness as I wrote about my assumptions, feelings, reflections on the research process, and my own personal impact on the research process.

CHAPTER 4

RESULTS

This chapter is divided into two sections. The first section discusses parents' narratives of the transition of raising a child with ID. The second section discusses how this experience affected the parent's health.

When reporting results, exact frequencies were presented in some cases and other times words such as majority, some, and a few were used; these words represented approximately 75%, 30%, and 10% (Bloomberg & Volpe, 2008) of parents' narrated experiences, respectively. As interviews were semistructured, participants had leeway to discuss aspects of the question they found important. Parents told a story framed by their experiences, so it was not a direct index of the experience itself. Some participants may have commented on a certain subject if prompted. I reported what parents said; if information was not reported, it probably was not mentioned. For example, 5 mothers shared how they helped their son or daughter reach developmental milestones; the others did not mention this topic even though it may have occurred.

Research Question #1

In answering the first research question, I describe how parents caring for children with mild to moderate ID narrate the transition of raising such a child. During the first interview, parents answered the question, “Tell me about your experience raising a child with ID from the beginning.” As parents told their stories, the child was the main character and they were mostly in the background. Parents typically began with their child’s birth and told about the experience of having him or her diagnosed with ID, followed by a series of events in the child’s life.

A theme of resilience or adaptation ran through stories. Parents described challenges or disruptions encountered and personal actions taken to improve the situation. The stories were mostly about resilient reintegration where parents learned from their experiences; however, there were times when parents reintegrated back to their comfort zone or homeostasis (Richardson, 2002). The following six challenges were identified as parents shared their journeys of resilience: (1) discovering, receiving, and accepting my child’s limitations and diagnosis of ID, (2) caring for my child’s health issues, (3) managing behavioral issues, (4) facilitating attainment of early developmental milestones, (5) ensuring a good education for my child, and (6) increasing my child’s autonomy.

Although each parent had a unique journey, all described struggling with two or more of these challenges. Most parent narratives centered around one main challenge. For example, one mother spent a good portion of the interview telling about the ways she taught her son and advocated for him in the school system. She was a strong believer in mainstreaming and fostering autonomy. When he was young, she talked about some health issues. As he got older, his health was rarely mentioned. He was well behaved, so there was little information about behavior management issues; she was resourceful in obtaining help from others. Other narratives focused on the child’s behavioral problems or health issues and did not mention much about advocating. There was a lot of variation, but the six challenges were commonalities among all participant stories. Each challenge was typically a major part of the story for 3 or 4 of the parents. Numeric references are included for context; however, these are not meant to be endorsements of the categories. The first five challenges were mainly resolved for all parents at the time of the interview while the last two were more ongoing.

In order to adapt to challenges of raising children with ID, parents performed two types of actions. Initially, these action included behaviors such as learning everything about the diagnosis, sacrificing time and energy, utilizing resources, being creative and ingenious, and persevering. Over time, they learned to reflect back on their lives and situations seeing a different perspective of themselves and the child. Participants recognized and accepted their own personal strengths and limitations. Sometimes, this meant making personal changes and adapting. Parents relied on humor and other ways of coping for support. As parents adapted to challenges, they learned lessons and gained skills useful throughout their lives. Each challenge is described in this section intermixed with behaviors parents performed. The concluding section describes the best parts about parenting a child with ID and conclusion tying the story of resilience together.

Discovering, Receiving, and Accepting My Child's Limitations and Diagnosis

The first challenge was to learn the child was different and initiate help-seeking and diagnostic workups that often led to ID diagnosis. The process of accepting these changes and adjusting to them took varying amounts of time. Parents made a commitment or adopted an attitude to carry on, and became mentally prepared to raise a child with limitations even in the face of doubts or difficulty. If negative emotions initially accompanied the awareness and diagnosis period, they dissipated quickly and parents felt a strong determination to help their son or daughter.

Although the awareness of difference and effort to identify or diagnose the child's needs happened many years in the past, most parents presented vivid details in relating their story. They told about the conditions and behaviors that led up to their realizing they needed to seek help. Then, they related how the diagnosis transpired, was confirmed, and how they either prepared for or reacted to the diagnosis, and the beginnings of treatment plans. Some experiences among parents were similar based upon similarities among their children, thus the next sections provide a summary of parents' experiences grouped by the four main types of ID diagnosis. Evidence of parental behavior considered resilient mainly included accepting the child's limitations, providing appropriate care, and returning to life as usual.

Down Syndrome

The most common diagnosis among participants' sons and daughters was Down syndrome. Ten parents (7 children) shared their experiences of raising children with this disability, and revealed Down syndrome was typically diagnosed at birth or shortly thereafter. One mother, Dorothy, had a premature baby and the diagnosis was not made for about 6 weeks. Gail, the mother who adopted her son, was the only parent informed prior to birth that her son would have Down syndrome. Three mothers mentioned refusing to have amniocentesis tests performed during pregnancy as they knew results would not change their course of action. After children were diagnosed, chromosomal blood tests confirmed the diagnosis within 2 weeks or less.

Some parents were able to see Down syndrome characteristics from the beginning while others were not. Kathleen, Betty, and Kenneth provide some examples. Kathleen said, “The doctor held the baby up and let me look at it and said, ‘What do you think?’ And I said, ‘It looks like just the rest of the kids to me.’" On the other hand, Betty could tell something was unusual when the doctor held her baby up. She said, “His body was different than any other newborn we had ever seen because his arms were out hanging and his legs were out hanging. And most babies are tied up in a little knot and he was just hanging out… limp.”

Kenneth experienced people with ID because his mother worked at a facility for people with ID. On his way out of the hospital following the birth of his son, he stopped by the nursery and the nurses invited him into see his baby. He said, “They told me, ‘Sit down,’ and they handed the baby to me, uh, and he opened his eyes and I said, ‘Oh, he has Down syndrome.’"

With the exception of Gail, who adopted her son, and Kenneth, none of the other parents felt prepared to have a child with Down syndrome. Kenneth said, “I had always suspected that somewhere along the way I would [have a child with ID].” He felt comfortable with people with disabilities because he had had many opportunities to be around them. After he recognized Down syndrome in his son, he said, "Well, this is going to be different—it’s a little bit of change. It's going to be kind of pleasant to have something besides normal brats to deal with.”

Although Bernard did not feel prepared for the diagnosis at the time, he explained how he reflected on the knowledge he gained as a result of having an older son born with a cleft lip and palate. He learned from this experience the hurt he felt was basically a loss of expectation of a “perfect and whole, fully functioning” child. This realization helped him to cope when a different son was diagnosed with Down syndrome.

Two mothers, Kathleen and Betty, recalled feelings of shock and sadness as they shared their experiences of having a child diagnosed with Down syndrome. Neither had much previous experience with people with ID. Kathleen said,

> I was shocked. The only experience I had had with people with Down syndrome was when my oldest child was born 15 years before that approximately, the woman in my room had a baby with Down syndrome. It was her fifth child, she was very young, and her priest came in and told her to put the baby in an institution, and she said, “Absolutely not. I'm keeping this baby at home.” So that's the only experience I'd had with anybody with Down syndrome.

After learning her infant son had Down syndrome, Betty cried as she recalled a memory of a girl she knew in her childhood with Down syndrome. She said,

> I cried that night. I know I cried that night because I had memories of a little girl in the [church congregation] I grew up in who had Down syndrome and of course that was a lot of years earlier. She didn’t have opportunities for schooling or anything like that. There were days when she would be playing out in her front yard and the school kids would walk by her house and yell at her and make fun of her and that… thoughts of that happening to this brand new baby of mine were not nice.

Following that night, though, she did not cry again.

Linda, who was from a different country, told the doctor he did not know what babies from her country looked like, and “that’s what was wrong.” She did not believe her son could have Down syndrome. Bernard could not see the “visual markers” of Down syndrome in his son, so he denied the diagnosis until they had the “genetic study… completed.” Eventually, he said, it “grew on [him].” Dorothy was just excited to have a baby. She said, “He was my baby. He was my first child. To me he was beautiful and…I was happy with him as I think I would have been with any other child.” She and her husband were surprised when the doctor and a prominent church leader asked if they were going to keep him at home or put him in a facility. “It never occurred to [them] that there would be any other choice but to take him home” and love him.

Helen said her obstetrician was suspicious her son was born with Down syndrome because he was floppy and had only one simian crease in his hand. After 5 days, the results came back and her son did indeed have Down syndrome. The first person who talked to her about the diagnosis did so in a positive manner. She said her son came to this “earth with something extra—an extra part of a chromosome.” She smiled through the whole conversation and concluded by saying, “He’s going to write his own book.” Helen adopted this philosophy of hope and optimism. She said, “Ok, he’s different, where do we go from here?” She was interested in learning more, although she admitted she did not always feel “competent” or have “confidence in her choices.” These examples demonstrate the variety of reactions displayed by parents as they learned about their child’s diagnosis of Down syndrome.

As parents started working with their children and feeling comfortable with the diagnosis, perceptions changed and they rarely spoke about negative feelings. Kathleen was the only mother who described feeling depressed about her son’s diagnosis for an extended period of time. She said her “affect was absolutely flat,” and nothing impacted her emotionally for about 6 months. Those feelings of depression mostly went away, but occasionally certain events would trigger a recurrence. For example, attending annual Individualized Education Program (IEP) meetings for her son reminded her of his limitations, and usually brought the feelings back.

Betty did say one of the hardest parts of raising her son was “coming to realize that he wasn’t going to have the same life that his siblings had. His potential was…different.” She went on to say it gave her comfort “knowing that we’re doing whatever we could to help him… try to reach that.” Realizations such as these were difficult hurdles parents surmounted in the process of accepting their child’s limitations and diagnosis of ID.

After reflecting back over many years, parents’ narratives recounted facts related to the awareness and diagnosis period. Although references were made to emotional feelings, parents did not express these emotions as they spoke. They were rehearsed and practiced stories. The way the stories were told demonstrated acceptance of the child’s limitations and diagnosis.

In summary, parents raising children with Down syndrome had very little time to prepare for the knowledge their child had ID and would experience related limitations. Their child’s differences were visible and diagnosable shortly after birth. Some of them could see the characteristics of Down syndrome, while others could not. Even if no characteristics were recognized, the diagnosis was confirmed in less than 2 weeks with a chromosomal blood test, so there was no question as to whether or not it was accurate. In response to definitive and confirmatory diagnoses, they reported initial feelings of shock, denial, sadness, hope, and love. Their reflections on this period of time had a logical beginning and set the stage for the following narrative.

Brain Damage

Similar to Down syndrome, the diagnosis of brain damage happened fairly quickly when the children were very young. Three parents—Anita, Martin, and Martha—began noticing suspicious behaviors when their children were between 3 and 6 months of age. They took their children to the doctor; it took a few appointments for the doctors to diagnosis the children and to give them needed treatments. Anita's daughter had hydrocephalus, and Martin and Martha's son had a brain tumor the size of a tangerine.

After diagnosis, parents knew their children were going to have disabilities, but did not know how much their son or daughter would be affected. Anita did not get clear answers when she asked the doctor, and described her experience with the doctor as follows,

> I was young and had two small children and I didn't think of all the questions to ask. Ya know, and all the things to find out and know what to accept. …and I asked the one doctor, I says, "Is she going to be retarded?" And, his answer to me was, "well we're all retarded in something." He says, "I'm retarded when it comes to math." And, I thought, "Well, ok, that doesn't really answer my question," but that's what he gave me.

Both children with brain damage were slow to reach milestones and had long-term effects from their medical conditions. The son with the brain tumor also had physical disabilities. He had two surgeries to remove the tumor followed by chemotherapy every 3 weeks until he was about 2 ½ years old. The surgery left him blind in one eye and partially paralyzed on his left side. It was hard for Martha to see him struggle with things he had once been able to do. She said,

> I think the saddest thing… after I got him home from the hospital the first time is he had been crawling everywhere. …And [after the surgery] I put him down on the floor and he tried to crawl and because of the damage done to his left—I think it was his left side and then the tumor, he was blind in his right eye because the tumor had pressed against the optic nerves in his right eye, and then his left side

> just didn't want to work, and he just couldn't figure out how to get it to work. And just this little teeny thing and he went to crawl across the floor and he couldn't and he'd look up at me and cry and try again and look up at me. He could not figure out what was wrong. He could not figure out why he couldn't crawl.

Despite feeling sad, Martha pushed on and did what she could for her son.

Anita also described difficult feelings she experienced. During the latter part of one of her interviews, she said, "I was never disappointed in having [my daughter]. I was never disappointed…the only disappointment I had about her being retarded and not being able to do things was the things she would miss out on." She related the following experience which gave her comfort at the time.

> … I think the gospel had a lot to do with it, ya know. Just knowing who she is and what she is. … [a friend] …said well she had one that died when she was just a baby. And, she says I get to raise [her] in the millennium and I just was kind a flippant and I said oh, I won't get to do that with [her] because I'm raising her here. And, she says, yeah but just think of her and all her glory. And that really got me thinking, ya know and I thought she's really a special person.

Anita's friend helped her reframe the experience of raising a child with ID and to see a bigger picture. In addition to feeling comfort, she inevitably felt liberated from the difficulties of the disability and at the same time felt a heavy responsibility to care for such a person.

These parents' factual accounts of the diagnosis were similar to and different from parents' raising a child with Down syndrome. Brain damage was diagnosed when the children were a few months older than the children with Down syndrome. However, in contrast to Down syndrome, the diagnosis of brain damage took several appointments. Similar to Down syndrome, diagnoses were medically verified. On the other hand, prognoses and treatments were much less clear for these children compared to those with Down syndrome. Finally, the 2 mothers expressed sadness about the diagnosis, and the father said the whole experience of diagnosis and treatment was very stressful—an "emotional rollercoaster." They did not mention denying the diagnosis, or feeling angry or panicked like parents of children with Down syndrome.

Autism Spectrum Disorder

Unlike the experiences of families raising children with Down syndrome or brain damage, none of the 4 parents (3 children) of the children with ASD knew anything was different about their children until they were over a year old and started exhibiting unusual behaviors, such as crawling backwards, crawling under tables, not being able to understand physical limitations, and babbling without ever putting words together. Language acquisition was delayed, as were other developmental milestones.

Parents of children with ASD recalled their child's diagnostic period lasting varying amounts of time. Clifford and Catherine, for example, started worrying about their son when he was about a year old. Although he was delayed in reaching milestones, he seemed to keep accomplishing them. Finally, when their son was 2 years of age, extensive testing was done to determine why he was delayed in meeting developmental milestones and how to better help him. He had a 6-month developmental delay, which did not really help the parents. Finally, when 7 years old, he received an official diagnosis of ASD. Helen's son was diagnosed when 3 years old; she was told her son should look and act "normal" by the time he was 30 years old, but would need intense work to be that way. Jean, the grandmother who adopted her grandson at age 10, said he was diagnosed at 2 ½ years of age.

Of the 4 parents raising children with ASD, Catherine, Jean, and Helen appeared to have strong reactions to the diagnosis. When Catherine arrived home after learning her son had a 6-month developmental delay, she realized the information was not helpful. She said, "I don't even know what that means. I don't know what we're in for. I don't know how I work on that…that was just too vague for me…. it was blah." Her husband, Clifford, told the story a little differently. He said they were told their son

> …will never probably speak, say daddy or mommy. He'll probably never walk and he'll really never be able to run or be a very physical child his whole life. We figure like he's got some severe, uh, disabilities and I would really think about maybe putting him in a home. So you need to get on some sort of—some listings in that to put him away.

Clifford said his wife started bawling and was adamant they would keep him in their home. She started researching his disability extensively. Eventually, Clifford said the pediatrician decided to diagnose him with ASD so schools would know how to treat him; however, his official diagnosis came later. Interestingly, Clifford never mentioned how he himself felt about the diagnosis.

Jean knew something was different with her grandson from the very beginning. She said "it was obvious [he] was in a strange world" when he was born. "He looked about very curiously…He was not bright eyed and bushy tailed from the get go." As he grew, she explained:

> Clearly something was wrong, but not knowing the clearly defined definition of Autism, I could not put my finger on it for the love of Pete. But finally when he was diagnosed, it was the worst diagnosis I could have ever been presented with…All my life I read lots and I am smart, intelligent, and the one thing I have always dreaded is if we had to have a disabled, mentally challenged child, that we would have an Autistic child. Because so little is, has been done about Autism for so long and they're just locked in closets often and forgotten about, locked away, and forgotten about.

Jean was devastated to learn he had ASD. The diagnosis was difficult for her grandson's father to accept as well. She said, "Once it was clear and obvious that [her grandson] was diagnosed Autistic, [his birth father] left. He just abandoned them."

The third mother, Helen, had a different reaction. Her son with ASD was her second son with a disability. The first had Down syndrome. When he was diagnosed with ASD, she "became severely depressed because [she] knew at some point [his] progress was going to surpass [the developmental progress of his brother, who had Down syndrome], and that discouraged [her]." He was going to get taller and communicate. In comparing herself with other parents of children with ASD, she said she was much more relaxed with him and did not push for his "changing and learning." She knew her son with Down syndrome would be with her for the rest of her life, so why not have two kids with her? "It simply would be an equal partnership of four people."

For these participants, ASD was diagnosed at a later age, and some children took years before being accurately diagnosed. The diagnosis was made through behavioral tests rather than medically as with Down syndrome and brain damage. The long span of time between symptom manifestation and diagnosis allowed parents time to work with their children and adjust to their behaviors. Three parents expressed strong negative emotions towards their child's diagnosis. Parents did not have much trouble getting help for their children once they had a diagnosis, even though they experienced delays in arriving at a diagnosis and encountered less clear treatment plans and resources than did parents of children with Down syndrome.

Asperger's Disorder

Norman and Nancy were the only parents in the study who had a daughter diagnosed with Asperger's disorder. "It was a challenge all the way through," Norman said. The journey towards diagnosis was long, hard, and embarrassing at times for them. It did, however, become a key element they believed could explain and justify their situation.

As a baby, Nancy described her daughter as “bubbly and cute.” She did not sleep well and got sick often. When she was about 5 months old, her older sister knocked her off the counter where she was sitting in an infant chair. Nancy said, “that might have messed her up, I don’t know.” Her father said, “…as a young child growing up...” he watched her and thought, “this little girl is going to achieve even greater than her [older] sister…” He saw “signs of really bright abilities and …thought well this is going to be interesting raising her.” She taught herself to read and seemed to be doing really well in school. In first grade, she “seemed to do a 180” and everything changed. Norman recalls she was supposed to “get up and say something” at a school function, but instead “stood there and could not say a word.” The teacher dismissed her. She became scared of doing math and “reached the point where she became horrified…of making a decision.”

Something was wrong, but no one could identify exactly what it was. They got her involved in a program at school for children with disabilities. A therapist prescribed crawling exercises for her, because she believed she lacked skills as a result of not crawling. Norman did not think she was “socially acceptable in high school. He “kept hoping. I thought I can’t have a disabled child. I wasn’t really willing to admit that I had a disabled child because she seemed so bright in so many ways.”

Nancy said she “didn’t really have very many friends as she was growing up.” In high school, “She hardly talked at all. You could see whatever she was trying to tell you in her eyes.” Nancy went on to say, “she ended up actually, she got raped by her high school counselor because …he was trying to help her get some extra credit and that’s what ended up happening.”

They got her an apartment in college with some girls. Norman said, “She functioned there. I kind a think they looked at her as a social outcast. The older she got, the more of this Asperger’s thing came on.” She attended college and her parents helped her with schoolwork. She was raped again, but would not tell anyone about it. Her mom could see in her eyes something was wrong. Finally, after doing 50 questions with her, she opened up. Her daughter became pregnant and after much deliberation she decided to give up the baby for adoption. After the child was born, she returned to school and graduated with an associate’s degree in early childhood development.

Later, their daughter married, and her husband began verbally and physically abusing her. He was “mean to her and…saying that he was going to lock her out of the house naked.” He insisted she go to work, so she did. They had two boys together. While they were married, her husband had a girlfriend. His girlfriend became pregnant with his child. The husband became abusive and Norman and Nancy’s daughter feared for her life. She moved back to her parents’ home only to learn she was pregnant with a daughter. “She tried for a few months to hold things together… and kept working at McDonald’s, but her husband did everything he could to make things bad… he was giving the boys ideas to make her look bad and make it look like she was a mental case.” She finally put up a “protective order against him.” She went through a divorce and a 5-year custody battle for her daughter costing $42,000. Nancy reported that her daughter’s boys live with their father, and she never sees them.

Following the divorce, their daughter had two psychiatric evaluations; one was court ordered and the other was a private test requested by her mother. Nancy thinks both resulted in Asperger's disorder. Norman suspects she may be bipolar as well. As a result of the diagnosis, Nancy said,

> we applied to get her on disability and it took us a couple years to get it but we finally got disability for her. It's kinda sad because …Here she was taking care of the kids, I mean, she didn't do a great job…It seemed like she went backwards after we showed that she had disabilities cause she was able to do things that she shouldn't have been able to do.

This narrative, similar to the others, was told about the parents' child and not about themselves. Through this story, I believe parents were trying to communicate their understanding of the situation and rationalize their own behaviors as well as those of their daughter. The lengthy process of diagnosis was a key element in the story. They had hoped their daughter would be intelligent and excel in school. Socially, they wanted her to develop healthy relationships and eventually marry and have children. They had a vision of what success should look like, and they were saddened when it did not happen and her life was instead filled with searingly painful events and many challenges.

In the beginning, they thought they were doing well with their daughter; she showed signs of being gifted. Then, she started acting differently. She struggled socially and academically, which was hard on her parents. How could they have a daughter with a disability when their other sons and daughters were all so well accomplished? What did they do wrong? They searched for answers and ways to help her. Others, such as the two men who raped her, were aware of her differences and took advantage of her. Life became even harder and more embarrassing for her parents when she was raped twice and gave up a child for adoption. They thought her marriage would be a positive turning point in her life, but it quickly became a horrible and expensive mess. They continued to do everything they could think of to help their daughter.

Though a bit skeptical about the ASD diagnosis, the diagnosis was a key element in this story. It was used strategically by Norman and Nancy to explain the situation with their daughter; much as the parents of the child with ASD used a diagnostic label to help the school know how to treat their son. It provided a rationale as to why their daughter was different and acted the way she did. It explained why people took advantage of her. It justified all the time and effort they put into helping her. The diagnosis provided a legitimate reason for their pain and suffering. The additional income from her disability was helpful. Despite the understanding the diagnosis provided for Norman and Nancy, it appeared to have a negative effect on their daughter's ability to function.

The narrative told about the experience of Asperger's disorder was similar to other narratives in that it centered on their daughter and not on the parents. In other regards, however, it was much different from the other diagnoses described. The unique aspect of this diagnosis was the tardiness and uncertainty of the diagnosis and treatment plan. Norman and Nancy struggled with their daughter for many years to help her get an education and be successful in her relationships. They knew something was not quite right, but were unsure what it was. The narrative centered on the hope their daughter would be successful like her siblings. In the end, she seemed to digress and become more dependent. The diagnosis was achieved through psychiatric testing and was not made until she was in her 30s. Her parents questioned its completeness and it provided limited understanding or assistance for them. There was a lot of frustration, ambiguity, and sadness.

With the exception of Norman and Nancy, all parents appeared to accept their child’s diagnosis of ID within a fairly short period of time after receiving it. They adapted to the situation and adjusted their lives to accommodate to the situations. At the time of the interview, Norman and Nancy expressed a mixture of emotions regarding their daughter’s diagnosis of ID. They loved their daughter and were fully committed to helping her. They did what they could with resources available to them; however, the diagnosis remained ambiguous to them. They had unanswered questions and were not really sure how to best help her at this point in their lives.

Reacceptance of ID

The previous section described parents’ acceptance of their child’s limitations and diagnosis in the early years. Interestingly, the topic was revisited as the children grew older and began asking questions about disabilities. Most children with ID knew they were different from other people, and it bothered them. They wondered why they could not do what other people could do or why they had to face the challenges associated with the disability. Some wondered when it would go away. Parents now had to provide explanations the children could understand. During this time, parents reconsidered what raising a child with ID meant. Several anecdotes are included here.

I begin with Dorothy and her description of how hard it was for her son to have Down syndrome. She said,

> It’s hard to be disabled. It’s really hard. Um, there are times when my other kids come home with their um little children, and at night [my son] will cry and say it’s not fair that he didn’t get to be a daddy. … he’s very aware of the normal realm of experiences. And it’s hard for him to have um people come into his life. Like he has lots of friends …and they come in and they grow up and they move away. …that’s hard. He sees the rhythms and patterns of life in others. And he still just wants a movie for Christmas. And he has to be driven everywhere. And sometimes it makes him mad and sometimes it makes him frustrated. And, and

> it's hard to be intellectually disabled.

This quote focuses on how difficult it was for the son to have ID, but the mother never described in the interviews how she herself felt. This practice was common among participants, especially during the first interview. Parents are close to the experience, almost to the point of taking ownership of it themselves. In this instance, Dorothy found it hard to have a grown son with a disability and watch him miss out on the "patterns of life." She yearned for him to be a father and experience life like everyone else. However, he was still her little boy and she enjoyed caring for him. At times the dichotomy of being a child in a grown man's body was frustrating both for him and for her.

Other parents shared similar stories about seeing their grown children miss out on adult experiences. Linda provided additional experiences or turning points that were difficult in her son's life and also in hers. She said,

> I mean there are certain …parts, turning points in their lives that it's difficult to handle like driving. …they get to a point where they want to drive, you know, just like everybody else, and you go, "Well, you got to pass a test. Well, you got to be able to read and you got to be able to write. You got to be able to drive." So that's a difficult time for parents to deal with. …They want to have relationships just like us, everybody else, you know. …They want to have a girlfriend. They want to get married. They want to do all these things. But he doesn't want just a girlfriend with a disability. He says, "Just because I have Down syndrome doesn't mean I have to have a girlfriend with a disability." So he wants a supermodel just like any other man.

Again, Linda's narrative is about her son, but she too seems to be saddened by the disability. She wants her son to drive and have intimate relationships, but does not believe he is capable of these responsibilities. It is hard to explain to him why he cannot do these things.

Many of the children asked when they would be getting married. Four mothers shared how they would tell their son and daughter he or she needed to wait until the next life to get married and have children. Most children seemed satisfied with this response. Gail, however, said her son “talks about getting married. He did for a while; he talked a lot more about it. Now, he just -- he doesn't so much. But I told him, I said, ‘That might not happen on this earth, it might be in the next world.’ And he said, ‘That's the wrong answer.’"

Anita and Martha’s children with ID seemed to be more understanding of the need to wait. Anita said her daughter told her frequently she wanted to get married and have children. Anita would respond by telling her she will, in the millennium. Members of the LDS Church refer to the millennium as “the 1,000 years following the Savior's Second Coming” (The Church of Jesus Christ of Latter-day Saints, 2014, para. 1). It will be a time of “complete righteousness and peace” (para. 5). Her daughter went around telling people she was going to get married in the “maniminum.” When her daughter asked why she could not get married now, Anita would respond by telling her because she needed to learn how to read and write first. She would not be able to cook if she did not know how to read a recipe. Anita’s use of simple and logical justifications satisfied her daughter. Being able to laugh about her daughter’s response helped Anita cope with the situation.

Martin and Martha’s son also sensed he was different. Martin said, “he wanted to experience the things that other kids experienced.” Martha shared how he would ask when he was going to be able to shave, “'cause he sensed that he wasn't -- even though he was an adult, that he wasn't quite like, you know, the other guys.” She went on to say, “that's what made him so delightful is he was so innocent and yet mischievous. And he could be a tease and sneaky and, um, I don't know. He liked girls. He would go ‘hubba-

hubba' whenever he'd see cute girls."

Their son seemed to understand he needed to wait until he got to heaven to get married. Martha said,

> …He kept, you know, wanting to know when he was going to get married and, you know. I remember one time… he says, "When I get to heaven, I'm going to get me a red convertible and a girlfriend." So somehow we kind of told him, you know, that he'd probably have to wait to get married, you know, later on. And he was okay with that, I think. But it was cute.

Martin and Martha were also able to laugh about their son's response, which helped them cope with the disappointment of the situation. Their son's recognition that he needed to wait for certain experiences seemed to provide comfort to his parents and helped them be okay with the situation.

Clifford and Catherine also had experiences with their son struggling with his understanding of ASD. Clifford mentioned a difficult conversation he had 2 or 3 years ago with his son when they heard on the news a doctor was going to cure ASD. Clifford's son looked at his parents and asked, "Well, what's going to happen to me [when I no longer have Autism]?" Clifford "broke down" and told him, "You're still Christopher. It doesn't matter, you're autistic, normal… whatever. You're still Christopher and that's the way it is, Christopher." Clifford and Catherine were both upset that this information would be broadcasted without considering how it may affect people with ASD. He did not like the unrealistic hope provided.

This conversation made Clifford think about how ASD affected everything his son did. If ASD was taken away from him, what would happen? What would his son do? How would they treat him? They spent his whole life building a world for him centered on ASD, and thus helped them accept his limitations. This news put all this into question.

Clifford had to remind himself he loved his son regardless of whether or not he had a disability.

Catherine recalled another conversation she had with her son about the challenges and opportunities of having ASD. She said,

> He knew he was different and he still does. And he said to me one day, um, a big old sigh, and he said, wow, this Autism, I don't know. Am I going to have this forever? And I said, yeah. Yeah, and I said, ya know, I'm sorry you are. And I said, but we all have things and I said, ya know I need glasses. And I put my contacts in every morning, but I said, ya know that's not a big deal and I realize Autism is a lot bigger deal for you. Um, but you're going to have it forever and we're just going to have to keep working on being able to do the things that you want to do. And, um, make life the way you want to do it and never quit learning. And, that's what's going to be the key so that your life is more comfortable and I think it wouldn't matter who asked him if he was happy. I'm sure he would say he was. I'm sure he would say he has a good life.

As Catherine comforts her son, she also gives herself a pep talk. She reminds herself her son is always going to have a disability and they cannot give up. She focuses on his continual learning and doing what he wants to do as keys to his happiness. Knowing she created opportunities for her son helps her feel secure that she is doing what is best. However, there is still some sadness knowing her son has to "keep working on" his ASD the rest of his life.

Many parents recognized their sons and daughters knew they were different and wanted to have grown-up experiences; however, they also feared the outcomes of these experiences. For most parents, there seemed to be no doubt in their minds that their son or daughter could not handle these more mature situations. They were not going to allow, let alone encourage, their child to develop intimate relationships. They had pat answers for the continual questions that included simple and logical explanations as to why the child could not engage in certain behaviors. Some used humor to lighten the situation.

Parents seemed comfortable answering these questions for their sons and daughters over and over again. However, these were hard conversations for parents, because they questioned their previous commitment of accepting the diagnosis, and seemed to assume the child's sadness and longed for them to have normal life experiences as well. I believe some parents learned to laugh about their children's responses as a coping mechanism; it was hard for parents themselves to understand why their child had a disability, and even harder to explain the concept to the child. The explanations they provided to their children were like personal pep talks that helped them cope with their own feelings of sadness and disappointment.

Caring for My Child's Health Issues

Another challenge parents described was caring for the son or daughter's health issues. Although not always a direct result of ID, many children experienced health problems. In fact, parents described in detail a range of health concerns ranging from minor, fairly routine problems to more serious and frightening issues. Some had little effect on parents and the children, whereas others were major challenges impacting them for extended periods of time. Fortunately, as most children grew older, their health improved and demands on parents decreased; however, there were a few children who continued to be affected with health issues throughout their lives.

With a few exceptions, parents talked matter-of-factly about the child's health problems. There seemed to be few options but to make sure their son or daughter's needs were being met. This required extra time, energy, sacrifice, and patience. Parents did not elaborate on many aspects of their caregiving responsibilities; rather, these experiences were taken-for-granted as they narrated, second-hand, their child's life stories. In this regard, their narratives were sublimated by stories they preferred to tell of the child's life, health, and challenges. Glimpses of their narratives are presented in the next section, beginning with a summary of the routine health concerns followed by a section about parents who shared experiences with their son or daughter's health that affected parents' narratives.

Summary of Routine Health Concerns

As previously mentioned, several of the children had health concerns when young that they grew out of. For example, at least 4 of the mothers' narratives addressed difficulties with breastfeeding or eating as infants. Parents of children with Down syndrome commonly described them as placid and noted they slept a lot. Gail's son required surgery immediately after he was born, and failed to thrive for his first year of life. He was constantly sick, so they avoided taking him out in public as much as possible. Two or 3 other parents described their child as exhibiting failure to thrive while young. A few parents described how their child did not sleep well as an infant or toddler. Potty training was a major struggle for Martin and Martha's son that lasted many years. Anita's daughter had occasional seizures throughout childhood, but they were mostly controlled by medication.

Five parents said their son or daughter was constantly sick; there were a lot of ear infections. Linda described how stressful it was every time her son got sick because of the strict absenteeism policy at her work. She worried about who she was going to leave him with and if they were qualified to watch him. Would they love him like she did?

Several parents described surgeries the children underwent, ranging from fairly minor and routine—tubes placed in ears, "large protruding tongue" fixed, tonsils removed, hernia and carpal tunnel surgeries—to more serious surgeries—re-creating a diaphragm, tracheostomy, brain surgery, shunt placement, cancer removal, and hysterectomy. The surgeries that impacted the parents' lives the most were re-creation of a diaphragm, tracheostomy, brain surgery, and cancer removal. These are described in in the next section.

This summary portrays the matter-of-fact manner in which parents described their son or daughter's health concerns. There were glimpses into challenges both groups experienced, including limitations in parents' time and accessibility, and a great deal of stress. They rarely complained about sacrifices they made for their son or daughter. Rather, the focus was on taking action and helping the child maintain or improve their health. Parents did not describe lessons learned or growth experienced as a result of these health conditions, so it was more a case of reintegrating back to their comfort zone.

Health Concerns Impacting Parental Narratives

A few parents described their son or daughter's health concerns in more detail and with more emotion. Parents described instances of resiliently reintegrating to their situation. Some of these health concerns affected the children's behaviors, others taught parents skills and lessons of life. Each is described.

Affecting My Child's Behaviors

Three parents (2 children) described health concerns resulting in behavioral issues. Betty's son grew out of his troublesome behaviors, but Martin and Martha's son did not. For example, Betty described an issue they had with their son when he was about 4 years old. He developed alopecia areata, resulting in bald spots on his head. The ointment used for treatment "made him extremely sensitive to the sun," so he always had to wear a hat. In addition, "he had crossed eyes and so early on he started to wear glasses." The challenge for his parents was that he loved to throw his glasses and hats out of car windows and from high places. They retraced their steps many times and finally learned to attach strings to the items to prevent them from being lost.

The second example is from Martin's and Martha's narratives. Their son's health concerns were probably the most challenging part of raising him, because of his diagnosis of brain damage and subsequent treatments. These were obviously tough times. Later, they dealt with annoying effects of the surgeries, namely hormonal changes resulting in him being thirsty all the time and lacking appetite control. Both parents spent quite a bit of time sharing what it was like to work with him. Martha said, they "had to lock the fridge and the cupboard" and "hide everything." "He went through a stage where he'd go eat frozen hotdogs out of the freezer." She continued "…he would scrounge and he would find things." Then, "he would hide the evidence. …I think kids gave him stuff… it was just hard to control his eating at school. … that was just part of the metabolism that was part of him not having the normal hormones. …he didn't burn off…his calories like a normal person would because he wasn't active." His father said the following about his son's eating:

> He would make midnight raids on the fridge. …he would find whatever he could find to eat and…polish it off. He'd eat whole loaves of bread. He would get, oh, shoot, boxes of cereal and bags of potato chips and crackers and just anything he could find to eat…wherever he went, uh, people would give him stuff, you know, give him soda pop or candy or cakes, cookies, you name it. …he would camp himself by the soda machine or the candy machine [at school] and…bum food or soda pops.

His father said he wanted to make him a t-shirt that said, “Hi. My name is Michael. Do not feed me."

These parents took action the best they knew how to help their children, including patience, creativity, and ingenuity. Martin exhibited humor to help them through a difficult situation that did not seem to have any resolution in sight.

Learning from My Child’s Health Issues

The next three examples illustrate technical skills and lessons parents learned caring for their child’s health problems. First, Anita shared a story about learning to give enemas and digitally extracting stool from her daughter. She said, when her daughter was about 8 or 9 years old, she “started having trouble with bowel movements,” so needed enemas. Her mother “[wore] rubber gloves and …had to dig in and get it out. It was hard…she would cry and scream…because it …was kinda painful for her.” The unique part of this story was how her daughter acted when it was all over. Anita said, “she would come over thank you for doing that. She’d thank me for it, ya know. Cause she knew I was trying to help her.” In addition to learning some technical skills, she learned a new respect for her daughter, who could see the value in what her mother was doing and thanked her for helping.

The second example is Helen. Her son had a major surgery when he was 12 years old during which a diaphragm was created for him, and surgeons "put all the other organs where they belonged." Previously, "an MRI showed he had the tissue for a diaphragm, but it never grew in utero." This was not discovered until he caught a "relentless cough" and the doctor ordered an x-ray. "All of his organs had been living up in his chest cavity. His lungs were tiny whiny little palm fists up under his collar bones and we never knew this."

Prior to the surgery, she creatively came up with a way to help her son sleep, because he could not breathe well. She said,

> He ate normally, he was healthy. He was active. Nothing seemed strange except how he went to sleep which was going into the bathroom, sitting [cross-legged] style, putting two to three pillows in his lap. He'd put his arms over the pillows, lay his head down, and I had to turn the shower on hot water, steam.

This position and the steam helped him to breathe better.

After 10 days of being in the hospital, he went home. About a week later he started to struggle breathing. Apparently, when they put his stomach in place he developed reflux. Consequently, acid bubbled up into his vocal cords and lungs, leaving him unable to speak or breathe normally. He had a tracheostomy placed and "has never had another issue since." Over the years she became an expert in caring for his tracheostomy.

The final example is from Dorothy, the mother of a son with Down syndrome. She shared a story that occurred when her son was about 20 years old that changed both mother and child forever. He had kidney cancer requiring one kidney be removed. She said he went to the hospital healthy, happy, and whole. He woke up after the surgery in pain. He had been "cut on two sides," and had staples. "It was really traumatic for him" and it "really kind of mentally changed him." He was no longer a "cute little kid." The pain and suffering made him grow up. He lost some of his ambition, industriousness, and physical stamina. He recovered well, but it left a deep impression on him. Every time he gets sick, he remembers all of the sad, hard things he experienced and talks about them.

Dorothy's perceptions of her son changed following this surgery as well. As indicated, she recognized he changed. He was no longer a carefree child; he had experienced pain and suffering causing him to mature. She also recognized her son was not going to live forever. He was human and she could lose him at any time.

These 3 parents described skills and lessons they learned as a result of their son or daughter's health concerns. Other parents learned various skills while caring for the child, but they typically did not describe huge learning curves they experienced while acquiring specialized knowledge about the individual conditions. Parents somehow became keen observers and tuned in constantly to their son or daughter's specific ailments. They knew when the slightest deviations occurred and when and how to act in each situation. Some were ingenious in their solutions, while moving along their journey of resilience.

In conclusion, issues presented by the children's health concerns were challenging. Parents put forth great effort in helping their sons and daughters with their health issues, and did so with few complaints. Parents worked hard, exercised patience, and acquired various skills. They used creativity, ingenuity, and a little humor, suggesting parents developed resilience as they adapted to challenges experienced while traveling through their journey of raising a child with ID.

Managing Behavioral Issues

As children grew older, all parents' narratives described difficulties they had with their son or daughter's behaviors, a major challenge mentioned by at least 5 parents (3 children). Parents described the behavioral issues with slightly more emotion than health concerns. For a few parents, it was the worst part about raising a child with ID. Mostly, it seemed parents demonstrated a tremendous amount of patience in dealing with the behavioral issues. Fortunately, the issues seemed to either decrease as the children got older or parents learned to adapt to them.

Some behaviors described were one-time incidents. Others were annoying tendencies the children developed that parents had to learn to live with. This section describes examples from eight parents (seven children) divided into those two different categories. Behavioral issues described by the other parents were not included because they were fairly minor parts of their parents' stories or were similar to those already described.

One-Time Incidents

The one-time incidents impacted 2 parents (2 children). They were dangerous or serious acts sometimes involving law enforcement. There was not a lot parents could do to prevent these incidents once they happened; parents dealt with the consequences and tried to teach their son or daughter not to do them again.

Challenging behaviors were probably the biggest trial Eddie and Evelyn faced with their son, so examples of his behaviors are scattered throughout this section. Evelyn said most of the local police knew their son. For example,

> Probably the worst was when he got arrested. Let's see… maybe around 14 or 15, 16, somewhere in there that age, he was um, home alone and he got cold. And so, he um, lit a candle and his bedroom was in the basement at that time and he'd come up here and gotten, like a decorative candle, and lit it and then he was walking downstairs and there was a plastic bag hanging on the railing and it caught fire from the candle. And, so, he was able to take the bag and put it into the bathtub and put the fire out, but then he called 911, which he has done that throughout his life, a lot. They know who we are. …he called the fire department and they came out… before he had come up to get the candle, he was in his bedroom and he was eating some food and he had a steak knife cutting the meat and so he still had this knife in his hand. And, the policeman and fireman showed up and this one policeman didn't know how to handle him… and he… was trying to be very authoritative, which … was not the way to handle [my son], ya know. Ordering him to put the knife down, ya know, and so, I guess he finally did, but then they arrested him. Yeah,… he had to go to juvenile detention for a night, I think. And then, a, we had to go to court and I think … he had to do community service. It was terrible.

This experience was especially difficult because of the way their son acted and how law enforcement agents responded. There was very little the parents could do except to follow through with the ordered consequences, continue to teach him about safety and communicating with others, love him, and hope their son learned from the experience.

The next example is Kenneth. He described two instances during which his son got involved with the police. First, when his son was under 10 years of age, he misbehaved while his sister was watching him, so she restricted him from watching TV. Kathleen said he had a "temper tantrum … and he was breaking dishes because he'd seen this in a movie." He called 911, and told the police his sister was being mean. They obviously came and talked to him about what was going on. His father told him not to do that again. His phone usage was restricted because of this incident and his tendency to frequently call people at odd hours of the day.

The second of Kenneth's example was when his son had been watching one of his favorite TV shows about vampires. "It had a lot of violence in it, and he got concerned

…so he carried a knife … one of our kitchen knives to work with him, and somebody saw it and they…called the security." The security officer happened to live around the block from them, so he called them and explained the situation to the parents. The security officer "had a good talk with him and [he] doesn't take knives with him anymore." Kenneth and Kathleen were able to discipline their son following these incidents and curb the dangerous behaviors.

The last examples of one-time incidents involved children of 2 parents who wandered away. These were frightening times resulting in varying degrees of parental stress. Again, there was not much parents could do to prevent their sons or daughters from wandering or do after they wandered.

Kenneth said his son wandered a couple times:

> …This one day he went on the bus … down to work, [15 miles away, and]…there was …nobody there. …by himself [he] caught another bus, went downtown…, transferred to a bus and went out to the airport. …somehow he got to a phone and phoned our home... He says, "Can you bring my suitcase down to me?" …[he wanted] to see his sister up in San Juan Island. …he did all of that by himself. …he is very intelligent.

Another incident occurred a few years ago. Kenneth and his wife came home from church and could not find their son. After searching for some time, they called the police. They looked all over and finally found him in the unoccupied home of one of his church youth group leaders; he packed some of his belongings and made himself at home in one of the bedrooms.

Dorothy also described an experience when her son wandered away from home when he was 8 or 9 years old. He walked to a hardware store, filled a shopping cart full of toys, and stood in line to purchase them. The cashier rang up the toys, turned to the man behind him, and told him the amount. The man said he did not know the boy. His parents found him shortly after. Dorothy and her husband, like Kenneth and Kathleen rescued their son and brought him home again.

Having encounters with law enforcement and searching for wandering children were challenging events for parents. Fortunately, these experiences were not frequent across parents, although Eddie and Evelyn described several. Parents were patient and must have disciplined their sons the best they could. Being able to have law enforcement agents who understood the situation and were supportive was helpful. Most one-time acts had natural consequences, sometimes scaring the children enough so they did not do them again.

Annoying Behaviors

Most parents talked about their son's or daughter's annoying behaviors which required patience and adaptation. These included rigid routines, showing inappropriate affection, misbehaving to be accepted, and some that were unique to the specific child. Examples are presented from each of these areas.

Rigid Routines

Most parents described how difficult change was for their son or daughter, and how they needed to prepare him or her ahead of time if there was going to be a change. The children liked their routines and doing things their own way. Four examples are presented.

Dorothy said her son loved continuity and sameness; for example, he liked to eat the same thing at every meal, wore the same clothes every day, and always watched one episode of Little House on the Prairie before bed. In addition, he always sat “shotgun” in the car, so he could control the radio and DVD player. She said, “If it’s what he wants to do he’ll do it. If it isn’t what he wants to do …It’s easier just to do it yourself than to make him do it. I mean you really can’t make him do anything that you want.”

Bernard, the second example, said the following about his son’s difficulty with change:

> It’s hard to talk to him about the future …we have to be very patient with him, and make sure we talk …things over with him… or he’s apt to say no. He transitions slowly, so we have to allow transition time so that he gets used to a concept—used to what we will be doing.

Anita, the third example, described how her daughter picked up the habit of doing certain things certain ways, especially over the last few years. She explained how no one is allowed to eat at their home until they have offered a blessing on the food. Her daughter will sit there and look at other family members until the prayer is said.

The fourth example, Nancy, described how her daughter “just loses her patience once in a while when things don’t go like she wanted them.” Norman said, “That Asperger’s has been so frustrating because …you can’t reason with her and you can’t…get her to change her mind about anything.” He went on to say, she “gets really bent out of shape.”

As parents transitioned to understanding and managing these behaviors, they provided examples of preparing their child for anticipated change, abandoning lost causes resulting in frustration for themselves and their son or daughter, and providing extra time for transitions. Parents also provided glimpses of their own understanding of when and how to expend effort to achieve smooth, meaningful behavioral change, or when to preserve their energy for other purposes. In the end, they did their best to work with their children’s rigid routines.

Showing Inappropriate Affection

A few parents described how their son or daughter with Down syndrome demonstrated inappropriate affection and got into some trouble for these behaviors. Linda described how in “their younger years… they teach them hugging and being friendly to people and then all of a sudden, you're in high school and no more hugging.” She added, “That is not as easy for people with Down syndrome to do, you know, because they like to hug, genuine, you know, affection and friendliness.” She went on to describe the affectionate feelings her son had and some resulting problems:

> Unfortunately, these kids with intellectual disabilities, God has given them a disability but hasn't taken the desire away for the, you know, hormonal changes in their bodies and he wants a girlfriend. So they do run into problems in the workplace, you know, wanting to flirt with an associate, so he had a problem with that at the workplace. And some people are real great at understanding it's harmless and say, you know, "Oh, well, come on … Get to work. Get over it and let's work." Instead of doing that they go, "Oh, I'm scared." You know, they complained and so he actually ended up leaving that place. And now he works at [a] grocery store. He's been there for five years.

Kenneth described a relationship his son developed in his “own mind with one of the people” at his work. It “was getting a little bit too intense in his mind,” so they terminated his employment and moved him somewhere else.

Expected sexual and loving feelings were not necessarily the issue parents saw as problematic, but managing those feelings in socially acceptable ways was challenging. Attention to social norms and others’ behavioral cues was often difficult for their son or daughter. The net result was a more complicated social disadvantage. Parents’ watched this difficulty restraining feelings with empathy, and sometimes saw these situations escalate and jeopardize scarce employment opportunities in a spiral of social misunderstanding. Consequently, parents sometimes removed their children from the situation.

Misbehaving to Be Accepted

Sometimes the children acted inappropriately so other people would like them and they would fit in. Watching these behaviors was hard and saddened parents; they wanted their son or daughter to have friends and fit in. Evelyn and Linda shared specific examples.

Evelyn said, my son

> was so impressionable and wanted to be so much a part of everything… and be normal, like everybody else. And, he gravitated towards kids who had behavior problems…And, they… gravitated towards him, too, because he was easy to manipulate …and [would] do things that they thought were funny.

Linda said, her son “was friendly with everybody and he wanted to be a friend to everybody, and …he would do anything to gain friends.” She thinks he was “probably bullied in school.” She was “called into the… principal’s office all the time because some kids had taught him how to go pinch a girl's bum. ‘We'll be your friend if you go pinch that girl's bum.’"

Neither parent shared many details regarding what they did in these situations. Their narratives show they stayed involved and intervened at an individual level when necessary.

Behavioral Issues Unique to My Child

There were 7 parents (5 children) who experienced challenges with their son's or daughter's unique behavioral issues. However, at the time of the study, parents were in various stages of accepting and adapting to the issues. The first example is from a parent whose son displayed extremely difficult behavioral issues, but fortunately grew out of them over time. The next are from parents still figuring out how to handle the situation. The last examples are of parents who explained how they were handling or had handled the situation.

Jean is the first example presented in this section. When her grandson first started living with her, he had some difficult behaviors. She said,

> He was a caged animal. One morning we got up to five different packages of beans and a huge bag of rice spilled all over the kitchen floor. Cereal mixed in and he was sitting in a 5 pound blue porcelain roaster …with all of those cereals and little bits and pieces of beans and rice all over the floor. One morning he got up and … he had pooped his pants and taken off his diaper …and he had smeared it everywhere all over that room and that was a common occurrence. I couldn't… once I heard the pitter patter of his little feet, I could not get up out of the bed quickly enough and get dressed and get to him before he could do things like that. He was just wild. Wild.

Fortunately, he calmed down after a while and became much easier for his grandmother to care for. She says he is quite the gentleman now.

Anita, the next example, was in the process of figuring out how to work with her daughter's new behavioral issue. She said her daughter recently started "doing just the opposite of what I tell her to do." She is not sure "if she knows what opposite is… but if I tell her leave that there, she'll pick it up and move it. If I'll say don't touch that, she touches it and if I say stack those up and put them in there, she'll scatter them around." This quote also demonstrates how the children changed over time. Their parents would learn to work with one issue, but then a new one would present itself. Parents constantly needed to learn and change with their children.

Next, Nancy described challenges of living with her daughter with Asperger's. She and her husband were in the process of learning how to help her. Norman did share some of his thoughts about how to work with her. Nancy said,

> I guess the worst part is when she has to… well, she kind of sometimes follows you around. She wants to be with people, but she isn't very social. Like when we get together as a family she'll just sit there and knit. She'll listen to what is going on, but she doesn't say anything.

Nancy also has difficulty because her daughter likes to shop at thrift stores and has a hard time throwing items away or keeping them organized. She and her husband gave her a shed to put the items in and continually help her to clean, but the problem does not seem to improve.

Nancy also mentioned how her daughter's behaviors negatively impacted her ability to be a mother. As a mother, she struggles with reasoning, disciplining, and sacrificing, which results in a lot of frustration for Nancy's granddaughter. Nancy said the two have "big fights all the time" and Nancy's granddaughter now calls Nancy mother because her own mother is "too mean." Nancy said it is hard on her "because basically I've got two little kids that fight all the time."

Although both parents were still learning how to help their daughter, Norman described some tactics he uses. Patience, he said, is the best way to react. "You just have to tell her what it is and then leave her and let her work it out in her own mind and then after a while she comes around." She has a tremendous need to be loved and understood. He also said she requires love, understanding, and some pulling back. He does not think they do enough with her, so he would like to "just take her and go do things with her."

Another thing he likes to do is get her to laugh. He said, “When she laughs she goes on and on and almost shakes the house. And I tease her about that the University … seismic center is going to call us to see what’s going on because she laughs so hard.”

Martin and Martha’s son also had some unique behavioral issues challenging and frustrating for them. For the most part, they adapted to these challenges. Martha described how her son would steal money. She said,

> …it did not matter how much we tried to say, "…that's just not what you do." To him it was -- it enabled him to use the pop machine at school or the candy machine. And so, I just finally …kept my purse in the car. We just got so -- we just did not ever leave money because I remember one time I went to the store I had a $20 bill, I opened up my purse and it was gone and it was when he was in middle school and I had no idea. Finally, we figured out that he was taking it and he would give money to kids at school. We found out because the teachers said "Oh, [your son] gave us like a $20 bill." He didn't know the difference between a $1 bill. They said [your son has] been passing money out at school. Oh. So that's one thing we had to be really careful about and we had to warn people, you know, don't leave your money out, he'll take it. As sweet and nice as he was, he could not …figure that one thing out. But that's probably the only fault he had.

Martin described how they modified their house to accommodate their son’s physical disability. He described how his son “could not control the amount of toilet paper he used when he went to the bathroom and was constantly plugging the toilet. “Constantly.” They finally installed a “power-assist flush toilet and that kind of solved that problem.” He went on to say, “…he'd go through a whole roll of toilet paper in a day or two. And he just wadded up, and wadded up, and wadded up. That was pretty bad.” These were difficult experiences for Martin and Martha, but they learned to accept their son would most likely never change and adapted to the situation.

Another challenge for Martin was his ability to handle his son’s habit of repeatedly losing or misplacing items regardless of how many times he tried to teach him to put things away. Martin had difficulty remaining patient and often became angry, and expressed feelings of guilt for not being more patient.

Kenneth also shared how he lost patience and argued a lot with his son while he was growing up. Unique to his story, however, is some insight into how Kenneth changed as a result of the challenge. Kenneth began by describing instances when he became frustrated when his son did not do what he wanted him to do. He said, “I accepted him, but yet, I expected things which he wasn't able to do. I think … that was a problem for a while and I would become impatient.” For example, when his son was a little boy, a gun fired during a play. The noise startled his son and since that time he did not like impact noises, including fireworks. His dad was determined he would watch the fireworks at Disneyland, so he held him there while they were doing it. Kenneth realized it was a “stupid” thing to do, because it left everyone feeling miserable.

Similar to the other parents, Kenneth gradually started seeing how he needed to make some changes to how he interacted with his son. However, he then shared an epiphany he had when his son was in his 20s that helped change his own behaviors and improve their relationship. Kenneth and his wife served a 2-year mission for the LDS Church and left their son with one of their daughters. When they arrived home, their son with ID ran up to him and gave him a big hug. At that moment, Kenneth realized he wanted a different relationship with his son, so he treated him better from that point on. In the end, Kenneth said, “the biggest lesson that I learned from [him] through his growing up was just patience and acceptance, uh, and realizing he was very special and I have to appreciate that and not expect things that he could not do.” This is a good example of a parent who learned to adapt to the situation through seeing the bigger picture of his son’s strengths and weaknesses.

As these stories show, there was a wide variety of behavioral issues the children demonstrated that parents had to work with, which resulted in varying levels of parental experience and growth. They were different in frequency, duration, severity, and impact. Parents were in varying stages of learning to adapt to these challenges in their lives; they demonstrated acceptance, patience, perseverance, love, humor, and humility.

In telling these stories, parents exhibited a self-awareness that was both factual as well as emotional. They were able to identify and describe frustrating and self-defeating behaviors their son or daughter exhibited, and did so in such a way that the child was not demonized but portrayed as uniquely challenging in ways they had not anticipated. The emotion they expressed showed both endearment ("the pitter-patter of his little feet") as well as frustration in not knowing how to discipline and help their son or daughter act appropriately in society. The resilience demonstrated by these narratives was the ability to stand back, outside of the behavior, and describe it in a journalistic fashion. The emotion was present, but parents continued to put the child with ID at the center of their story, relying again on empathy for the child's situation.

Facilitating Attainment of Early Developmental Milestones

In their narratives, all parents reported their children were slow to reach developmental milestones like crawling, walking, and talking. The children required extra help from parents and others in reaching their potential. Five mothers of the children with Down syndrome and Catherine, the mother of a son with ASD, described how they helped their children. The fathers and other parents of children with ASD and Asperger's disorder did not describe much of what they did in the early years to help their children.

Almost immediately after the children were diagnosed with ID, parents started learning about the diagnosis. Mothers especially spent countless hours at home teaching their children and helping them reach developmental milestones, so they could function as normally and independently as possible despite limitations. Dorothy and Gail remembered doing therapeutic activities with their children to help them reach developmental milestones. Dorothy described some "little assessment cards" someone from a parent intervention group told her about. The cards provided activities, stretches, and exercises to help her son continue to advance.

Kathleen described how her son with Down syndrome essentially needed to be taught how to do everything. This example also demonstrates some parent responsibilities during the younger years helping their children reach developmental milestones. Kathleen said,

> It was difficult because he did not know how to … suck. So we had to teach him how to suck. He was home about three days and he slept for 17 hours. He didn't wake up to eat. So we had to put him on a schedule. We had to teach him how to eat, when to eat and how to swallow. And basically, we had to teach [him] everything. We had to teach him to walk. We had to teach him to crawl. We had to teach him … everything, because really nothing that I can think of came naturally for him... We made charts for him to learn how to talk. We kind of programmed him and patterned him so he could learn how to crawl. He didn't walk till he was 2 ½ years old. And then he started school 5 days a week when he was 3, and that was -- then he went to special classes all the rest of the time, um, except when he was in -- well, in elementary school…

The children with Down syndrome started therapies at an early age. Helen said her son, "came home and at 12 weeks old he was to a physical therapy type school. …they began working immediately because muscle tone was so horrible." Before the children in the study attended public schools, most of them did therapies several times a week for a couple hours at a time; therapy was a significant time commitment for parents.

Linda said she had to quit her job to take care of her son. She took him to preschool three times a week, a nurse came to their home to work him, and she took him to “a lot of doctor visits to get his health, organs, and everything checked out.” The following describes what her son did in his early intervention program. She said,

> In the early intervention, what we would do is like he would learn how to sit at the table and eat with a spoon or, uh, get down and crawl and, you know, wash hands. …But they would teach them just skills, like normal skills that we wouldn't really worry about with other kids, you know, like sitting up, how to prop them up so that they're able to sit up and how to help them move their knees so they're learning how to crawl and things like that, just simple steps.

During Catherine’s interview, she shared ways she helped her son with ASD learn. She always looked for opportunities to teach him and constantly explained things to him in great detail. When he was young, she would take him to the grocery store early in the morning when few people were there. She asked him to find certain types and quantities of foods. Sometimes, she would change her mind and have him return the items and get different ones. They would figure out the coupons together.

In summary, parents took an action-oriented approach as they taught their children and helped them reach developmental milestones. They learned about the diagnosis and did whatever was necessary to help the child progress developmentally, sometimes being quite creative. They became experts in working with specific issues, and they took their children to hours of therapies. All required a great deal of patience, time, and sacrifice on the part of the parent.

Ensuring a Good Education for My Child

All parents described their experiences with their child attending school. It was difficult for at least 4 parents to find appropriate schools or to get him or her involved in specific programs. Five or 6 of the children were not treated appropriately in the programs, or their education was not helpful. There were a few complaints about certain teachers and experiences.

Despite these difficulties, most parents seemed pleased with their experiences. This was largely a result of parents advocating for their children when they did not agree with their educational path. They took an action-oriented approach and made sure their children received services that would help them progress educationally, emotionally, and socially. Mothers did the main work of advocating; 4 mothers described advocacy as a major part of their entire story. Those mothers who did not describe advocacy were either pleased with the school experience, accepted it the way it was, or were disappointed. This section describes the difficulties 3 mothers encountered with the school system and concludes with examples of parents who became strong advocates.

The first experience I share is from Anita. She struggled to find a school for her daughter with brain damage and her well-meaning friends compounded her frustrations. She said,

> Everybody used to drive me nuts because they'd ask me what are you doing for Amanda? What about her school? And, ya know I just wanted to yell at them. Well, if you're so concerned why don't you do something? Because, like I said I'd start out at one place and went to five different people and ended up at the original place. And, I got nowhere.

Eventually, Anita switched pediatricians for her daughter and he was able to find a school for her to attend the very next week. Her daughter started school at age 7.

Evelyn, the second example, described being disappointed her son did not learn how to read. In sixth grade, he was finally learning to read, but in junior high school, the emphasis was only on sight words. As an adult, he really wants to know how to read.

Jean, the third example, was the only parent who described her grandson's overall school experience as "horrific." She said he was expelled from school because he got upset when his teacher would only give him one green M&M for accomplishing a task when he had politely asked for two on his "peck strip"—picture cards used for communicating. In frustration, he yanked on her lanyard and it did not come free causing her great discomfort. While he was away from school, the school did not provide a tutor for him "which the law requires." In seventh grade, his teacher put him in a corner with his desk facing the wall, and "put up a board around him…He spent the rest of his school years… being uneducated sitting in a corner… When junior high ended, we told the junior high thank you for teaching our child how to learn to be bored and complacent and content with himself, because that's what they taught him."

Jean said in high school her grandson was not allowed to attend choir or band rehearsals, basketball games, or plays "because that might be too detrimental to all the normal students" or "that would have been too embarrassing for who had to go and sit by [him]." Her grandson was a good runner and swimmer, so she requested training for him at the school; she was told they lacked the time and resources to assist him. She was disappointed in the lack of assistance, but did not describe further efforts to have him involved.

The remainder of this section describes mothers whose advocacy encompassed a major part of their story. These mothers either wanted their child to have more services or opportunities or they did not like what was happening at school. In both instances, they made changes in order to benefit their child. Advocating took parents a lot of time and effort. Most did not enjoy doing it, but wanted their child to be taken care of.

Advocating for Additional Services and Opportunities

There were 5 mothers who shared stories of advocating for their children in order to secure additional opportunities and services. Each circumstance and mother was different suggesting they accomplished the tasks in a variety of ways.

Gail, the first example, was a strong advocate of inclusion for her son with Down syndrome. When he was very young, she attended a class with him and was told, "Love him, but don't expect much." Later, while working with a therapist in the class, she asked how to position him so he could get better upper body strength. The therapist said, "I don't show parents what to do." Gail was not pleased with these responses, so her solution was to start a program with other parents to better support and help parents.

Later on, she wanted her son to attend the same preschool as her other children and was initially told no. She explained,

> The interesting thing was they felt that they had to have somebody from the special ed department there with him. And I said, "Why?" "Well, you know, what do we do if he needs to go to the bathroom?" I said, "What do you do if the other kids need to go to the bathroom?" "Well, they go." "Well, he goes too. He's potty-trained," you know. Anyway, they soon relaxed a little bit when they found that he was far more like the other kids than he was different. The only thing is he could go down their slippery slide with his legs apart like this because of the low muscle tone, so the other kids try to imitate that, you know. I mean, he could do special things that they couldn't do. …it turned out to be a good experience.

In this example, she calmly resolved the concerns of the preschool workers and reassured them her son would be fine in their care.

Throughout her son’s education, Gail worked closely with teachers to help him “to be able to do as well as he can and learn how to be a seventh grader or an eighth grader or a ninth grader.” She did not want them to “bring him up to a grade level because I know as kids get older that gap's going to get bigger.” Gail also explained how she worked with his peers to help him learn certain skills. For instance, she paid some of his friends to teach him to tie his shoes. When her son was in second grade, the kids helped him with a reflux problem he had had his whole life. She did not need to ask them to do anything; they did it on their own. It may have been a result of her strong push to have him included. She said,

> And oh my gosh, it was just gross. He'd be eating and then ooph, it would all come. And, you know, we'd taken him to doctors and tried different medications, it was a still a problem. But when he started eating lunch with the second graders, I think the kids said to him, "Eww…" And he learned how to handle it. He learned how to wait and then swallow, you know, and he learned how to handle it. Now all the experts on earth, I don't think, could have taught him that. Second grade kids. Peer pressure, it's wonderful.

Before her son started junior high, she invited the boys his age in the neighborhood over for a barbecue so that they could provide some information about the school. As a result, they also helped him with his lockers and showed him around the school building.

Gail did not find advocating for her son to be pleasant. She said she lamented being the “bad guy.” She was told she was “such a pain in the butt” because she did not accept her son’s disability. She said, "I know he's got Down syndrome. He's always going to have Down syndrome, and that's fine with me. I just don't want him categorized and pigeonholed [with] …the expectation…that he couldn't learn, because he could." Despite the challenges Gail encountered with the school system, she was pleased with what her son was able to accomplish and experiences he had. It seemed her advocacy paid off for her son.

Catherine, the second example, shared a few stories about advocating for her son, mostly when he was young. Her journey of advocacy began when she took her son to a doctor who recommended he receive a special therapy. When she called for an appointment for the therapy, her son was put on a long waiting list. This was not acceptable to her, so she called the doctor and told him to put her son at the top of the waiting list. When he refused, she threatened to not pay her bill. She did not know if he called, but she received a phone call the next day to schedule an appointment for the treatment. Catherine knew what she wanted for her son and figured out a way to make it happen.

When her son was a little older, she acted as an advocate for her son to her husband. Being in public situations helped her son to learn and he enjoyed being out. The trouble was that he was disruptive and could be embarrassing. Clifford, her husband, wanted to prevent their son from getting upset and protect him from stigmatizing responses like disapproving looks and rude comments. The biggest fight they ever had as a couple was over taking their son out in public. One day, Clifford was complaining about going somewhere as a family. She said to him, “Screw ‘em. Screw ‘em all. I don’t care. We’re going to go and we’re going to let him learn. We’re going to let him experience life and I don’t care. Let them look. I don’t care what they think.” She determined from that day on she did not care about the perceptions of others, including her husband’s. She wanted to do what was best for her son. She said Clifford often accompanied them to various activities, even though at times he was initially hesitant.

Clifford and Catherine were pleased with the therapy their son received prior to starting in the public school system. There were limited resources available in the school district where they lived, so they moved to a different district where he could attend a school with better services. For the most part, they were extremely pleased with their son's educational experience. He made a lot of friends and spoke at his high school graduation.

Kathleen wanted her son to learn to read, but every year the school wanted to put him in a training program where he would learn personal skills. "Every single year" she fought to have him taught to read and he eventually learned. She demonstrated great persistence over the years and was grateful in the end when her son was able to read.

The final example in this section is from Helen. With a few exceptions, she was pleased with the education her sons received. One problem was a "tennis match" she believed was played among teachers and therapists regarding her son with Down syndrome. "It's your job, no it's your job, no it's your job, no it's your job. And [her son] got nothing." She believed this match resulted in her son lacking some major skills such as writing and speech, which was disappointing.

Over time, Helen learned to advocate more for her sons by working together with their teachers and therapists. She disclosed her secret to "having an effective IEP… you always feed them." The school would reserve their "big administrative office where they have fancy meetings" because she would bring such a spread of food to eat. The teachers would look forward to her sons' IEP meetings. As a result of her advocacy, she has seen positive results with her sons, especially her son's (with ASD) ability to communicate.

Advocating to Protect My Child

Sadly, some mothers found it necessary to protect their children in the school system. Gail, Kathleen, and Linda described negative experiences where they felt the need to make changes for their children. With the exception of Gail, these issues were related to teachers and school administration.

First, Gail told of a time when some older boys "kind of started picking on him." Her other boys wanted to beat them up for being mean to their brother, but she suggested they think of another solution. She decided to invite them over to her house. She told them her son "got some games for Christmas and I'm really tired of playing them, will you come over … and play these games?" They did, and she made cookies for them to take home. She went on to say,

> They didn't become his best friends because they were in fourth grade and he was in second, but they became kind of like, you know that movie, "The Bodyguard?" They watched out for him all through the years, even in high school and junior high. They were just kind of there for him. And if there was ever a situation, they'd call me, you know. It was just a really–it was a really good thing.

Gail found creative ways to advocate for her son and protect him from harm.

Another situation Gail described when she felt she needed to protect her son was when the school was out of compliance with busing. She filed a complaint and ended up sending her son to a different school despite some resistance from school administration. She knew when the situation was not right and had the confidence, knowledge, and drive to change it.

Kathleen shared some experiences when her son was in elementary and junior high school where school was not going well. When her son was in third grade, he and the teacher did not get along. Kathleen tried to hold him back, but the school refused. It did not take long before an issue arose and the school decided to put him back in the second-grade classroom. The next year when she was told her son had no choice but to be in with the same third-grade teacher, she moved him to a different school. She was working and teaching, so she got "special permission to find a babysitter in the area where another school was, a special ed school was, and so for the next 3 years I dropped him off at the babysitter every morning." The babysitter put him on the bus and met him when he got home from school. Kathleen said, "It was helpful to know the system."

In junior high, her son was put "with regular kids for homeroom" and he was teased. He hated it. She wanted to put him in a private school because he did not do well in a big group. She was told she could not do that, but she knew otherwise. While she was working on getting him into the private school, he had two bad experiences in gym. First, he needed to use the bathroom before class started; he got dressed too slowly so they did not let him go to the bathroom. As a result, he wet his pants out at the playground in seventh grade. Later that year, she said, "they had a fire drill and he was very slow getting dressed …so they left him alone in the school. Well, everybody else went out on the playground. …one of my coworkers' daughter happened to be an assistant in his classroom and she told me what happened." At the next IEP meeting, Kathleen threatened to take the school to court over the two instances in gym if they did not let her transfer her son to a private school. "He was in private school for the next 3 years." In both these instances, Kathleen knew the situation was not ideal, so she pushed through resistance for change to occur. Fortunately for her, she knew how to work within the system to get what she wanted.

Evelyn told of an experience she had with her son when he was in his early 20s.

The program he was involved in at school was not working, so she made a change in his schooling. She said,

> …after being in the Gate Program for several years they thought [he] might be able to move into the Gifts Program … he was very interested in the medical profession because he got interested in ER, the TV show…so they tried having him go up to the Hospital and take [public transportation] … One time that he did it, when he was first starting, … I just remember he had a leather jacket on and he got off at [a] field instead and… ran all the way around the track a few times and it was warm weather and then he got back and he went up to the hospital and then he was sitting there sweating profusely and someone came by and they said, are you ok? And, he says "my chest hurts." And so they take him to the ER and they do all these tests… every heart test you could do…No, they didn't find anything. And this happened like two or three times…And I finally called up the school and said this is not working. He cannot do this. I can't do this anymore. Because I get these calls at work, ya know, and say we have your son in the emergency room.

Evelyn decided to put her son back into the Gate Program after this experience. He was able to continue learning there and has had a variety of opportunities to be involved in different activities since then that have not caused his parents as much stress.

Linda, the last example, described how she fought for proper care of her son throughout his school years. She said the following about teachers and children with ID. They wanted to "give them drugs to teach them appropriate behavior" and "humiliate them in the hallway in front of all the other kids" for discipline. It was a nightmare." She described middle school as a

> nightmare because that's when they started the mainstreaming. They decided that they would start mixing the people with intellectual disabilities, mainstream them into certain classrooms, and … -- not all teachers were really qualified to teach to people with special needs.

In order to make changes, she said she was "always at the school checking things, helping them, and volunteering in class or writing to the Board of Education trying to improve things." Linda, in contrast to Gail and Kathleen, did not have the advantage of being an educator and really knowing the system. She did not specify whether or not the situation improved.

These 3 mothers recognized their child was not thriving in the setting where they were placed or were not pleased with their situation, so made changes. Although they were met with resistance, they pushed forward and, for the most part, got what the child needed.

For some parents, the school system presented challenges for parents and children with ID. A few became involved and made major changes. Overall, they were pleased with their children's school experience. Those who were successful advocates described a variety of effective tactics. All needed confidence in standing up for what they believed was right, persistence, communication skills, determination, and a lot of effort. Knowing the school system and their rights as parents of children with ID was helpful. It was not an easy journey, but they knew what they needed to do.

Increasing My Child's Autonomy

As the children with ID grew older and were more independent, 7 parents (8 children) grappled with how much autonomy their children could handle related to self-care. Transitioning from providing for the children's every need to allowing them to take care of themselves was difficult, especially since the children were happy to have parents do everything for them. Increasing autonomy also brought into question for some parents the issue of allowing their child to live independently.

Giving My Child Additional Responsibilities

Five parents shared concerns about how much their offspring did for him or herself. One parent knew they were always going to do a lot for their child. Others knew their son or daughter could do more, but did not know how to motivate him or her to be more independent. Two shared success stories about turning over more responsibility to their son or daughter.

Bernard accepted the fact that he and his wife were always going to do a lot for their son. He described the additional planning necessary to make sure someone was always with their son. Often he and his wife made special efforts to schedule outings when their son was not at home or they had respite care. Although Bernard did not talk about wanting his son to take on more responsibilities, he did say, "The hardest part I think is that he's always there." He seemed to lament his son could not do more for himself, but recognized it would not happen.

Helen, similar to Bernard, knew her son with Down syndrome was not able to do much for himself. She recognized, however, her son could probably do a lot more on his own, but she was "not going to change that" now. Early on in his life, she decided her responsibility "was supposed to be to keep him from suffering." She went on to say,

> …If he is ever suffering, I'm not doing my job. …Life's about suffering, but I have done my darndest to minimize it as it comes to him. Therefore, maybe had I let him suffer a little I might have gotten more of a sway and [gotten him to] communicate with me. If I make it a little tough. But I haven't, so he's happy. And he's learned he can be a plant and get everything he needs.

Helen took on some of the responsibility for her son's dependence. Interestingly, she said he had a "second personality" at school where he did help in the classroom. The respite workers were working with him at home to get him to do more.

Nancy, another mother, knew her daughter with Asperger's disorder could do more and expected her mother "to do too much." She said,

> …I always do whatever I can, but I've been getting frustrated because I need more help. I think one of my friends explained to her that she is a guest in our house and that she needed to help with the dishes, so she has been doing a lot better lately and not expecting me to do everything. But, she will crawl under the bench and let me take over. I do. But, then when I leave she seems to be ok, mostly. Sometimes she and [her daughter] get into a big fight. They call us; "We need some help right now."

Nancy wanted to help her daughter, but became resentful when she did too much. It was a hard balance to find because her daughter was willing to let Nancy do everything. This quote shows that Nancy demonstrated some recognition of the benefits of outside influence and leaving her daughter to fend for herself.

Anita, similar to Nancy, knew her daughter with brain damage could do more, but did not know how much. Her sons told her "she's not normal and you're expecting too much of her to be normal." "Normal children," she said, "let you know [when] you're too bossy," but her daughter did not let her know. It was hard to know how much their children could do on their own and how to motivate them to do more.

In contrast to the previous examples, Linda was very much in favor of her son with Down syndrome doing as much for himself as he could. They converted their basement into an apartment where he could have his own space and cook his own simple meals. She wanted him to make his own decisions, but struggled with the consequences. She reported "he'd be more than happy to live there 24/7 for months at a time" playing on his computer. He is "hooked on media." The following describes the struggle she had with allowing him to make his own choices while living in his basement apartment.

> Uh, I mean [people with ID] don't have friends that come and pick them up and go out and do things, socialize, get out and do stuff on their own unless the

> parents are taking them out or you assign, you know, line them up with someone to go do something with. So they spend a lot a time in front of the TV and in front of their laptops or with their headphones listening to music, and then you're going, "Well, that headphone is going to make you -- give you nerve damage in your ears. You're going to be deaf." But how you convince them to turn it down, that's another struggle. So independent living skills, there's a fine line between allowing him to live totally independently versus, you know, helping him out because his food choices are not always the healthiest. So, you know, they put on weight and they'd get accustomed to their lifestyle or certain shows they get hooked on, and you go, "Come on. Let's go play basketball." "No, I got my show to watch." …I should never have gotten him involved on watching TV or getting him a laptop, a computer. And yet, you got to know those things to live in this world, you know. But then, they pick up a lot of bad stuff from those things that's hard to… So anyway, that is really stressful to me because I worry about what he's eating and how much exercise he is getting. And his health is important to me, but I have a hard time keeping on top of it because he is supposed to be living independently and learning how to survive when I'm dead and gone.

Linda wanted her son to be in charge of his own life and decisions, but did not approve of his decisions. She somehow wanted to figure out a way to help him make better choices on his own.

Although encouraging children with ID to take on more responsibilities and make wise decisions was challenging, it was not impossible. Helen shared some successes she was having with her son with ASD. She said she was starting to let him do more on his own. After realizing money was not a significant motivator for him to work, she decided to allow him more opportunities to choose items for purchase at the store. She also figured out he could earn money to attend college basketball games, which he enjoyed. As Helen allowed her son to have more responsibilities, they both benefited. He enjoyed the new freedoms and developed additional skills. She gained confidence in her caregiving abilities and had additional time to care for her own health and well-being.

I conclude this section by sharing an experience Kathleen had when she was able to recognize what her son could do for himself. She said when her son was about 16, she was thinking about how difficult her situation was. She asked one of the mothers at a Special Olympics event, who had a son in his 40s, if she thought it was hard to have a child with ID. To her surprise, the mother said "Heavens, no. He could take care of himself." At that moment, Kathleen thought "Oh! Hmm, [my son] can take care of himself. It's not hard after all." A weight was lifted off of her shoulders as her perspective changed about caring for her son.

Resilience for these parents was developed as they recognized their children were capable of doing a lot more for themselves than what they were most likely doing and encouraged them to reach higher plains. Getting to that point was challenging because they were used to caring for their children's needs and the children were used to being cared for. These parents share how it required some risk, ingenuity, and trusting others.

Pondering Independent Living

Closely connected with allowing children to take on more responsibilities was the question of independent living. Three parents shared thoughts and fears about allowing their children with ID to be on their own. They wanted to protect their children, but did not elaborate on what they were protecting them from.

I begin with Bernard. Previously, he talked about knowing they were going to do a lot for their son and this would not change. He did not picture his son ever living on his own; however, he described his need to protect his son and his fear of letting his son live independently. He said, "From an early age …The kids seemed to want to protect him and I think I did, too." Even though he was older, the need to protect him was still there. He said, "You have to be cognizant where he is since he has no fear. …He doesn't bother to mention he’s going to do that. …since he is at risk of being taken advantage of, we feel like we have to watch him closer.” He does not describe in what ways his son could be taken advantage of.

Clifford wanted his son to live independently, but it was worrisome. His son was fairly high functioning and Clifford knew he would enjoy having more freedoms. Therefore, he spent the last 10 minutes of the first interview explaining how he felt regarding his son’s independence. He worried “that there’ll be something out there that’s going to knock [his son] down” or “take advantage of him.” I believe he was concerned with someone emotionally hurting him causing him to suffer. Clifford knew he could not protect his son his whole life, but wanted to do it as long as possible. He looked forward to his son living on his own, but said, “I hope when he does decide to do that I’m around so that Catherine and I can sit in the car down the street, watch, you know, gaze.” Even though he knew they were protecting him too much, he did not want his son to get hurt.

Unlike Clifford’s son, Evelyn’s son asked “a lot about living independently.” His caseworker suggested a group home, but “he wants to live by himself.” While on a church mission, her son learned about some possibilities for independent living from his supervisor who has a son with a disability. The son “lives in an apartment by himself. He has someone that comes and checks on him. [Her son] found out about that, so now he wants to pursue that. [Evelyn doesn’t] really want that.” She did not describe her rationale for not wanting her son to live independently in an apartment.

These parents were still in the process of figuring out how independent their son or daughter could be and how to encourage them to be independent. Parents were fearful this would be a big change, and it was risky. Allowing children to take on more responsibility took courage, humility, and patience. Most parents were still trying to figure out the right amount of independence their son or daughter could handle.

Best Parts about Raising My Child with ID

Although raising a child with ID was not easy and came with challenges, all parents shared positive aspects of their experience. When asked, "What is the best part about raising a child with ID?" they told about their child's positive qualities, accomplishments achieved in spite of having a disability, opportunities received because of their child, influence the child had in shaping and refining their parents' characters, and how important the child was as a family member.

Recognizing My Child's Positive Qualities

Parents had many positive things to say about their children with ID. Martha said, "Well, there are so many bests!" Some attributes mentioned were the children were fun and had great characters, were even-tempered, "always happy," and grateful. Anita enjoyed her daughter's daily statements of, "I love you," and "You're beautiful, Mom." Gail said, "[he] was never a burden." They treasured the relationships and took pleasure in having the children with ID around.

Two mothers said their children with ID caused them fewer problems than their other sons or daughters. Kathleen said, my son didn't "complain…like most kids do." Evelyn said, "…he didn't give us the same kind of problems that our normal kids did as teenagers." When Kathleen's son was born, her pediatrician said, "The happiness of the parent has nothing to do with the IQ of the child." She always remembered that quote and believed it to be “completely true.” She said, “The children that have given me the most problems are my two boys who have the highest IQ. …There’s a heck of a lot worse things out there than having a child with Down syndrome.”

Martha said “everybody loved her son” and “everybody was his friend.” She expressed the positive outlook her son had on life mixed with the reality of his situation. He was excited about everything and his enthusiasm was contagious. She said,

> His motto literally was “This is the best day, ever.” [He] was so excited about anything. Any new movie that came out… he was just so excited…. “Oh, that's the best movie I've ever seen”…. ”That was the most fun I've ever had.”… so he was just fun.… the best is Christmas. [He] just made Christmas. I mean, he was so excited every year, it did not matter…. so he was 24 when he died and he told me one day, he says, “Mom,” he says, “I don't think there's an Easter Bunny.” And he says, “I don't think there's a Tooth Fairy. I know for sure there's Santa Claus.” I mean, he never let it rest. And he just made all the holidays so fun for us, you know, the fireworks. And we just… figured we'd… always be Santa Claus, you know, because he was a believer. He was. So I think just his outlook in life.
>
> His father, Martin, added,
>
> …he really saw life differently than, uh, most people do. He really had, uh, had quite a Pollyanna type attitude, but more of, uh, he took nothing for granted. He lived every day the best he could and he appreciated, um, the experiences that he had. It was the simple things that made him happy. Uh, it didn't have to be complicated, didn't have to be grandiose, just simple things.

Martin and Martha’s son made life more enjoyable for them; they especially appreciated his simplicity and positive outlook.

Exceeding Parental Expectations

Five parents (four children) said they enjoyed seeing their child with ID accomplish things they never dreamed possible. Dorothy said when her son with Down syndrome was born, “They give you a list of things that he'll probably never do…he's probably far exceeded what they said."

Parents were thrilled when their sons or daughters reached developmental milestones. Kenneth described his son's first word:

> I think I remember the first words that he spoke, probably he was already over a year old, … we were recording some family activity, maybe home meeting, I don't know. But, uh, I told [him] to say hello or something and he just said hello. And I said "Oh!" and we screamed. And so anyway, that was, uh, his first words...

They were so surprised and excited that evening.

Catherine noted her son's learning was slow, but occasionally would see him do things causing her to think, "There's somebody in there. I just gotta keep working to get him out."

Clifford said, "I think that's the best part, watching him do something and do it well, watching him grow to a point that you're not a hands-on individual anymore. That makes me feel great about him." Catherine, his wife, described how she gave so much to her son, but it was worth it because of who he became. She said,

> … People said… You've given up so much, but I don't feel like that. I guess I'm crying because I'm proud of him. Because he's amazing as an adult. He's an amazing person. So, I feel like that trade was so much, was just so worth it. That I invested time in something really good and had a good outcome, a really good outcome. He spoke at his high school graduation. And, if he had to be on his own, he could be. It wouldn't be optimal. He'd struggle financially, but he could.

Gail spoke of how courageous her son was, and described a time when he was transitioning to high school. She said,

> I thought, "I can't do this. Those kids are so big and there's so many of them and high school…Oh, I don't know that I can do this." But I walked over with him, because it's just across the street, walked over with him that first day. And I was just sitting there, thinking, "How are we going to do this? How are we going to do this?" And he stood right by me and he said, "Mom, look at this. Look at this. Look at all these kids that are going to be my friend." And I said, "You don't need me." I'm getting a little emotional because that's how he's always been. He just takes us to the next level and it's just, you know, you asked about how it is to raise

a kid, and it's been so fun. It hasn't been easy, but –“

Gail went on to speak about her son’s religious involvement and service, saying, “The best thing… it’s to see him in the temple. To see him in the ward as the young men’s second counselor. Um, and it’s just a natural given thing.” She and the other parents in this section were proud of their children’s accomplishments despite the disability.

Opportunities Resulting from Raising My Child with ID

As parents shared stories, they highlighted opportunities they had because of raising a child with ID. Four parents described these opportunities as one of the best parts of having a child with ID. One family went horseback riding and on helicopter rides, visited a movie ranch, and became involved with Special Olympics because of their son with Down syndrome. Parents appreciated the other “wonderful” parents and families they met and shared struggles with. Gail started a successful nonprofit organization providing services for children with special needs and assisting families. She traveled to Israel and Russia to speak about abortion and work with families of children with Down syndrome. Kathleen earned a master’s degree and worked at a program for infant children with Down syndrome.

Linda described how she got her son involved in Special Olympics when he was about 10 years old. In addition, they did not have a youth team near her home, so she started her own. They

> …got totally absorbed in Special Olympics advocating for people with disabilities and doing… charity events. And [her son] got, you know, a lot of exposure because he's very charismatic, good-looking, smart. He has good speech, clear speech. So he was invited to be a spokesperson for Special Olympics. And from

> there, a lot has happened. It's just taken off. But it was a lot of work.

Linda went on to say she got “really involved on a national and even international level with advocacy.” As a spokesperson for Best Buddies, her son did “a little show and dance on stage and [spoke] about… its benefits for people with disabilities.” They went to Russia to “participate in their dance, uh, festival …to bring about awareness about people with disabilities and inclusion.” She said her son

> serves on a lot of different organizations like the law enforcement torch run for Special Olympics where, uh, he goes to meetings with all the law enforcement people…and they do torch runs for Special Olympics. So he's had a lot of exposure and he's been advocating for people with disabilities since, gosh, I think developmental school.

Despite the additional work required, she was proud of what her son was able to do and pleased with the experiences she had with him.

These parents were grateful for the life-changing events they were able to experience as a result of raising a child with ID. They never would have happened had they not had a child with ID.

Parental Character Development

Parents described the influence their children with ID had in shaping and refining their characters. Nine parents shared lessons learned and attributes developed, such as gratitude, compassion, selflessness, love, patience, tolerance, simplicity, planning skills, and friendship. The children with ID provided them with a chance to serve, care, and be benevolent. They also began to appreciate human potential, beginning with their own and their child’s, and developed a broader view of human value and worth.

Anita said her daughter “helped me to learn to accept things as they are. And then, do something about it if you have to. But, to accept it, not to fight. Cause you don't get anywhere if you fight it."

Kenneth described how his son did not judge others. He said,

> …they'd have balls and things like this, and he would go on dates and he would ask girls to go and they would. …he has absolutely no, uh, all people are I guess very attractive to him. He doesn't have the problems … of our perception of beauty and our perception of… compatibility. … This one girl he took, I don't know, somehow we became aware that she was black, but it wasn't a problem for him. He … had a girlfriend for a while who was extremely overweight. It wasn't a problem for him because he didn't -- he just doesn't have those -- those perception problems that we all get in society as people.

It took Kenneth some time, but he eventually recognized the amazing qualities his son possessed, such as being open-minded and nonjudgmental towards people. Reflecting on his son and experiences he had with him helped him to see how he changed into a better father and overall person. Other parents had similar experiences.

<u>My Child as an Important Family Member</u>

Three parents (two children) said the child with ID changed the lives of their other sons and daughters. Kenneth and Kathleen's son with Down syndrome showed unconditional love to one of his brothers who was having a hard time as a teenager, which helped him. Kenneth said his son "had a great influence on the other kids." He had "a bit of moderating influence in their lives especially our teenage boy. He …didn't care what he was doing…so [he] always felt accepted by [him]." They appreciated his love and tried to learn from his example.

Gail also commented on how her son influenced his siblings for the better by saying,

The absolute best part was just having him in our family. And watching him grow

> and develop and um, seeing what happened to my kids…. Seeing what happened to my kids in terms of who they became. They became much more aware of other people’s strengths. They became more tolerant of a people who had different abilities.

Although caring for her son was not always easy, she appreciated the unique experiences and applied lessons her children were able to have as a result of having him in the family.

Looking over the lifetime of experience parents had with their children, they remembered how frightening and disappointing it was at first. They recognized the difficulties and hardships they experienced. In the end, however, they were able to say it was worth it. Martin said, “I don't feel like I've lost anything because of it. I'm happy with the ways things are and … I don't regret it [at] all. … I wish things had been different for [my son] so that he could've experienced more and done more. But for me, it's, uh, it wasn't a challenge or a problem.”

Evelyn said “starting out not knowing what to expect being ya know, scared, disappointed, whatever, ya know. It’s when you look back on it it’s all turned out to be really wonderful. Because he’s, ya know, he’s a really good person, a neat kid.” Her husband said, “The good outweighs the bad. You know you end up thinking, ‘Well, maybe. It was worth it.’” These parents summed up well the overall experience narrated by all of the parents. Raising a child with ID is challenging, but it is also full of amazing opportunities and enjoyment. Parents were grateful for the positive influence the child with ID had on them and those around them.

Conclusion: Research Question #1

Parents caring for children with ID narrated the transition of raising such a person by chronologically describing the events that occurred in their son’s or daughter’s life.

Although each story was unique and contained deviations related to individual variations and contextual situations, all stories focused on the child and how parents adapted to a constellation of challenges encountered. However, variation across parents occurred in the number and intensity of challenges and how they demonstrated resilience, although all portrayed a gradual acquisition of skills and ways of thinking demonstrating resilience.

Stories were mainly told of parents resiliently reintegrating; however, reintegration back to homeostasis without acquiring new skills or growth occurred with minor and short-lived challenges. When resiliently reintegrating, parents exhibited two types of behaviors, taking action to provide for the child and reflecting on their lives and situation while utilizing additional coping mechanisms. As parents adapted to challenges, they shared lessons learned and how they became better people. In the end, they acknowledged difficulties of the experience, and expressed gratitude for blessings received. Also, parents shared both positive and negative aspects of raising the child with ID, and believed the experience of raising a child with ID was “worth it.”

The story of raising a child with ID was not complete for parents at the time of the interview, except for possibly Martin and Martha. Parents were still challenged by the situation and learning resilient skills. Developing resilience was an ongoing process encompassing the whole of one’s life. Parental concerns at this time were mostly related to balancing the needs of the child with their own and helping the son or daughter take on more responsibilities of everyday living. Interestingly, most parents were currently developing resilience as they worried about their other sons and daughters without ID and personal health problems.

Research Question #2

The second research question presents a description of the influence of raising a child with ID on parental health trajectories—patterns of health over time. Data from lifelines and interviews were used. This section is divided into two parts. First, there is a brief summary of parents' perceptions of their lifelong health, and how it was affected by their child with ID is presented. The second part contains a series of health trajectory graphs created for each participant using major transitions they identified in their lives.

Influence of Child on Parents' Health Trajectories

Parents were asked to tell about their overall lifetime health and well-being and describe how it was affected by the child with ID. Parents' immediate response was to provide a physical health history. After this, I asked them about the other three areas of health—emotional, social, and spiritual—based on the World Health Organization definition of health (Frequently asked questions, 2011). With some probing, they were able to provide this information.

Interestingly, little information was included when parents were asked to share their experience of raising a child with ID in the first interview. That narrative focused on the child; references to the parent and others were limited. When asked directly about different aspects of their health, parents easily shared information, and highlighted many benefits they received from raising a child with ID.

Physical Health

Twelve of the 18 parents said they have been fairly healthy, but were experiencing more health issues with age. Parents mentioned varying health concerns including surgeries, diabetes, high blood pressure, high cholesterol, injuries, thyroid, cancer, heart problems, alcoholism, weight issues, poor diet, miscarriages, arthritis, and sleep apnea.

Seven parents recently began paying more attention to their own health because they had more time or were now more concerned about it. Three different fathers said they recently made changes to their physical habits, 1 as a result of seeing a picture of himself appearing overweight, and the other after experiencing the death of a family member who had not been taking good care of himself. Some recent experiences of a 3rd father led him to look for small ways to improve his life physically in order to live longer for his son with ID, wife, and grandchildren. Parents said they were exercising more, eating better, and losing weight. By observation, most were somewhat overweight, and 1 father was most likely obese. One mother did say she lost 50 pounds and has kept it off for the past 6 or 8 years.

Only 2 parents said the child with ID may have affected their physical health; the others said their health problems either originated prior to the child's birth or were a result of their own personal actions. Evelyn said her son kept her more active as she chased him around, and Eddie, her husband, stated his son may have caused his blood pressure to be elevated as a result of worrying about him. Dorothy decided she could eat healthy and exercise despite her son being a picky eater and not liking to exercise. Three or 4 mothers stated their health came after the needs of their son or daughter and did not become a priority until the child with ID was grown.

In summary, parents' narratives described health issues or concerns they had and were experiencing in their lives. For the most part, these concerns were not directly related to raising a child with ID.

Emotional Health

According to parents' interviews, children with ID did influence parents' emotional health. Although there were additional challenges and stresses related to raising a child with ID, parents learned to adapt and cope. However, upon reflecting on their experiences, parents identified several positive benefits of the experience to their emotional health.

In describing their emotional health in general, a little less than half of the parents said their emotional or mental health was essentially stable over their lifetime with a few situational ups and downs. Five said they struggled with depression, which was often attributed to other issues besides raising a child with ID.

In regards to their children with ID, the most common negative emotions expressed was worry and concern. See Figure 4.1 for other negative feelings mentioned by parents. Three parents mentioned specific concerns—the child would not be able to do anything, funding would disappear, the child would be taken away for poor parenting, and the family would not have enough money to meet their financial obligations. Other feelings are shown in Figure 4.1. Stressors parents mentioned included the unknown, physical and structural damage to home, time, energy, child's medical needs, and fighting for rights and opportunities for their children with ID.

As part of their emotional health, parents shared various coping mechanisms they found beneficial as they raised their children with ID. See Figure 4.2. Some form of self-care was mentioned by 13 of the 18 parents; this included balancing one's life, going on vacations, retiring, setting boundaries, creating "me" time, advocating for self, and spirituality. The next most common coping mechanism was building and strengthening relationships, including accepting help from others. Keeping things in perspective included not overreacting, being calm, and taking one day at a time. Professional help included counseling, antidepressants, and other resources.

As parents reflected on their experiences raising a child with ID, they described several benefits to their emotional health. For example, parents said their child with ID brought them joy, cheered them up, and made them laugh. They enjoyed being with the child and seeing their accomplishments. The children with ID taught their parents appreciation, compassion, selflessness, patience, tolerance, simplicity, patience, planning, and friendship. Their children made them emotionally healthier and more adaptable, and brought confidence and emotional strength. Overall, parents believed the experience had a positive influence on their emotional health. Even Jean, who described a great deal of emotional challenges as she raised her grandson, shared similar emotional benefits.

Social Health

As part of social health, parents discussed various relationships throughout the interviews. I divided this section into relationships with spouse, family (children and extended family), and other people. The section concludes by describing the challenge some parents encountered in asking for and receiving help from others. Children with ID

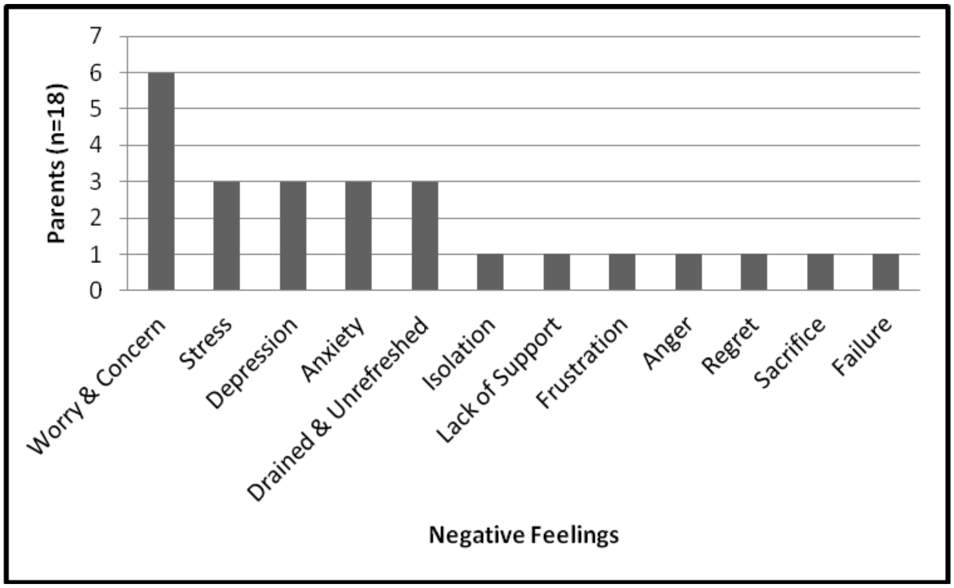

Figure 4.1. Negative Feelings Expressed by Parents

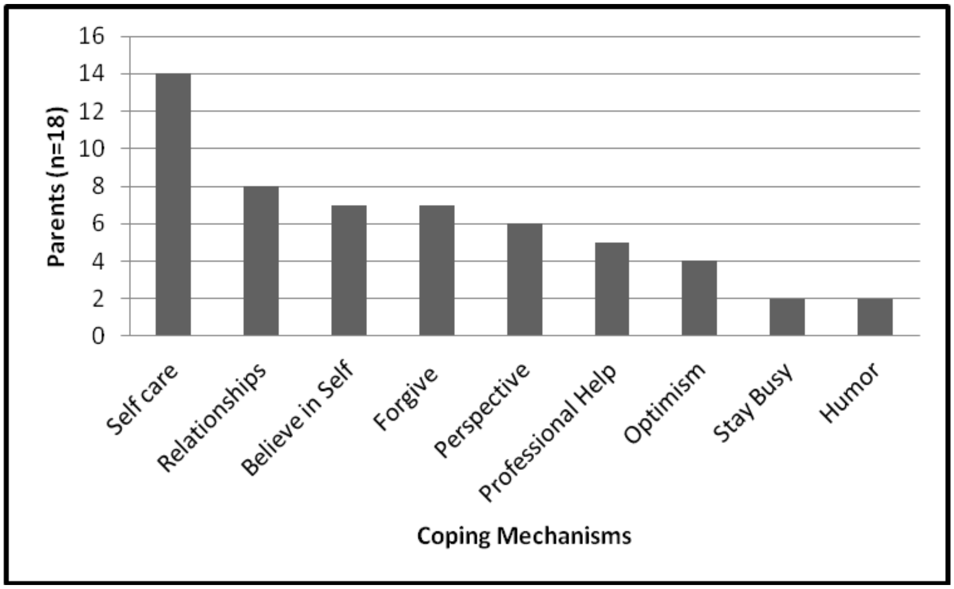

Figure 4.2. Coping Mechanisms Used by Parents

influenced all relationships, mostly for the better. This section describes each.

Relationship with Spouse

Most of the parental narratives portrayed raising a child with ID as an overall strength to the marriage relationships despite difficulties presented. Twelve of the 18 participants said their child with ID helped strengthen their marriage and brought spouses closer. They talked about the goal or commitment they made with each other to stay together and have a strong relationship. The child was a responsibility they shared, and both were concerned about the child as he or she became a tie binding them together during hard times. Martha said staying together was important to their son, and getting a divorce would have devastated him. Kenneth said he tells his wife, “You're not going to leave me because you don't trust me with the kids and you don't want him by yourself." Maintaining the marriage also meant receiving additional help. Helen described a back-to-back relationship with her husband as they cared for their boys. She said they are like “a machine in morning routine, nighttime routine”; it is like a “huge dance” that is choreographed. Parents worked together, communicated, showed understanding, and exercised patience.

Several parents mentioned the difficulty of always having the child present. Helen recalled a conversation she had with her husband when their son with Down syndrome was a baby. The thought of never again living alone with her husband saddened her. Their marriage did not receive much attention from her because she was focused on the kids. She asked, “Why work on a [marriage]? We’re always going to be a group. We’re never going to be a couple.” Many years later she realized the importance of making her own life and marriage a priority. They now have regular respite workers who allow time for themselves. Two or 3 other parents mentioned the importance of having someone else available to watch their child with ID, so they could take time for themselves and spend time on their marriage relationship.

Two mothers talked about strained marriages, mentioning a lack of support or presence from husbands. Eddie said he and his wife were sometimes at odds about what should be done with their son with ID. They took turns being annoyed and defending the son. He believes, however, their son was a glue that made their marriage stronger. He was proud that they have been married 31 years. Clifford and Catherine said their marriage was strained in the beginning. Catherine did most of the work caring for their son, while Clifford engrossed himself in his work. As their son became more independent, their relationship was rekindled and they enjoyed being together again. Indeed, raising a child with ID produced extra stress in parents' marriages; however, many described making a commitment to stay together, working hard when it became difficult, and developing positive relationships.

Relationship with Family

Parents' narratives were crafted to describe the positive effects of raising a child with ID on family relations. Twelve parents described how their other offspring helped the child with ID. They said siblings were loving, accepting, helpful, protective, and good caretakers. Some children with ID were spoiled by siblings; siblings would do anything for them. Many siblings planned to provide care for their brother or sister with ID when parents were unable. The child with ID in turn provided an opportunity for siblings to serve, and gave them a different perspective on abilities. Four parents said the child with ID drew or cemented their family together.

In addition to these benefits, some parents also talked about family relationships that were altered or strained by the situation. One third of parents talked about typically developing siblings who had difficulties when the child with ID was young; siblings acted out, repeated grades, were teased, or just had difficulties. Four parents mentioned spending additional time caring for their child with ID and less time with their other sons and daughters. Two parents occasionally talked to the typically developing siblings or treated them similarly to the child with ID and found this was ineffective; the siblings did not want the same level of detailed instructions as their children with ID.

Most parents described their extended families as either supportive or not. Seven parents said their extended family was supportive, 5 parents said they lacked understanding or were judgmental, and the rest did not mention their extended families. Some extended family members took time to become accustomed to the child with ID, and some extended family interacted better with the child than others.

Similar to marriage relationships, parents chose to report raising a child with ID as mainly a benefit to family relationships. The child with ID influenced siblings' lives as they learned to love and accept them, but it was not always easy. One third of siblings had difficulties when the child was young; they were required to help and received less parental attention. Extended families provided some support to parents in raising their children with ID, although a few parents had difficulties with these family members.

Relationship with Others

Raising a child with ID generally was a benefit to relationships with other people. Ten participants reported meeting more people or building stronger relationships with others because of the child with ID. Some participants mentioned receiving support from friends in church, the community, schools, and other organizations. Dorothy said one of the things helping her cope was the strong support network at school with other parents who had children with disabilities. Five participants said they gravitated towards friends and associates who were supportive, accepting, and understanding. There were parents who said their children with ID were helpful in judging character. Betty said her daughter watched how people treated her brother with ID to determine if she wanted to date them or not. Two parents said they treated people better because of what they learned from their child with ID. Many parents learned to be more accepting and less judgmental. Helen said she was grateful for the helpful role her community played in raising her boys.

Other parents mentioned the limitations the child with ID placed on social relationships. Leaving the home to do things with friends was difficult. Nine parents mentioned having limited friendships because they lacked time and energy, or others did not understand their situation. Overall, parents were grateful for the relationships developed and support received as a result of raising a child with ID. They did not seem overly concerned by limitations this situation placed on social relationships; they were used to it and made necessary arrangements to accommodate for the child.

Asking for and Receiving Help from Others

All challenges I describe involved an intense amount of parental work and responsibility. Fortunately, the workload decreased over time, but it was never completely eliminated. Oftentimes, parents' own needs became low priorities as they worked to care for their son's or daughter's needs. Some parents were better than others at asking for help, but others learned this skill over time. For various reasons, at least half the mothers had difficulties asking for and receiving help from others. Two fathers mentioned the respite services their sons received, but none of them talked about asking for help. This section begins with a description of four mothers who struggled to ask others for help and describes how they handled their situations.

Helen, the first example, found herself caring for her two sons with ID almost entirely on her own. Her husband and other children helped when they could. She did not feel comfortable asking for help outside her immediate family, especially early on. Support groups were not helpful, because she had a different philosophy or did not fit in with the other parents. She said, "I have not been a… let's all share, let's all cope [parent]. We do this in our family, alone."

The issue of her feeling she was a low priority began when her son with Down syndrome was 2 weeks old and a physical therapist from the county health department came to her home. "Her thing was progress, progress, progress." Helen "felt like if we didn't make that progress she'd disappear, the benefits would disappear, the help would disappear and I would be left alone." Each time someone came to her home to help her son, she felt she "was under a microscope" and feared he would be put in a home and adopted out. As a result of this pressure, she did everything she could to teach him and help him achieve his goals. She “disappeared from [her] own plate” and stopped doing what she loved. It was not until her son was about 8 years old that she gained a better understanding of the service system and learned her son would not be taken away.

This knowledge decreased her stress to assure developmental progress; however, she still spent most of her time caring for her sons and very little time on herself. It was not until recently she read a book titled, “*Mom, More than a Parent*.” After reading this book, she said,

> …it’s ok for me to go back and like a hobby I had. It’s ok for me to take time and not respond. Realizing I had the right to put me on my plate led me to be more of an advocate to get the opportunity. And now I have two respite workers. Somebody’s there Monday, Wednesday, and Friday with [my son], 9-3. Wow! Used to be I only got that when he went to school. And now, it’s summer. And I used to be a prisoner in my home in the summer. I never left, I never went. I never… The oppression used to be horrible. …But I have somebody that lets me go and do. I never felt that I had earned it. The worst person coming through all of this has been me.

Following many years of neglect, Helen finally realized how important it was for her to take responsibility for caring for herself. Asking for and receiving help from others became essential in her own self-care. She utilized her daughter and professionals for respite services.

Jean is the next example of a mother who did not find asking for and receiving help easy. She shared the following about learning to ask for help:

> I don’t ask for help. And that’s my fault. …But it took me these kinds of things to make you realize you have to be big enough and strong enough to ask for help …I’ve grown in so many ways that it taught me to be strong enough to go and admit that I have downfalls and that I need help and that I need to let others be able to help me like I want to help others. ...It’s humbled me and taught me how to be able to ask for help. And it’s an art to know how to ask for help… You don’t just grow up knowing how to ask for help or maybe that’s how I lived a privileged life... That we never needed to ask for help that I was aware of. We didn’t, I didn’t, we were always helping everyone else and that’s how I was …I was always helping everyone else.

Although Jean did not learn the skill of asking for help growing up, she developed it while caring for her grandson.

At the time of the interview, Jean felt very alone and overwhelmed with caring for her grandson. She was frustrated with the school system, struggled with her grandson's behavioral issues at home, and experienced financial problems. She was unaware of the many resources available, and told me she was worried about who would care for her grandson when she passed away, because she did not believe the world was "progressive enough" in their knowledge of ASD "to include him." She explained,

> No matter how much good we do now, no matter how much groundwork we lay or no matter how rich we get. Nothing, money won't guarantee us that someone good is going to come along who sees how we take care of him and wants to follow in our footsteps. Not family, no Mormon, no Jew, no Greek, no Gentile, no one. You find me someone. I wish. That would be an interesting search on the Internet. Put out a page that would save [my grandson]. We don't know; we're still puzzling. That's one piece we've got to figure out. Is we're still puzzling on how we can guarantee a good after life for him.

At one point in the interview, she described a plan to end his life so they would not have to "leave him for this world to take care."[2] Her grandson is still alive, and their situation has improved dramatically since this statement was made. Fortunately, her financial situation changed, and she was able to quit her job. She receives funds to care for him and is connected to many resources. He attends a day program part time, and she enjoys taking him on outings. There are also fewer behavioral issues.

Jean's story was different from the others because of the accompanying circumstances and outside stressors she experienced. The first half of the interview was

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[1] Participant was reported to Adult Protective Services. The IRB was notified and appropriate actions were taken.

about the abuse and neglect her grandson experienced while in the custody of his mother. These experiences most likely contributed to his behavioral issues when Jean initially cared for him. In addition to behavioral issues, Jean struggled financially and had little support from family, friends, and the community. Her husband had passed away many years earlier and she relied on her daughters for help.

All other parents interviewed raised their child with ID with a spouse, and none described any abuse. Some had financial issues, but these did not surface as major difficulties. At the time of the interviews, Jean's world seemed to be collapsing around her as she struggled to give her grandson the care she knew he deserved. Once she obtained adequate resources and her financial situation changed, her story seemed to improve.

The last examples, Kathleen and Dorothy, described their thoughts regarding respite services following their child's graduation from the public school system. Neither felt comfortable leaving their sons for extended periods of time. Kathleen said, "Having other people have to be responsible for what I felt was my responsibility. …was hard. … I didn't want to give that burden to other people. I felt that I should be doing it." She shared an experience when she and her husband served a 2-year mission for their church, and they left their son at a group home. During this time, family members occasionally took him to do things in the evenings. "…One of them forgot him one Friday and so he was [left] by himself practically all night until they found him still sitting there waiting for her to come sort of thing." Kathleen did not think her son was "really happy" at the group home. She concluded by saying, "It doesn't mean he's 100% happy here either, but, you know, he would like to go to Hollywood."

Dorothy explained the respite care she felt comfortable with was limited. She preferred to make plans that involved her son. She said,

> …my children have young children and so I don't feel like it's necessarily um good for them to have [my son] thrown into the mix in their homes because they're very, very busy. … It's very limiting sometimes as to what [my husband] and I can go do because we have [him]. …there are group homes or places, but he would hate it. And, so it has to be the resources that I'm comfortable having him …It's easier for me to just plan things that I can take him with me. I would rather have him come with me and just deal with …and enjoy the issues that go along, hand in hand with him sometimes than just leave him to somebody else.

Kathleen and Dorothy developed skills as they recognized and accepted what worked related to respite services. They believed as long as their sons were alive, they could not be away from their offspring for extended periods of time.

In summary, the behaviors these mothers demonstrated were understanding their personal limitations and figuring out the amount and type of help they needed. When the balance was right, they were happy and had sufficient personal time. At the time of the interview, the other parents seemed fairly comfortable with the level of assistance they received for their children, and appreciated respite services available. Four or 5 of the children had respite workers who did activities with them on a regular basis. Eddie and Evelyn paid their other children to watch their son with Down syndrome at least once a week so they could have a date night. Some parents were working on making themselves more of a priority by taking time to exercise and perform other self-care activities.

Spiritual Health

Although religious affiliation was not asked, it was mentioned during all interviews. Of the 12 families, 75% were members of the Church of Jesus Christ of Latter-day Saints (also known as " Mormons" or "LDS" (Latter-day Saints)), only slightly higher than the 67% Utah average in 2004 (Jones, 2004). Two families were Lutheran and 2 did not affiliate with any religious groups.

Parents described many benefits of spirituality in their lives, particularly as they raised children with ID. Six parents said God or religion provided support, strength, hope, and help to get through difficulties. Three parents described spiritual growth they experienced from serving in church and support received from church members. Faith—having hope and trusting in a higher power—was mentioned by at least 6 parents. Three parents mentioned the importance of regularly performing religious activities such as reading scriptures, attending church, and praying.

Some parents found strength from spiritual knowledge while raising the child with ID, and others spirituality increased because of the situation. Three parents said their son or daughter was a special child from God. Two parents said the child was given as part of His plan. Three parents explained how their child with ID would be perfected in the next life. Martin questioned why he deserved to have his son with ID; his son was so good and he felt inadequate to teach him. Martin tried to be like his son by "lov[ing] without question" and "accept[ing] people and situations for what they were, not what [he] wanted them to be, and be ok with that." Kenneth worried about living worthily in this life so he could live with his son after death.

Several parents mentioned events or situations difficult to reconcile with their religious beliefs. Two mothers said being married to a man who was not religious or interested in church was difficult. Others mentioned their faith or church activity was affected by such events as a mother passing away, a son with ID who was disruptive at church, having to get married because of pregnancy, and a daughter's out-of-wedlock pregnancy.

In summary, spirituality or religious beliefs were mentioned as a benefit by over half of the parents in the study. They received support, strength, and hope from God and other church members. Their religious beliefs provided understanding and greater perspective as they raised the children with ID. Out of the 10 parents who said the child impacted their spirituality, only 1 shared a negative experience where they stopped attending church for a few years due to his disruptive behaviors.

Health Trajectory Graphs

In order to better understand parents' health over time and the impact the child with ID had on their lives, I created a health trajectory graph for each parent. Health trajectories are composed of transitions, so I first determined how parents identified transitions. Then, I selected those transitions I thought had the greatest impact in their lives.

Parents identified many transitions during the course of the interview process and on their lifeline drawings. When asked to identify a transition, parents tended to name experiences or events (e.g. getting married, having a child, or moving to a new home) affecting their lives. The process of identifying transitions essentially consisted of putting a name to events participants found significant that changed their lives.

I determined main transitions were those described in more detail and with more emotion. I also took into account transitions they chose to talk about when asked to describe a main transition. Figure 4.3 graphically depicts transitions with the greatest impact on parents' lives. Raising a child with ID was the most common event, but

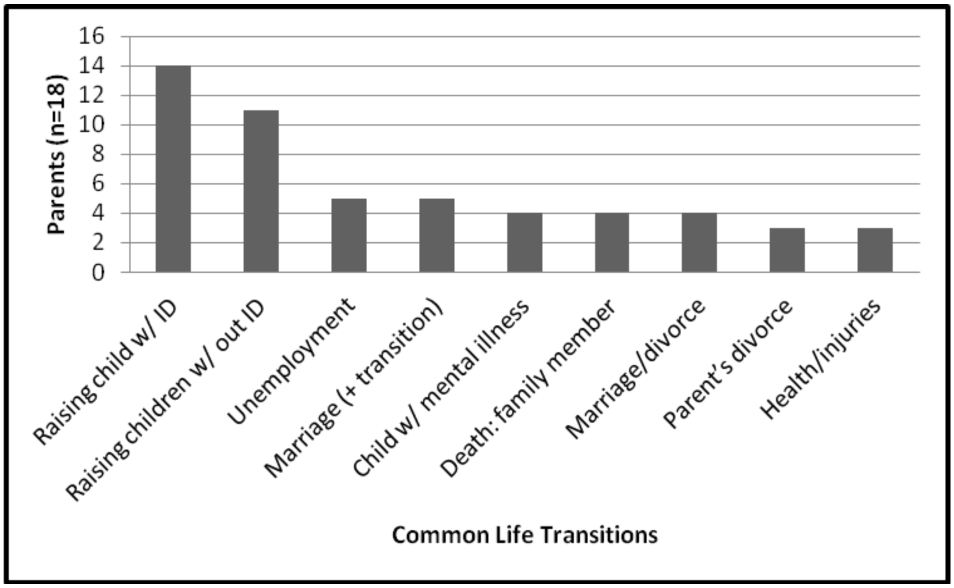


Figure 4.3. Common Life Transitions for Parents

surprisingly, it was only represented by 72% of parents. Raising typically developing children followed closely behind. The other main events were mentioned less frequently.

Other transitions parents discussed varied in seriousness; intensity tended to increase with parental age. For example, in their own growing-up years, parents mentioned playing school in the garage and hunting for frogs. Later, they experienced marriage, divorce, having children, losing jobs, and even serving in the Vietnam War. Transitions impacted parents in a variety of ways—physically, financially, emotionally, and spiritually. The range of control parents had over their transitions varied. For example, parents had control over graduating from college, but no control over the death of a loved one. There was minimal control over choices their children made. The only transition unique to this population was raising a child with ID. Otherwise, they struggled with transitions appearing to be similar to the general population.

Using the identified transitions, I created a health trajectory graph for each participant. Figure 4.4 contains the graphs of the parents of the children with Down syndrome and Figure 4.5 contains graphs of parents of children with other diagnoses. Health and well-being are plotted on the y axis, with time (birth to present) on the x axis. The mothers are on the left with corresponding fathers on the right. After detailed analysis of the cumulative narrative and graphic data from parents, I systematically organized each parent's life story into a timeline of events. Then I applied positive or negative valuations to those events using parents' own descriptions. I used my own judgment to determine the impact the transition had on parents' health and well-being and link the transitions together. As previously stated, these decisions were based on how the parents talked about them.

Based upon the graphs, there did not seem to be a prototypical example that emerged; however, some common elements and interesting points were noted. Four parents did not put the child with ID on their graphs; all were fathers. They were more concerned about their other sons and daughters and employment issues. Of those 14 who put the child with ID on their graph, 4 of them noted the child was the largest transition in their lives. For the mothers, if the child with ID was not the largest transition, it was difficulties with their other sons and daughters they struggled with most. Often siblings had mental illnesses or made poor choices, resulting in difficult consequences. For fathers, either employment issues or the siblings were larger transitions. This is most likely because fathers felt responsible for financially providing for their families, spent a lot of time at their jobs, and felt pressure when the situation was not going well.

There were also differences among the graphs depending on the child's diagnosis. Graphs for parents of children with Down syndrome and brain damage were similar. The

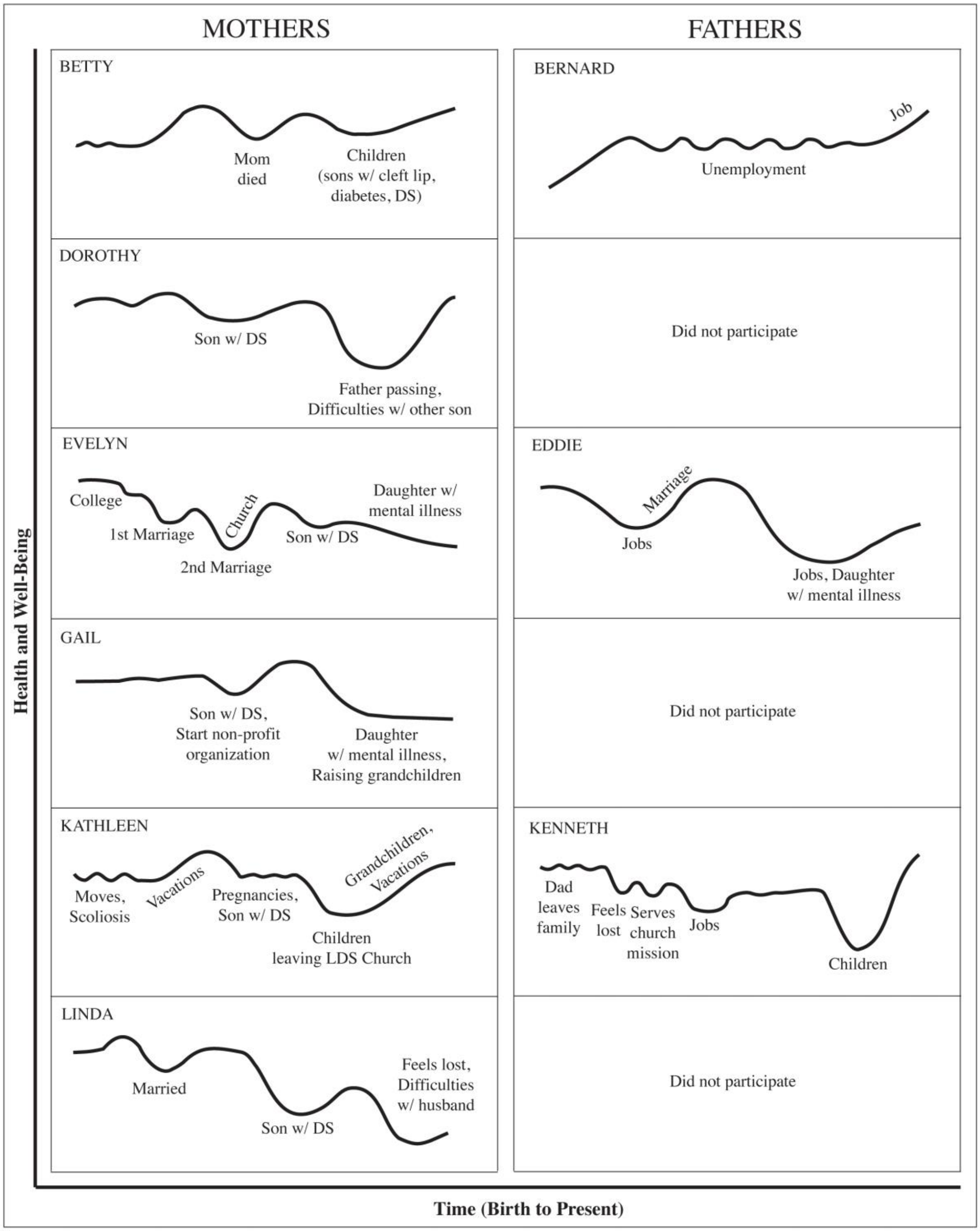


Figure 4.4 Health Trajectory Graphs: Parents of Children with Down syndrome (Ds)

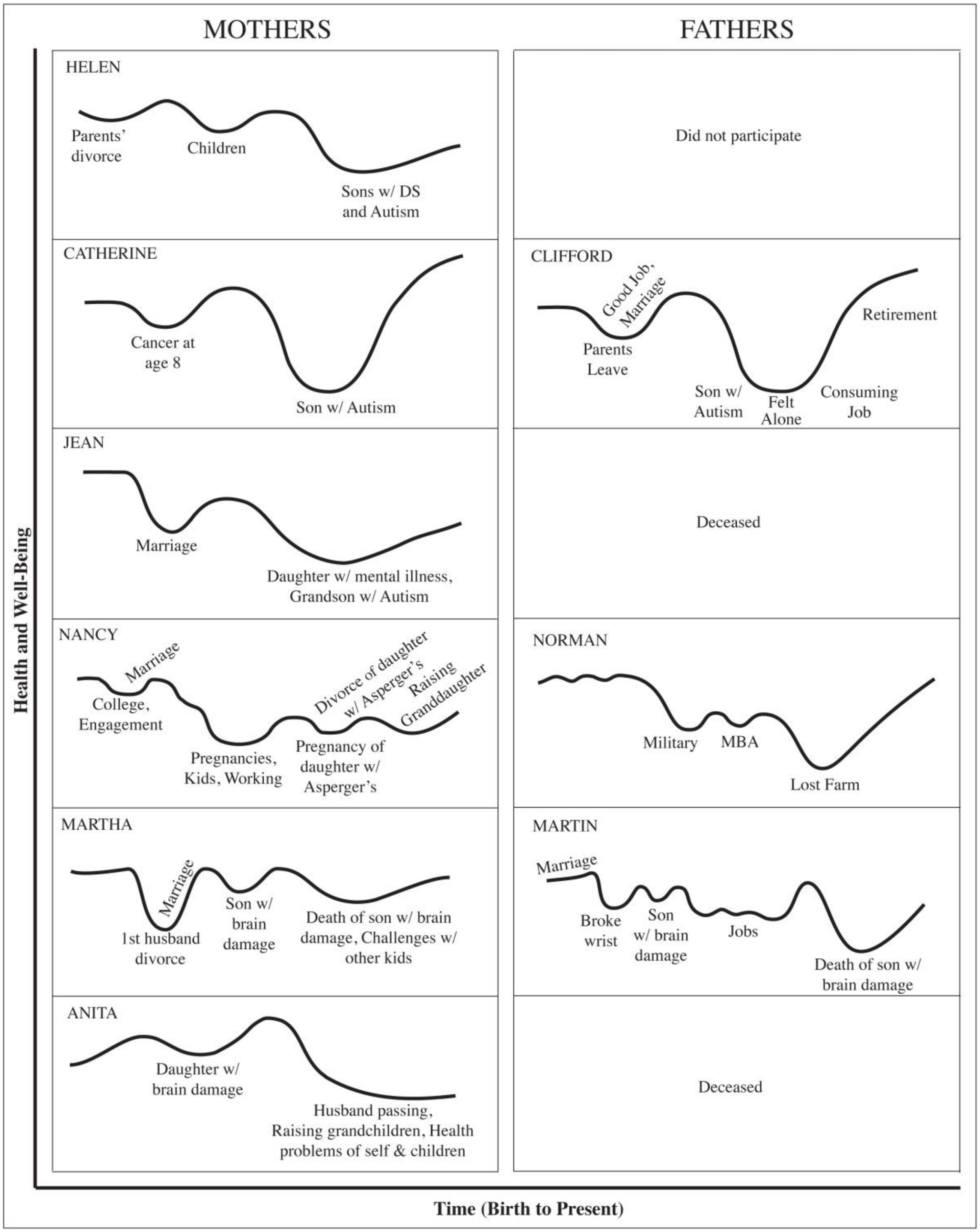


Figure 4.5 Health Trajectory Graphs: Parents of Children with Other Types of ID

transition related to the child with ID generally occurred in the middle of the graph, and was preceded and followed by other transitions. Most parents had other, much larger transitions after the transition of their child with ID. Of the 13 parents with children with Down syndrome or brain damage, Helen, the mother of 2 children with ID (one with ASD and the other with Down syndrome), was the only mother who described the child with Down syndrome as the biggest transition in her life, whereas all 4 participants raising children with ASD identified that situation as the biggest transition. It should be noted that Helen's largest transition included both her children with ID. Parents of children with ASD or Asperger's disorder placed the transition related to the child with ID later on, and it was generally one of the last transitions on the graph. Nancy had many ups and downs in her life, and several were related to her daughter with Asperger's disorder. Her husband did not put their daughter on his graph.

In general, once the children with ID were older and more independent, parents experienced fewer difficulties. Catherine, for example, spent a great deal of the interview time talking about her son and the dark time she experienced with him when he was younger. At age 7, he received the diagnosis of ASD and her world seemed to open up. She knew what she was dealing with and could handle it better. As he grew older and became more independent, she was able to do more for herself. To me, her narrative felt like the sun coming up after a stormy night.

The health trajectory graphs were helpful in visually portraying an overall picture of parents' transitions over their lives and put their experience of raising a child with ID into context. Most parents' health trajectory graphs were influenced to some degree by the transition of raising a child with ID, although the timing and effect varied.

Conclusion: Research Question # 2

This section described parents' narratives regarding research question #2 about the influence of raising a child with ID on their own health trajectories. Physically, the work of raising a child with ID did not appear to result in health ailments for parents, at least none they chose to narrate. There were relationships between the work of raising a child with ID and parents' health and health promotion activities, as well as their day-to-day hassles and worries. Almost half, however, described steps they were currently taking to improve their own physical health. Most parents talked about benefits to their social, emotional, and spiritual health gained from raising a child with ID. Emotionally, there were challenges, but also joys. Parents appreciated positive character attributes gained as a result of challenges encountered. Many marriages and families were strengthened as people worked together to raise the child. Parents described people they met and opportunities experienced as a direct result of their situation. Finally, spiritual health was either strengthened or provided strength for many but not all parents.

Health trajectory graphs visually depicted major transitions parents experienced throughout their lives. Graphs revealed that for some parents, raising a child with ID was the biggest life-changing event, and for others it was not. Four fathers did not even put the child with ID on their graphs. Depending on the diagnosis, transitions occurred at different places in parents' graphs; the diagnosis of Down syndrome and brain damage occurred earlier. All parents of children with ASD noted this situation was the largest transition they experienced. Difficulties decreased as children grew older and became more independent.

In summarizing both research questions, parents' narratives and health trajectory graphs together showed an overall theme of resilience. They described in their narratives sequential challenges in raising a child with ID, and throughout the process of parenting this child and carrying out their own lives, they struggled, adapted, and made positive life changes. Parents resiliently worked to provide for their children and also learned to step back and reflect on their lives and the situation. Their emotional, social, and spiritual health were benefited to some extent whereas their negative physical health conditions were not directly related to raising a child with ID. Resilience was demonstrated not only in the way parents met their unique constellation of individual challenges, but also in how they portrayed the experience overall, and the general positive slopes in their health trajectories graphs. The rebounds from setbacks portrayed their hardy, dogged, and patient responses to challenges they encountered in raising a child with ID.

CHAPTER 5

SUMMARY AND CONCLUSION

The purpose of this study was to describe how parents caring for children with mild to moderate ID narrate the transition of raising a child with ID, and to explain the influence the child had on parents' health trajectories. This chapter begins with a brief summary of study findings as they relate to current literature, more specifically family-based literature regarding children with disabilities and the effects of said disabilities on parents and parental resilience. Next, implications for the areas of health sciences education, healthcare practice, and health policy, as well as suggestions for future research are considered. The chapter concludes with a review of study strengths and limitations.

Discussion

The overarching theme of resilience summarizes parents' narratives about the transition of raising a child with ID and the influence that child has on their health trajectories. As described and defined in Chapters 2 and 4 of this study, resilience is the process of encountering challenges, adapting, and experiencing personal growth as a result. Parental narratives demonstrated various challenges that arose in the course of raising a child with ID and resilient actions taken to adapt. Each story was unique and had a main focus of one or two challenges. All parents demonstrated personal growth as they shared lessons they learned and personal and parental improvements made as a result of raising a child with ID.

This section begins by comparing and contrasting challenges, resilient behaviors, lessons learned, and health outcomes described by parents with similar studies. A comparison of this study with research similar in topic and participant population then allows unique contributions of this study to be apparent. Subsequently, theoretical perspectives about resilience are compared and contrasted with the dominant narrative theme from this research to refine the conceptual clarity of resilience as it applies to this particular population.

Challenges and Stressors Experienced by Parents of Children with ID

Several articles substantiate the fact that raising a child with ID is challenging and results in increased stress (Bekhet et al., 2012; Dillenburger & McKerr, 2011; Woodman, 2013), thus posing threats to parental health. In the literature review, a number of articles regarding stressors parents encounter as they raise their children with ID were cited. Table 5.1 lists challenges in the literature review and those found in the current study as they were presented in the study. A discussion comparing and contrasting the challenges follows.

In comparing challenges in Table 5.1, some overlap is apparent. To begin with, three challenges from the current study, namely caring for the child's health issues, facilitating attainment of early developmental milestones, and ensuring a good education for the child, could be considered increases in responsibilities and time for parents, the

Table 5.1. Challenges from Literature Review and Study Findings

Literature Review	Study Findings
Increased responsibilities	Discovering, receiving, and accepting my child's limitations and diagnosis of ID
Time burden	Caring for my child's health issues
Behavioral problems of children with ID	Managing behavioral issues
Transitioning to adulthood	Facilitating attainment of early developmental milestones
Unmet expectations	Ensuring a good education for my child
Stigma and stereotype	Increasing my child's autonomy
Finances	
Traveling with and without child with ID	

first challenge described in the literature review. Behavioral issues of children with ID are clearly a challenge described in the literature review and also found in the current study. Transitioning to adulthood and increasing child's autonomy, and unmet expectations and accepting a child's limitations and diagnosis are also common to both the literature review and this study.

The remaining three challenges from the literature review were either not mentioned or dealt with only minimally in the current study. Parents expressed some ideas about stigma and stereotypes of people with ID in the beginning when sharing their experience of having a child diagnosed with ID. However, once the initial shock wore off and they began making adjustments in their lives to accommodate their child with ID, the importance and influence of stigma was not central to their narratives. This could reflect the large amount of time passed since diagnosis giving them ample time to adjust. Only one parent described finances as a major challenge, and several others acknowledged financial difficulties, but discussed them in little detail. This was most likely a result of the demographics of the population. Only one couple mentioned the challenge of traveling with their son; he had physical disabilities.

In short, the central challenge of parents in this study was adapting to the stressors and difficulties of raising a child with ID. This study brings to light the unique parent-focused aspect of the experience that is only beginning to be found in the disability literature. Also, the literature presents a negative slant towards disability, whereas this study provides a more balanced perspective. The remainder of this section describes, compares, and contrasts the parental challenges in the current study with articles in the disability literature; both parent- and child-focused sources are cited.

Discovering, Receiving, and Accepting My Child's Limitations and Diagnosis of ID

A comparison among parents about their reactions to their child's limitations and diagnosis has not been commonly studied; therefore, this section focuses on parents' long-term acceptance and responses to the challenges and stressors of raising children with ID. Although the narratives did not incorporate the word "resilience," my narrative analysis identified this pattern across parents and situations. A concept similar to resilience is the ways parents cope or adapt. Problem-focused strategies of coping can be applied to the way most parents described their experiences raising children with ID in the first interview. The function of this type of coping strategy is "management of the problem that is causing distress" (Folkman, 1984, p. 844). As parents shared their experiences of raising the child with ID in the first interview, their main focus was on the child and strategies they used to help him or her. In general, parents sacrificed time and energy, demonstrated patience, persevered, and used creativity and ingenuity. Some examples from study findings include taking care of health concerns, observing and learning how to care for his or her specialized needs, preparing for change, teaching child, and helping child reach developmental milestones. Parents also learned what types of help they needed and how to get that help. For many, this included learning and exercising skills of advocacy.

Over varying amounts of time, parents learned to reflect back on their experiences, and see a different perspective of themselves and their child. They recognized and accepted their own personal strengths and limitations, but sometimes this meant making personal changes and adaptations. This was the beginning of emotion-focused coping used to regulate emotions or distress (Folkman, 1984). When asked specifically about coping strategies used in subsequent interviews, parents described these additional types of coping mechanisms for support. Examples from study findings of these types include spiritual beliefs, optimism, and humor. These are described in the section about the influence of the child on parents' health trajectories

Another study suggests parents of children with disabilities use a combination of problem- and emotion-focused coping (Kelso, French, & Fernandez, 2005), but problem-focused coping tends to be more prevalent (Glidden et al., 2006), especially among mothers (Essex, Seltzer, & Krauss, 1999). There is evidence parents use more problem-focused strategies of coping when the children are younger and more emotion-focused as they get older (Gray, 2006; Kim et al., 2003). The sample in the current study was composed of 67% older mothers (mean=65.8 years old) which could explain the greater tendency to use problem-focused coping. Although coping mechanisms were not directly studied, these parents described the same patterns of coping in their narratives as referred to in the literature. They tended to describe the use of problem-focused coping strategies in the younger years and emotion-focused in the later years.

Within the realm of problem-focused coping, parents employed similar techniques described in another study of parents of children with ID (Kelso et al., 2005). In studying older parent-carers of adults with ID in an Australian sample (*n*=64), Llewellyn, McConnell, Gething, Cant, and Kendig (2010) found the most helpful coping strategy, listed by 97% of the Australian sample, was "Relying on your own experience and the expertise you have built up" (p. 1182). Several parents mentioned this strategy; they learned how to work with their children's unique challenges and guide them along a course of reaching their potential. Another common strategy used by 83% of the Australian sample and many parents in the current study was "finding out as much information as you can about the problem" (p. 1183). This study confirms the similarities in problem-based and emotion-based coping strategies among these study participants with parents in other studies.

In contrast to study findings, Margalit and Ankonina (1991) and Margalit, Raviv, and Ankonina (1992) described parents of children with disabilities as using more avoidant methods of coping than parents of children without; no participant described themselves as using this method of coping in the present study. Rather, the parents narrated stories of actively managing the problems and challenges at hand and developing resilience in the process. Since no parent spoke of avoiding issues, the absence of this coping strategy may be related to the uniqueness of the participants sampled or their self-censoring stories that highlighted their avoidant coping methods. The next section describes some of the outcomes of parental resilience.

Caring for My Child's Health Issues

Parents described in detail issues their children with ID encountered with their health. These issues ranged in severity, duration, and impact, yet were among the most challenging. Although these concerns were not typically related to the ID diagnosis, they led parents to work hard, exercise patience, and acquire various skills. Even though parents provided little information about how they managed the issues and adapted to them; they used creativity, ingenuity, and humor. Fortunately, as most of the children grew older, their health improved and demands on their parents decreased; however, there were some children who continued to have health issues throughout their lives.

Similar to these participants, a few studies suggest caring for a child's health concern is a stressor for parents. For example, Jokinen and Brown (2005) found that the 15 older parents interviewed whose son or daughter with ID was over the age of 40 were concerned about the health of all family members, including their child with ID. Heiman (2002) found 87.5% of 32 parents in her study expressed concerns about their medical issues or extra stress when the son or daughter had a moderate to severe ID, a physical disability, or a learning disability. Chomicki and Wilgosh (1992) found a relationship between severity of ID and health concerns of the child; the preschool and school-aged children with more severe ID (n=25) had more health concerns than those of children of the same age with moderate ID (n=27).

Parents of children with ID should be concerned about their children's health. As a group, people with ID experience poorer health than the general population as a result of genetics, social circumstances, individual behaviors, and inadequate healthcare access (Krahn et al., 2006). Parents in the current study did talk about their children's health concerns, but mostly in reference to the child in his or her younger years.

This finding somewhat concurs with the literature, which suggests health issues are a concern for parents of children with ID, at least when the children are young. In this study, the more severe the health issues, the more parental narratives addressed stresses they experienced as they cared for the health condition and required care.

Managing Behavioral Issues

All parents described challenges they faced with the child's behaviors. The wide variety of behavioral issues ranged in frequency, duration, severity, and impact; however, behavior challenges were a major issue for at least 5 parents (3 children). Parents were in varying stages of learning to adapt to these challenges in their lives, and demonstrated acceptance, patience, perseverance, love, humor, and humility as they taught the children to behave in socially acceptable ways. Their narratives chronicled the process of learning how to work with and adapt to specific issues unfolding over time.

According to the Autism Spectrum Disorders—Behavior Problems for Adults (ASD-BPA) Scale, there are four main types of challenging behaviors exhibited by people with ASD; these could also be applied to the other children described in the study. They include aggression/destruction, stereotype, self-injurious behavior, and disruptive behavior (Matson & Rivet, 2007). The behaviors exhibited by participants' children involving law enforcement may be considered aggressive/destructive; however, the children were defending themselves and did not act out towards others. Most behaviors described by study participants could be described as disruptive. Specific examples parents mentioned included inappropriate sexual behavior, smearing or playing with feces, and leaving supervision of caregiver without permission (elopement). Other disruptive behaviors study participants described were doing the opposite of what is told, excessive collecting/hoarding, acting antisocial, stealing money, using copious amounts of toilet paper, and losing items.

The literature review describes negative impacts of challenging behavior on caregivers' physical and emotional health (Dyck et al., 1999; Gallagher et al., 2009; Mausbach et al., 2007; Pinquart & Sorensen, 2003). In addition, Schofield (2013) found the level of challenging behavior and parent's satisfaction with informal support were associated with parental quality of life.

Few studies examine the specific types of challenging behaviors exhibited by people with ID and how parents handle them. Hubert (2011) describes the perspectives of mothers caring for children with severe ID and challenging behaviors. Similar to parents in the study, her study parents said they used "determination and single-mindedness" (p. 220) in caring for their children. This study confirms the difficulties parents experience as a results of children's behavioral issues and the need to equip parents with the skills to work with children who have ID.

Facilitating Attainment of Early Developmental Milestones

All parent narratives reported the children were slow to reach developmental milestones; therefore, parents spent additional time and energy helping them reach their developmental potential. Some activities parents performed included learning all they could about the diagnosis, teaching and working with the child, and taking the child to therapies. All required patience, time, and sacrifice.

The challenge of teaching and helping a child with ID to reach early developmental milestones was not specifically described in the literature. However, as children with ID age, the stress and demands of caring for them decreases (Bekhet et al., 2012). This trend in the literature could partially be associated with a reduced need for parents to be as hands-on with teaching and helping their older children with ID. In the early years, parents focus on helping their children reach early developmental milestones such as eating, crawling, walking, using the potty, and dressing. In later years, the focus shifted to independent living skills such as establishing suitable employment, managing money, shopping, cooking, and developing talents. Similarly, parents in the current study were not nearly as involved in teaching and caring for their children now as they were when younger.

Literature about the benefits of involving parents in early intervention programs for children and parents is prevalent. Davis and Gavidia-Payne (2009), for example, found that in 64 families of children with ID between the ages of 3 and 5 years old enrolled in an early childhood intervention program, family-centered professional support was one of the biggest predictors of family quality of life. In a meta-analysis, Roberts and Kaiser (2011) found parent-implemented language interventions for children between 18 and 60 months of age with primary and secondary language impairments to be effective.

These parental narratives highlight the willingness and eagerness of parents to participate in early intervention programs and therapies benefiting growth and development. Despite their utility, however, these additional activities brought some complications to parents' lives such as time and scheduling burdens. Parents are desirous for help, but their concerns need to be considered when implementing these programs. Allowing parents to evaluate programs and provide input may be helpful.

Ensuring a Good Education for My Child

All children with ID attended public school for most of their education. Most parents were pleased with this education; however, there were a few parents who needed to advocate strongly for their children in order for them to be involved in certain programs and receive appropriate care. Advocacy became an important skill for some parents; it was challenging and required confidence in standing up for what one believed was right, as well as persistence, communication skills, determination, and effort. Knowing the school system and their rights as parents of children with ID were helpful. It was not an easy journey, but what needed to be done.

Similar to the parent narratives included in this study, Burke and Hodapp (2014) found being an advocate was stressful for parents and required sophistication about education structures and processes. The mothers of students with IDD (*n*=965) in their study who reported better parent-school relationships and engaged in less advocacy experienced lower levels of stress. According to Allen and Hudd (1987), advocacy "requires considerable technical knowledge of available services, familiarity with statues and laws, and the ability to exercise sophisticated strategies of influence" (p. 134). It "connotes an assertive confrontational style" (p. 134), which is foreign to some parents and demands a "great deal of time" (p. 134).

Parent narratives included in the current study confirm the parental experience of devoting increased time and experiencing some stress as part of advocating for their child with ID and working with schools to ensure a good education for him or her. The articles cited in the literature focused on concerns that parents are required to take on too many additional responsibilities related to advocacy, resulting in added stress. Conversely, advocacy in the current study focused on some challenges parents faced, but concluded with the positive results experienced. Also, parents who were skilled in advocacy mostly described their experiences.

Increasing My Child's Autonomy

Some parents grappled with decisions about how much autonomy was appropriate for their child with ID. Autonomy was mostly related to the child's ability to care for him or herself. Transitioning from caring for every need to allowing the child to take care of themselves was a big change for parents and children. It involved recognizing the child's capabilities, trial and error, risk taking, ingenuity, possibly trusted outside influences, courage, humility, and patience. For some parents, increasing responsibilities also brought into question the issue of allowing their child to live independently. There was a great deal of fear and hesitation surrounding this issue, as parents had a strong desire to protect their children. The majority of the parents in the study were still in the process of figuring out how much the child was capable of doing and how to encourage them to be independent. Many issues encountered by study participants and their children are also described in the literature.

The discussion about transitioning into adulthood found in the literature review began with a study by Schneider, Wedgewood, Llewellyn, and McConnell (2006), who suggested that as the children grew physically larger, they would be more difficult for parents to handle. Size, however, did not pose problems for parents in the current study, as the children were not dependent on parents to provide physical care. A similarity to this article that parents did describe was that their children wanted to do what their peers were doing—have boyfriends/girlfriends, get married, go to college, and have children. Another point the literature review made was the struggle to keep children engaged in meaningful activities post high school. Only a few parents mentioned difficulties in this area; most children had a routine of activities that included some type of employment or day program outside of the home. One couple faced the increased stress of helping to raise a granddaughter born to their daughter with ID. This additional responsibility and stress was described by Weiber, Berglund, Tengland, and Eklund (2011). Similar to the study by Bianco, Garrison-Wade, Tobin, and Lehmann (2009), parents struggled with increasing their child's responsibilities and freedoms yet also assuring the child's health and safety.

As described by parents, facilitating the transition to adulthood and helping their child achieve an attainable degree of autonomy was mainly about the day-to-day responsibilities of living. Parents encouraged the child to take on more responsibilities related to their own self-care, and these narratives focused on the level of care they were providing, questions about how much the children were capable of doing, and how to encourage them to do more.

Arellano and Peralta (2013) suggested parents may have some confusion between autonomy, defined as self-sufficiency, and self-determination defined as "seeing [children with ID] as individuals with rights, strengths and need for support" (p. 180).

Using their terms, parents tend to believe they are helping the child develop self-determination when in actuality they are focusing on autonomy. This appears to be the case with the parents in the study as they focused mainly on how to help the child become more independent by taking on increased responsibilities of everyday living.

In their article, Arellano and Peralta (2013) examined parents' (*n*=201) perspectives of self-determination. Using a Likert-type scale, the authors reported the parents strongly agreed or agreed to the following statements. They found the parents were "open to the idea of self-determination" (p. 179) and most (88%) believed their child should "achieve the greatest possible independence and autonomy" (p. 177); yet 57% believed "people with disabilities need constant supervision" (p. 177) and 46% of the parents believed their role was to "decide what is best for their children" (p. 177). They (44% and 40%, respectively) doubted their children "should make their own decisions" (p. 177) or "choose their own goals" (p. 177). Parents struggled to promote self-awareness and self-esteem. Their children had few household chores and the parents found "it challenging to encourage contact between their children and other people" (p. 178). Parents protected their children by presenting them with easy goals to avoid frustration and failure.

This study highlights how parents support the idea of self-determination among children with ID and believe to some degree they are successful at it, but in actual practice continue to strongly desire to control and protect them. The Arellano and Peralta (2013) findings mirrored fairly closely current study findings. Parents wanted their children to be as independent as possible, but at the same time wanted to maintain control over their lives, especially in social situations and situations of sexual or interpersonal intimacy. They continued to make many decisions for their children and did not expect a lot from them in doing household chores. Many parents did, however, support the children in developing work skills and personal talents.

The definition of autonomy by Wehmeyer, Kelchner, and Richards (1996) is similar to Arellano and Peralta's (2013) definition of self-determination. Wehmeyer, Kelchner, and Richards defined autonomy as a person acting "according to [their] own preferences, interests, and/or abilities and independently, free from undue external influence or interference" (p. 632). This type of autonomy is fostered through providing people with ID more freedom to make choices on their own. However, according to van Hooren, Widdershoven, van den Borne, and Curfs (2002), who studied parents and professional caregivers (*n*=37) of people with Prader-Willi syndrome (*n*=18), completely leaving choices up to the individual is met with resistance by caregivers. Instead, they reported many found forms of interaction in which they could foster autonomy by self-understanding, self-development, and self-realization. The alternative forms of interactions performed by these study parents could be beneficial to parents interested in fostering autonomy among their children. Instead of focusing solely on increasing the child's responsibilities, they could focus on the child's personal development.

Achieving autonomy for children with ID is not solely a topic of parental narratives, but is also a priority for people with ID themselves. Similar to findings in the current study, Mill, Mayes, and McConnell (2010) highlighted different levels of desire for personal autonomy by people with ID. By respecting autonomy and allowing children with ID to make their own choices, parents grapple with the responsibility to ensure the "safety, health and welfare of their children" (Almack, Clegg, & Murphy, 2009, p. 296).

The few parents in the current study who discussed the issue of the child living in an independent setting expressed similar fears, validating these previous studies. Almack, Clegg, and Murphy (2009) described the most common concerns about autonomy parents of 28 young adults with severe ID expressed. They worried about the risk of harm through accidents or various types of abuse, similar concerns of these study participants. In assisting parents to encourage autonomy, these concerns need to be addressed and resolved.

Interestingly, study participants mentioned little about their child's autonomy as it related to intimate relationships and sexuality, a topic of interest in the literature. In the section about reaccepting ID, parents shared their children's desires for intimate relationships and marriage; however, most parents had no intention of ever allowing their son or daughter to marry or have a serious relationship with anyone of the opposite sex. This finding is most likely related to the generation of these parents and also the strong religious background of many participants. Sexuality is not a topic openly discussed by this generation, and sexual relations outside of marriage are generally not condoned. This finding is similar to observations in a study by Foley (2013) who explored issues of social life and sexuality among 10 parents of adult children with Down syndrome living in Ireland. The parents in Foley's study believed their adult children were independent in many ways, but questioned their children's abilities to navigate the terrain of sexuality and relationships. Furthermore, this study took place in Utah, a socially, politically, and religiously conservative state.

The development of autonomy is a continuing part of the parents' narratives yet to be finished. It may increase in poignancy as parents age and see that their control is going to give way at some point. Parents want their child to act autonomously, meaning they would like them to take on more responsibility for their own day-to-day care, but struggle in making it happen for various reasons such as fear, lack of knowledge, and the child's resistance. They want to continue protecting their child and caring for his or her needs, and at the same time want to encourage him or her to do more. Parents were fairly closed about the idea of allowing more autonomy in regards to intimate relationships, sexuality, and even living in an independent setting. Making parents aware of this dichotomy, helping them resolve their concerns, and teaching them skills to foster autonomy and self-determination in the children could be empowering to parents and help the children to come closer to reaching their potential.

Best Parts about Raising My Child with ID

In addition to challenges, a subsequent narrative theme parents in the current study described was the positive aspects of raising children with ID. In particular, they addressed the positive qualities the child possessed, accomplishments achieved in spite of having a disability, opportunities they and their families received because of their child, influence the child had in shaping and refining parents' characters, and how important their child with ID was as a family member. Despite the challenges of raising children with ID, there is increasing evidence of strength and resilience among these families (Bayat, 2007; Hastings & Taunt, 2002).

Other authors found parents to have similar positive insights. For example, Hastings and Taunt (2002) performed a review of research on families' positive perceptions of raising a child with ID. Using a sample of five research studies, they created a summary of 14 key themes about parents' positive perceptions consistent with other studies. See Table 5.1. For example, Greer, Grey, and McClean (2006) found parents experienced "personal growth, happiness and fulfillment and increased family closeness" as they raised their children with ID. In another study, Scorgie and Sobsey (2000) reported results about personal, relational, and perspectival transformations or changes parents made as they raised the children with disabilities. Parents in the current study said they were more compassionate and confident, spoke out with more frequency, met other people/friends, and learned what is important in life. Current study findings confirm these findings of the best parts of raising children with ID.

A few studies examined characteristics parents develop as a result of this experience. For example, Schwartz (2003) studied the sense of gratification parents experience as they work with their children with ID. Girad (2011) examined character strengths parents developed as a result of caregiving, and noted they had:

Table 5.1 Key Themes about Parents' Positive Perceptions
(Hastings & Taunt, 2002)

1. Pleasure/satisfaction in providing care for the child
2. Child is a source of joy/happiness
3. Sense of accomplishment in having done one's best for the child
4. Sharing love with the child
5. Child provides a challenge or opportunity to learn and develop
6. Strengthened family and/or marriage
7. Gives a new or increased sense of purpose in life
8. Has led to the development of new skills, abilities, or new career opportunities
9. Become a better person (more compassionate, less selfish, more tolerant)
10. Increased personal strength or confidence
11. Expanded social and community networks
12. Increased spirituality
13. Changed one's perspective on life (e.g., clarified what is important in life, more aware of the future)
14. Making the most of each day, living life at a slower pace

optimism, patience, humor, love, perception, equality, previous experience, education, support, spirituality, positive self-esteem, advocacy, compassion, gratitude, curiosity, coping skills, values, grieving, acceptance, interest, deflection, perseverance, rationalization, isolation, communication, faith, hope, intuition, reflection, repression, sympathy, depersonalization, intellectualization, empathy, intellect, sublimation, and wisdom. Many participants displayed similar strengths. For example, faith and hope provided strength for some parents during difficult times. In addition, many parents described being isolated at times, especially when other people did not understand their situation. Some mothers mentioned being guided by intuition as they cared for their child with ID. A few parents learned to see the value and worth of others from their child with ID. Their perceptions of what was important in life changed, and they were grateful for lessons learned, even if challenging.

In conclusion, the accumulated emerging literature on parenting children with ID achieves consensus about the best parts about raising these children. Parents here did share stories of personal growth, change, and transformation for the better while raising the child with ID. Despite challenges, they expressed gratitude for their experiences.

Influence of Child on Parents’ Health Trajectories

With the exception of physical health, which was not influenced directly by raising a child with ID, study findings described benefits parents experienced in all aspects of their health. Data from the second research question about each aspect of health describe resilience and compare these data with current literature.

Physical Health

The parental narratives typically demonstrated a dissociation in parents' minds of their child with ID and any health consequences. Many parents stated they could not "blame" a specific health problem on the child with ID, and their health problems occurred before the child's birth or a result of their own actions. These findings are consistent with studies claiming the health of parents of children with ID is similar to the general population (Chen, Ryan-Henry, Heller, & Chen, 2001; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001) and in contrast with those claiming their health is worse (Seltzer et al., 2011; Yamaki, Hsieh, & Heller, 2009). However, conclusive evidence of objective health and its causation was not possible with such a small sample size in this study, no comparison group, and no objective measures of health. See Chapter 2 for descriptions of the limited number of studies about the physical health of aging parents of children with ID.

Emotional Health

A little less than half the parents in the present study said they were emotionally stable throughout their lifetime with occasional situational ups and downs. With the exception of Jean, who was emotionally distressed at the time of the interview, parents did not seem to be especially depressed, have a negative affect, or experience poor psychological well-being as other authors (Ha et al., 2008; Seltzer et al., 2011) found. All expressed feelings of worry, concern, or stress related to raising the child with ID as many studies have demonstrated (Dyson, 1996; Gallagher et al., 2009). As previously mentioned, despite the difficulties, all parents shared positive aspects about their experience. Similar to the previous section on physical health, without a comparison group, I could not state that the emotional health of these parents was different than other populations.

One mother clearly described chronic sorrow in her life, substantiating the literature on this topic (Eakes et al., 1998; Rossheim & McAdams, 2010). Others may have had similar experiences but did not describe it to the same extent. Some parents said they were sad because the child was not able to do what other children could do, or would not have the same experiences as others. They did not say when those feelings surfaced or if certain events would trigger them. It is important to note each parents' experience is unique. Not all parents expressed sadness about the child and when they did, it occurred at varying times throughout the child's life. The narrative deviation from one of chronic sorrow to one of intermittent sadness calls into question the chronicity of chronic sorrow. Perhaps in later years, parents come to a place of narrative equipoise in their representations of sorrow and joy, with more experiences over time with their child giving rise to more complex narratives.

Social Health

In the current study, most parents' narratives portrayed improved social relationships as a result of raising a child with ID. Most said their marriages and/or families were strengthened, and the children without ID were loving towards the child with ID. Some parents, however, did say one or more of their offspring without ID struggled because of the child with ID. Over half the parents said they met more people as a result of their child with ID. In contrast, some parents mentioned their relationships were limited because of the constant responsibility of care. However, parents learned to adapt and accommodate to the situation.

The literature about marriage and family relationships is mixed; some studies show positive results and others negative. Despite the relationship challenges, parental narratives support the research that couples generally grow closer to one another when raising a child with ID (Hock, Timm, & Ramisch, 2012; Stainton & Besser, 1998; Taanila, Kokkonen, & Järvelin, 1996) and siblings can benefit from the experience (Davys, Mitchell, & Haigh, 2011; Stoneman, 2005). For example, Hock (2012) described the marriage relationship of parents of children with ASD as a crucible or an “extraordinary trial and test of the couple relationship” (p. 409). Many parents here said their relationships were not easy, and took a lot of work and determination. The literature also supports the idea that parents develop more relationships as a result of the experience (Stainton & Besser, 1998).

Little is known about challenges of help-seeking, especially informal help-seeking, among parents of children with ID. Parental narratives in the current study described some parents who struggled to ask for and receive help from others, especially those outside their immediate families. They did not feel comfortable asking, did not want to burden others, or felt caring for their child was completely their own, personal responsibility. Two mothers did not feel comfortable with respite services available. However, after years of relying on their own efforts, some parents realized the value of asking for and receiving help from others. Others learned what level of help they felt comfortable with.

Douma, Dekker, De Ruiter, Verhulst, and Koot (2006) studied the steps of help-seeking behaviors among parents of children with borderline to moderate ID. They found only half of parents (*n*=213) who perceived problems with their children sought professional help. Parents were more likely to seek help when other stressors existed that may have lowered the "threshold to perceiving problems in their child" (p. 1239) such as the problem had persisted for over a year, additional problems were co-occurring in or with their child, certain parental characteristics existed, or there was deviant family functioning. Barriers to asking for help included parents' evaluation of the severity of the problems, not knowing where to get help, and "a desire to handle the problem themselves" (p. 1240). The authors concluded that many more parents could use help than actually asked for and received help.

Findings from the current study are congruent with those of Douma and colleagues (2006). Some parents described needing more help than they were receiving, but did not ask others for help for reasons similar to those reported by Douma and colleagues. Primarily, narratives highlighted parents' desires and sense of duty to take care of their children with ID on their own without burdening others. As their children grew older, some parents were more open to receiving additional help, possibly because they realized they could not do it alone or because they were more connected with resources. Understanding barriers to help-seeking can assist healthcare professionals in knowing how to better support parents in this area.

Spiritual Health

Spirituality was found to be beneficial to almost all participants. About half described methods used to strengthen their own spirituality such as reading scriptures, attending church, and praying. A few parents said their spiritual knowledge helped them raise the child with ID. They believed the child was special, a gift from God, and would be perfect in the next life. They tried to emulate positive qualities of the child. However, some mothers mentioned difficulties they faced with their spirituality; these were related to husbands who had different beliefs, the passing of their own mother, and a disruptive offspring.

Most participants were LDS; their comments about spirituality were similar to those found by Marshall, Olsen, Mandleco, Dyches, Allred, and Sansom (2003), who explored themes of spiritual belief and religious support among LDS families caring for children with developmental disabilities. Their core theme was “This Is a Spiritual Experience,” which described the up-and-down journey of parents “toward a transcendent sense of a unique perspective, …an ’exceptional’ way of life that was perceived as spiritual” (p. 63). The core category, “We have a different perspective,” explained how parents believed their religious beliefs were unique from other faiths, and were useful in raising children with disabilities. Some LDS parents here described the same beliefs and unique perspectives these beliefs brought into their lives. Those not LDS did not talk about this unique spiritual perspective regarding their offspring. The Lutheran couple focused on how their faith, hope, and support from members of the congregation helped them through the difficult times.

A few other authors studied spirituality among families and parents of children with disabilities. For example, in a qualitative study, Poston and Turnbull (2004) asked 187 parents of children with disabilities about the role of spirituality in family quality of life. Participants spoke about the importance of having spiritual beliefs—having faith, using prayer, attributing meaning to disability—and involvement in religious communities. The same themes surfaced here. Some parents said they relied on faith, meaning they had hope and trust in a higher power. A few mentioned the importance of regularly performing spiritual activities, such as reading scriptures, attending church, serving in church, and praying. Some participants used spiritual beliefs to provide meaning to their experiences.

A recent study by Ault, Collins, and Carter (2013) examined religious participation among 416 parents and their children with ID. Of these parents, 97.6% rated faith as important; this is higher than in the current study most likely because of the small sample size here. Attending religious services was the most frequent religious activity for the Ault et al. participants followed by religious education, small group discussions, and volunteer work. A few parents here mentioned attending church and giving service, but spoke more frequently about their own personal faith and relationship with God. Many parents in the Ault et al. study did not find a high degree of support in including their son or daughter with disability in places of worship. However, resources for assisting people with disabilities in faith-based communities are becoming more prevalent (Carter, 2007). On the other hand, only one couple here said they did not attend church for the first 10 years of their son's life because he was too disruptive. No other parent mentioned difficulties at church with their son or daughter with ID or a lack of support from their congregation.

An older study by Stainton and Besser (1998) found increased spirituality was one of nine themes used to describe the positive impact of raising a child with ID in the family. Responses for this theme were derived from only 4 of 15 participants, so authors suggested spirituality was not as frequent a response in the Stainton and Besser study as previous authors thought. The current study, however, affirms spirituality as an important resource for several parents and one means of creating meaning from the experience.

Health Trajectory Graphs

This study used health trajectory graphs to visually depict transitions in parents' overall lives. These graphs do not appear to have previously been used with parents of children with ID. The literature describes a variety of stressors in parents' lives and such stressors' influence on parental health (McKeever, 1999; Seltzer et al., 2011; Yantzi et al., 2007); however, it does not show the stressors across the lifespan or compare stressors to one another. This study's lifespan perspective shows the gradual transformation that takes place in parents' health trajectories following various challenges in their lives.

The overall story parents described here confirms Grant, Nolan, and Keady's (2003) findings. Their study mapped the lives of parents of children with ID in six caregiving stages. The first and second stages include preparing for caregiving responsibilities and becoming aware of the disability; these stages coincide with the beginning of these parents' story when the children were diagnosed with ID. Stages 3 and 4 deal with acceptance of realities of the disability and attempts to adapt to it. This is when parents became heavily involved in caring for the son or daughter with ID. The authors explained that as parents conclude stage 4 and enter into the final stages, they often observe more of a reciprocal relationship with the child, as well as a "heightened sense of caregiving enrichment" (p. 348). The final stages are reaching the end and a new beginning. The end could be death or the point at which the son or daughter moves out of the parents' home. The new beginning is when parents no longer have full responsibility for their children. Parents in this study were generally in stage 5, nearing the end of their caregiving responsibilities. They were mostly gratified by their relationships with their offspring.

In addition to providing confirming evidence of this model by mirroring the stages, the present study adds some rationale as to why parents experience greater caregiving enrichment towards the end of their experience. By stage 5, parents have struggled and worked through many challenges related to the son or daughter with ID. They have accepted the child's limitations and diagnosis, cared for health concerns, managed behavioral issues, helped the child achieve developmental milestones and experience educational opportunities in order to optimize the child's strengths, and helped them become increasingly autonomous. Parents figured out what works for them, and as they struggle and adapt to raising a child with ID, are transformed and can see the value of their experience.

Integrating Findings with Resilience Theory

A theme of resilience ran throughout the narratives parents told about their experiences raising children with ID. Parents described challenges or risk factors threatening their physical and emotional health, and personal actions taken to improve the situation. Parents used the protective factors to counter the risk factors. In order to adapt to challenges of raising a son or daughter with ID, parents performed various actions. As they adapted, parents learned lessons and gained useful skills throughout their lives.

In relating the current study with the resilience literature, the parents here experienced challenges or disruptions in their lives as they raised children with ID. Each challenge disrupted parents' lives. However, these parents adjusted to raising a child with ID. As Eakes et al. (1998) suggested, many parents experienced feelings of different degrees of grief upon learning of the diagnosis. They struggled and learned how to work with the son or daughter. They used problem-solving skills and taught their children, ultimately promoting personhood, potential, and autonomy. As they adapted to and managed challenges, they used their own gifts and strengths, and also developed new qualities and skills helping them grow stronger. These included the resilient behaviors I described as the parents adapted to the challenges with which they were presented. According to Windle (2011), they accessed individual assets and resources in their lives and environment that facilitated the "capacity for adaption and 'bouncing back' in the face of adversity" (p. 163). As a whole, parents mainly described the outcomes of raising a child with ID as resilient reintegration as evidenced by lessons learned and growth experienced.

Conclusion

The findings discussed in this section are generally consistent with those cited in the literature review comprising Chapter 2. The findings also expand knowledge about resilience as it relates to the experience of raising a child with ID, and transition and health trajectory research about a population rarely studied. Overall, this study confirms the high levels of stress parents experience, as described in Chapter 2. Many challenges were similar to those described in the literature with the exception of facilitating developmental milestones attainment. There was little information on this topic outside the importance and benefits of involving parents in early intervention programs. These study findings highlight the willingness and eagerness of parents to participate in early intervention programs and therapies that benefit their children’s growth and development. The findings also emphasize the importance of taking into consideration the additional burdens these programs can place on parents as they seek to balance these many responsibilities. This information can assist providers in developing programs and therapies to assist children with ID and their parents.

Other study contributions helpful in supporting parents to adapt to their situation include additional information concerning a timeframe for accepting the diagnosis of ID, resilient behaviors parents demonstrated, and the results of adapting to challenges inherent in raising a son or daughter with ID. Parents initially accepted the diagnosis rather quickly, and then often revisited the issue a decade or 2 later when the child asked them questions. Study findings also added rationale as to why parents experience greater caregiving enrichment after years of experience. As parents adapted to challenges encountered along their journey, they took an action-oriented approach. They also exhibited patience, sacrifice, persistence, courage, humility, ingenuity, and humor. As a result, they were transformed and could see the value of their experience.

Methodologically, parents’ individual and collective health trajectory graphs were valuable instruments in obtaining an amplified vision of their overall health. In addition, the graphs could be used to guide assessment and evaluation, prepare parents for future challenges, provide timely and appropriate interventions and resources, and better support parents through the overall experience. Health trajectories of parents who experienced the situation can be used to help prepare new parents for parenting their son or daughter with ID. As resilience fluctuates over time with life changes (Windle, 2011), health trajectory graphs provide visual images of the types of transitions that occur in parents' lives and their impact on parents' overall life and health. These graphs can be especially informative in assisting and supporting individual parents when co-created with the parents themselves.

Using a combination of resilient concepts was helpful in describing and understanding study findings. One of the most valuable and important lessons learned, assisting providers in supporting parents through the experience, is to solicit parents' unique and individual experiences in raising children with ID. Then, providers can aid parents in interpreting their own health trajectories in light of known challenges and widely variable patterns of recovery and resilience.

Implications for Practice and Policy

The knowledge gleaned in this study may be used to assist providers and policy makers help similar parents adapt to challenges or risks faced as they raise children with ID. Reducing risk factors and strengthening protective factors increases resilience. This section outlines ideas for improving practice and policy as it relates to these two areas.

Reduce Risk Factors

Rutter (1999) suggested reducing overall risks is helpful in preventing damaging effects resulting from the risk at hand. Risk factors are defined by Bekhet et al. (2012) as "factors that predispose people to physical and mental health problems because they affect how a person adapts to stress" (p. 651). This section provides suggestions for preparing parents of children with ID and helping them to adapt to the seven challenges or risk factors described by the parents in this study in order to preserve or improve their own health.

Discovering, Receiving, and Accepting My Child's Limitations and Diagnosis of ID

According to study findings, the process of accepting the son's or daughter's limitations and diagnosis begins shortly after symptoms are recognized; however, ideas about the realities of people with ID are formed in parents' minds long before the child is ever conceived. Many misconceptions about people with ID exist today. A recent article in the Opinion Pages of the New York Times (Edgin & Fernandez, 2014) discussed a comment made by a well-known biologist who recommended aborting a child with Down syndrome to reduce family and child suffering. The article noted some challenges of raising a son or daughter with Down syndrome and also shared results of recent research studies about positive aspects of the situation. Therefore, I recommend making community-wide efforts to educate people of all ages about the realities of family life with a child with ID and what parents should expect. Rather than relying solely on "expert" assumptions about dismal outcomes for parents and children with ID, sharing narratives of parents themselves is another form of expert guidance available to prospective parents of children with ID.

The key to raising awareness is increasing the visibility of people with disabilities, their families, and available resources. This could be done, for example, in a school setting where children without disabilities are taught to respect people with disabilities, recognize their gifts and talents, tolerate differences and diversity, and skillfully interact with others across cognitive capacity differences. Such an inclusive environment is aligned with the mainstreaming movement in education. Also, more programs designed to help people with disabilities and their caregivers write their personal stories and share them with the public could be available through public libraries and writers' groups. The act of expressing such stories not only provides support to other families, and challenges current belief systems about the pitiable plight of people with ID and their families (Edgin & Fernandez, 2014), but can also foster resilience among the tellers of the stories (Wild, Wiles, & Allen, 2013). Moreover, the stories would give voice to parents, allowing them to learn about the positive and negative aspects of raising a son or daughter with ID.

Knowledge about the realities of people with ID is especially important for women who are pregnant or planning to become pregnant. Knowing the realities of people with ID, especially when obtained from people with personal experience, could help provide balanced information about raising a child with ID and help parents make informed decisions if genetic testing alerts them to a particular risk.

Once signs or symptoms of ID are recognized–either prenatally or after birth–an accurate and early diagnosis needs to be made to avoid unnecessary stress and keep parents on a pathway of obtaining necessary information, support, and services. The way providers interact with parents concerning the diagnosis is vital and sets the tone for parents' experience. Skotko, Capone, and Kishnani (2009) performed a literature review about best practices of delivering the postnatal diagnosis of Down syndrome to parents; similar guidelines could be used with other diagnoses of ID. They recommend a person who is knowledgeable about the condition—usually the obstetrician, pediatrician, or both—should deliver the news, and do so “as soon as possible even when the diagnosis is not confirmed” (p. 754). The information should ideally be delivered in a private place with the mother, father, and possibly the infant present. During the visit, parents prefer information that is complete, accurate, balanced, realistic, and contemporary. Discussion of medical conditions should be limited to those most immediate or common. An up-to-date bibliography of references should be given, and arrangements for follow-up appointments made.

As part of the information provided in this initial meeting, I would recommend providers give information about services and support networks available to parents, as connecting parents with needed formal and informal support is crucial. Boström and colleagues (2010) suggest connecting parents of children newly diagnosed with ID with peers who have been through similar experiences helps “to diminish the sense of estrangement and gradually [accept] the special circumstances of their lives” (p. 99).

With a greater understanding of the lifetime trajectory of people with ID and the variety of their parents’ experiences, providers can amplify parents’ vision of their son’s or daughter’s potential for growth and quality of life, as well as their own.

Caring for My Child’s Health Concerns

The next challenge, caring for the child’s health concerns, focuses on supporting parents and ensuring the child with ID receives high-quality healthcare throughout his or her lifetime in order to enjoy good overall health. Chomicki and Wilgosh (1992) recommended providing more training to providers related to the specific healthcare needs of people with ID. This training should include best practices in working with parents to support them as they care for their son or daughter's health concerns.

In support of this focus, Krahn and Drum (2007) created a policy framework using principles from two Surgeon General reports, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* and *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*, and combines them with the Objectives from Chapter 6 of Healthy People 2010. This framework guided a review of recent U.S. literature on access to primary healthcare for persons with IDD. The authors recommended increasing attention in the area of health promotion with a special focus on holistic health. This "will require improvements in surveillance and measurement" (p. 166), increased participation of people with IDD in development and implementation of research, development of training programs in the care of people with IDD for providers across disciplines, and more and improved community-based care. Finally, healthcare needs to be affordable for people with IDD and their families.

Managing Behavioral Issues

Next, in order to assist parents in managing their son's or daughter's behavioral issues, high-quality interventions targeting behavioral problems need to be implemented at an early age and consistently available as the children grow older. The disability literature includes information about and evaluations of various types of interventions for parents working with children with ID. Some examples include modified motivational interviewing (Frielink & Embregts, 2013) and parent training programs in individual, group, and computer settings (Brophy, 2012; Hames & Rollings, 2009; Hudson et al., 2003; Shaughnessy, 2009). Continued support in managing behavioral problems needs to be available for parents as long as necessary.

Facilitating Attainment of Early Developmental Milestone

Connecting parents quickly with helpful information and resources is an important start in aiding parents in facilitating early developmental milestone attainment. This should happen at the time of diagnosis and continue throughout the child's life. Using a family-centered approach (Davis & Gavidia-Payne, 2009), providers should help parents develop a lifetime and holistic perspective about raising a child with ID as they pass through a number of phases. The first years of caring for children, especially those with ID, are the most time and energy intensive. Parents should not be made to feel they must care for their son or daughter stoically and alone. Education and counseling related to supporting and caring for a child with ID–as well as referrals to relevant therapies–should be made as indicated. Early intervention programs are extremely beneficial for children with ID (Guralnick, 2005). Providers should listen to parents' concerns and involve them as much as possible in their son's or daughter's care.

Ensuring a Good Education for My Child

The first step to support parents in ensuring that their son or daughter with ID receive a good education is for providers to foster strong relationships, allowing a forum in which they can communicate about the child's school experience. Some helpful supports for parents as they advocate for their sons or daughters may include helping parents identify what they want, providing information about the rights of people with ID and their parents, giving insight about what can and should be expected in the school setting, teaching advocacy skills, and explaining how to prepare for IEP meetings (Burke & Hodapp, 2014). Providers can help parents learn to cope with disappointment and be an emotional support to facilitate perseverance (Sweet, 2001). Helping parents connect with one another may also be beneficial. As strong and consistent relationships are built, providers are better able to assist parents and the children to have positive and beneficial educational experiences.

Increasing My Child's Autonomy

Finally, parents need to communicate with providers about concerns regarding their son's or daughter's autonomy and providers must be proactive in educating and encouraging parents concerning their child's potential in this area. Starting when the children are fairly young, providers can begin working with parents to help their son or daughter "become more self-determinative and to have more control over specific aspects of their lives" (Arellano & Peralta, 2013, p. 179). These skills can be developed throughout the child's life, preparing him or her to enjoy as much autonomy as developmentally possible.

Strengthen Protective Factors

As parents work to reduce risk factors, they are essentially strengthening protective factors. Bolstering parents' overall health is another way of providing them with extra strength and protection as they care for their sons and daughters with ID.

Following are ideas providers can use to encourage and support parental health promotion intermixed with suggestions from Rutter (2013), a psychologist who has done extensive research with resilience among children.

Physically, parents need to take care of themselves by getting adequate sleep, regularly exercising, eating a well-balanced diet, and performing other health promoting activities. Emotionally, Rutter (2013) suggested parents must be exposed "to manageable challenges or small doses of a stress experience" (p. 482) rather than completely avoiding the hazardous environment. Providers can assess parents' needs in order to better understand their individual struggles. By providing support and a connection to resources and educational tools, they can help challenges to become more manageable. Resources for emotional health include assistance in coping with stressors, and establishing realistic expectations of self, son or daughter, and others. Assisting parents to experience success in coping with stressors and challenges helps them build confidence and fosters further resilience (Rutter, 2013; Windle, 2011). For example, providers could assist parents in improving confidence in their own caregiving abilities through listening to concerns, giving encouragement, and suggesting ways of developing skills when appropriate.

Rutter (2013) also emphasized the importance of positive relationships and family environments. Having support available for parents to strengthen their relationships with their son or daughter, partner, and others would be helpful. In addition, Rutter pointed out the benefit of mentorship. Parents who have successfully raised children with ID can assist those currently in the same process. Providers can connect parents with support groups and encourage involvement. They could also assess and encourage spiritual participation and growth where parents can also find added support.

A final suggestion from Rutter (2013) was for parents to be involved in planning, self-reflection, and active personal agency. They "…must be able to take responsibility, exercise a degree of autonomy and have the opportunity to learn from their own mistakes" (p. 482). Providers can partner with parents to provide means whereby these principles can be promoted.

Future Research

This study provides ideas for possible future studies concerning the transitions and health trajectories of parents caring for children with mild to moderate ID. This section is divided into the expansion of knowledge among parents of children with ID in the following areas: risk and protective factors, experience of raising a child with ID, and resilience and transition theories.

Risk and Protective Factors

The next logical study would be to develop a better understanding of risk and protective factors of parents raising children with ID over a lifespan. Understanding how these factors are characterized, when they occur, and what facilitates and inhibits them may help providers better support parents through the experience. These objectives could be achieved by interviewing parents about risk and protective factors at different parental ages and stages of raising their sons or daughters. Once this is accomplished, interventions can be created and piloted. Then, screening and assessment tools can be developed and tested. To assist providers in selecting risk and protective factors, Luthar, Sayer, and Brown (2006) proposed four guidelines. Select factors "that affect a relatively large number of people" (p. 111), are relatively malleable or modifiable, are "enduring in the life situation" (p. 111), and set in motion other protective factors.

A community-based participatory research study may be helpful in gaining parents' support and enlisting their insights into what types of interventions would be useful. The parents in the current study seemed willing to help one another, but would likely need some help organizing. A possible intervention could be assisting parents to write their stories about raising children with ID. Parents could be involved in both the planning and implementation processes.

Experience of Raising a Child with ID

Several different types of studies could allow the experience of raising a child with ID explored in different ways. Possibilities could include studying parents' health trajectories in more depth among varied populations, such as parents of diverse ethnicities, religions, and ages. An alternative way of studying health trajectories could be to examine lifelines as assessment tools, or a longitudinal study could follow parents' health over time. Alternatively, younger and older parents involved at various stages in raising children with ID could be interviewed. A mixed-method study with standardized quantitative instruments could measure parental health and assess changes over time. This would be helpful in comparing findings with other studies examining health of parents. Including the children with ID in the study or observing them may provide a deeper understanding of parental experiences.

Additionally, a variety of options exist for varying the population in order to gain a broader understanding of the experience of raising a child with ID. Varying the demographics of the parents—SES, marital status, ethnicity, religion, educational level—may reveal new insights. Comparisons of parental health could be made among parents whose sons or daughters reside in group homes, have children with varying levels of ID, or specific diagnoses (ASD, Down syndrome, brain damage, Asperger's disorder). Eliciting stories from parents who are resistant in sharing their stories would be helpful in getting a different perspective. I believe service providers that are in close contact with parents and have established trusting relationships could facilitate this process. Gaining a better understanding of parents' barriers to participation would also be helpful.

As most participants in this study were mothers, a future study could focus on fathers. This could be valuable as men's health is already an area of public concern (White, 2006). A more rigorous comparison between health trajectories of fathers and mothers could be done. In addition to studying the parents of children with ID, the transitions and lifetime health trajectories as well as health and wellbeing of siblings and grandparents could be researched. Finally, a study could further examine resilience in parents of children with ID in order to teach others how to become more resilient.

Resilience and Transition Theories

In addition to the aforementioned ideas, theory development in both resilience and transitions could be studied, since they have not been created for this population. Ideas for resilience theory development among parents of children with ID can be found in the discussion section about resilience. I suggest combining several theories to augment the Resiliency Model (Richardson & Waite, 2002).

One such theory that could augment the Resiliency Model (Richardson & Waite,

2002) is the Meleis health transition model (Meleis, 2010). I found this model to be helpful in guiding my study. In Chapter 2, it was described in detail and was used as a framework to present literature about transitions of raising children with ID in parents' lives. The model provides a detailed system for describing the different aspects of transitions and analyzing them over time. I believe combining these theories could create an improved model for describing and assessing transitions–in particular the transition to resiliency. The detail in the Meleis health transition model (Meleis, 2010) would enhance phases described in the Resiliency Model. Risk and protective factors could be included. Additional information could explain what results when a person does not successfully transition.

The phases of the Resiliency Model (Richardson & Waite, 2002) would be helpful for healthcare professionals to assess parents and determine useful interventions and therapies in assisting them through the process of raising children with ID in a healthy manner. Parents need to be reassessed regularly as the process is fluid. Parents in the study rarely, if ever, mentioned nurses support through their experience, so I would question the section in the Meleis health transition model (Meleis, 2010) about Nursing Therapeutics/Interventions; this section could be expanded to include assessment and a broader range of interventions.

Strengths and Limitations of the Study

This study has strengths and limitations. The leading strength is the voice it gave to parents of children with ID, a population not commonly studied in nursing research. The open-ended questions and lifelines allowed participants to fully share their many experiences of raising children with ID, as well as the other major events in their lives. The qualitative nature of the study allowed refinement of the interview guide, and an even deeper understanding of the phenomenon. These changes elicited responses more helpful in answering the research questions, but presented some challenges in data comparison. The variety of methods used for analyzing data presented a deeper understanding of current knowledge about their transitions and health trajectories. Stories were examined holistically, thus offering a more complete picture of parents' lives and health above and beyond their caregiving responsibilities since the health trajectory graphs visually displayed this holistic story. The more traditional categorical-content method of analysis provided additional insights.

With regard to limitations, study results are based on experiences of 18 parents conveniently sampled; therefore, they most likely cannot be generalized with any other parents' experience. The nature of the experience was one of variability, based both on the child's variable health and ID status as well as family composition, parental life experience, and interpretations of raising a child with ID. The overall purpose of this study was to explore the transitions and health trajectories of parents caring for children with mild to moderate ID. Those interested in sharing their stories and participated may have possessed different characteristics than those who did not participate and would not or could not narrative their experiences. The participants were mainly White, middle-class parents of children with Down syndrome. There were not equal numbers of fathers and mothers in the study.

Several design factors may have also created limitations. For example, participants were not interviewed over time to collect longitudinal health trajectory narratives as they unfolded. Instead, data collected reflected a point in time over approximately a month of our research relationship and was retrospective. I relied on parents' memory to recall experiences occurring years in the past; the details may have been inaccurate or distorted. Conversely, as parents reflected on their experiences over the years and during the interview, they may have had more crystallization and self-reflection than would have been possible to report in the moment. The lifelines may have had limited value as some parents were hesitant to create them and made simpler life histories with similar results.

Finally, in Chapter 1, I disclosed information about myself that could have biased the parents' responses. I am a White, middle class, female student who at the time of the interviews was pregnant with my first child. In Chapter 3, I discussed how participants may have tailored their responses to me as an individual. I believe the most influencing factor was being a student; they wanted to help me and did their best to respond in a beneficial manner. Being pregnant was a good ice-breaker, but may have deterred parents from sharing some negative aspects of their experiences. Having a common religious background with most participants allowed for more open conversations of religious matters. Those of different religious backgrounds may have not felt the same connection with me.

Conclusion

Parents in the current study demonstrated resilience as they raised their sons and daughters with ID. They described challenges and struggles helping them develop additional resilient qualities. For example, they worked hard, especially in the beginning years, to provide for the physical and emotional needs of the son or daughter while continuing to manage stressors of everyday life. Over time, they gathered information about the diagnosis, adjusted to the diagnosis, learned how to work with the health concerns and behavioral issues specific to their son or daughter, and ensured their son or daughter received appropriate treatments and educational opportunities to help each learn and grow. Finally, they encouraged the child to learn skills needed as they became autonomous and independent while still being involved in the child's life. Eventually, parents' narratives reached a tentative sense of peace about the situation of parenting a child with ID, including the grandmother. Even though the children were now adults, the narrative continued. The challenges of raising a child with ID faded into the background, and other concerns took its place as parents contemplated their own aging and other life challenges. As parents reflected on their experiences, they shared many lessons learned and the positive aspects of the experience. The child brought parents joy and they were grateful to have him or her be part of their life.

With regard to the second research question, parents could not claim raising a child with ID affected their physical health; however, most described the emotional, social, and spiritual benefits their son or daughter provided. Parent narratives included strengthening their marriages and families, as a result of working together to raise their child. Of the participants, there were no divorces since the birth of the son or daughter with ID, and only one marriage that may have become weaker. Some parents met people they never would have met. They learned to ask for and receive comfortable levels of help from others, and most found strength and/or meaning in their religious and spiritual practices. Humor permeated some stories, and was one way they found connections to other people and to the ironies of life in general.

The study findings can help educate all people about the realities of parenting people with ID. Perhaps parents new to the experience would be most curious about the life experiences of those who have been through the experience and shared their narrative journey. In addition, understanding findings about transitions and health trajectories of parents caring for children with ID provides an excellent framework for supporting parents in maintaining and improving their overall lifetime health. The visual images of the lifeline graphs provided a beginning foundation for knowing when and how to intervene. Preparation for raising a child with ID needs to begin long before the child's conception, meaning everyone should be equipped to work with people with ID. Once diagnosed, study findings emphasize the importance of early interventions, resources, and support for children with ID and their parents, followed by a steady stream of support for parents throughout the son's or daughter's life to ultimately enhance parental health. Interventions to bolster parents' resilience are needed, especially at the social and community/societal levels. These could include trainings to build skills and confidence in caring for a child with ID and increasing availability of respite services.

This initial exploration of health trajectories uncovered and provided rich insights into the major transition of raising a child with ID and the overall health effects. More research is needed to gain an even better understanding of this transition so interventions and screening tools can be created and tested ultimately leading to improved health for parents and possibly their children. Society will be greatly benefitted as the realities of people with ID are better understood and appreciated.

APPENDIX A

INITIAL INTERVIEW GUIDE

Initial Interview Guide

<u>Supplies needed</u>: audio recorder, laptop with internet, 10 foot piece of butcher paper

Interview #1

1. Review timeframe and goals for interview, complete the consent document, explain the butcher paper for Interview #3, and complete the demographic form.
2. Interview Question
    a. I would like to begin by being sure I understand what the experience of parenting a child with an intellectual disability has been like for you. Would you tell me about it from the beginning?
    b. (If needed). How has having [insert child's name] as part of your life affected your life and health?
3. Schedule Interviews #2 and #3
4. Lifeline instructions to be discussed at Interview #1 and completed before Interview #3
    a. For our last interview, I would like you to make a lifeline for us to discuss. I only have two instructions.
        i. Create a chronological display on the butcher paper that I give you of your life. Start when you were born and go to the present.
        ii. Include events/transitions/turning points you consider significant during this time.
    a. Other than that, feel free to do what you would like. You can write words, draw pictures, use stickers, insert photos, or whatever. I'll have you tell me about it to during our last interview. It can be as simple or as creative as you like.

Interview #2

1. Review timeframe and goals for interview
2. Discuss preliminary results from interview #1
3. Interview Question
    a. During this interview I want to pick up where we left off last time. The last thing we discussed was… Can you tell me what happened after that?
    b. Now, I want to fill in the gaps. Examples: I noticed when you were telling your story that all of it was centered around raising your child. You have not mentioned anything about your own life, health, job, and relationships. Will you tell me about your own life in relation to raising a child with an ID?
    c. What would you say were the main transitions/turning points/changes you have experienced while raising [insert child's name]? What other transitions did you experience? Will you briefly tell me about a couple of the transitions from beginning to end? [If needed] How long did it last or is it still ongoing? What resources did you use? What changed? What did you learn?
4. Remind participant about interview #3 and review lifeline instructions

Interview #3

1. Review timeframe and goals for interview
2. Discuss preliminary results from the first two interviews
3. Interview Questions
    a. Tell me about your lifeline.
    b. What would you say the major transitions/turning points/changes are in your life?
    c. Will you tell me about your health (physical, mental, emotional, spiritual, etc) over your lifetime?
4. Inform participant I will e-mail him or her preliminary analyses of all three interviews and would like feedback. If spouse has already participated in three interviews, I will also send a preliminary analysis for feedback of data combining interviews from both people.
5. Inform participant I will be creating a CD of their story and presenting it to them at a later date most likely through the mail.

APPENDIX B

REVISED INTERVIEW GUIDE

Revised Interview Guide

Supplies needed: Audio recorder, laptop with internet, 10 foot piece of butcher paper

Interview #1

Review timeframe and goals for interview, complete the consent document, explain the butcher paper and instructions for lifeline, and complete the demographic form.

Introduction:

This is a study about the health of parents raising children with intellectual disabilities. I will ask you to describe your experience raising a child with an intellectual disability and how it has affected your overall health and well-being in the broadest sense. I am sure there are a lot of other life events you can think of that have affected your health, so I would like to hear about those, too. That is why I want you to create a lifeline, so I can better understand your health over time. “Your participation in this study is strictly confidential. Interviews are normally tape-recorded, and this simply provides for accurately keeping track of information. Subsequently the tape will be destroyed. Your participation in this study is important. However, should you at any time wish to stop, you may do so without [anyone being angry with] you… At any time you should feel free to ask me questions concerning the interview or the study. May we begin” (Hermanowicz, 2002)?

Questions for Interview #1

1. I would like to begin by being sure I understand what the experience of parenting a child with an intellectual disability has been like for you. Would you tell me about it from the beginning?

   Probes [if needed]:

   Tell me about…

   a. The beginning (i.e. diagnosis, finding out your child has a disability)
   b. Early childhood years
   c. Elementary school
   d. Junior high school
   e. High school
   f. After high school
   g. Future plans with [insert child’s name]
   h. The best/worst part about raising [insert child’s name]

   General probes [if needed]:

   a. Can you help me understand what you’re saying?
   b. Go back to that last experience. Give me a little more detail.
   c. Can you give me an example and/or story?
   d. OK, let me summarize for a second so we can move on.
   e. Is there anything else?
   f. What consequences have you seen as a result of that experience?

At the conclusion of the interview, lifeline instructions will be provided. The lifeline will

be completed before Interview #2 by the participant.
Instructions for the lifeline:

- For our second interview, I would like you to make a lifeline for us to discuss. I only have two instructions.
- Create a chronological display on the butcher paper that I give you of your life. Start when you were born and go to the present.
- Include events you have experienced that changed ***your*** life and well-being, health, relationships, and environment.
- Other than that, feel free to do what you would like. You can write words, draw pictures, use stickers, insert photos, or whatever. I'll have you tell me about it to during our second interview. It can be as simple or as creative as you would like.

Interview #2
Review timeframe and goals for interview. Discuss my preliminary insights and tentative results from the first interview.

Questions for Interview #2

1. How has having [insert child's name] as part of your life affected ***your*** life? What would you say were the main events you have experienced that changed ***your*** life? Please, describe.
2. How has having [insert child's name] as part of your life affected ***your*** health and well-being? What would you say were the main events you have experienced that changed ***your*** health and well-being? Please, describe.
3. How has having [insert child's name] as part of your life affected ***your*** relationships? What would you say were the main events you have experienced that changed ***your*** relationships? Please, describe.
4. How has having [insert child's name] as part of your life affected ***your*** environment? What would you say were the main events you have experienced that changed ***your*** environment? Please, describe.
5. Please, choose one or two of the events you described above and answer the following questions about it.
    a. How long did it last or are is still ongoing?
    b. How were you prepared?
    c. What resources did you use (personal, community, society)?
    d. What were the inhibitors? What kept the tranistion from occuring?
    e. What changed? How are you different?
    f. What lessons did you learn?
    g. Were you successful? Why or why not?

Remind participant about interview #3.

Interview #3
Review timeframe and goals for interview. Discuss my preliminary insights and tentative results from the first two interviews.

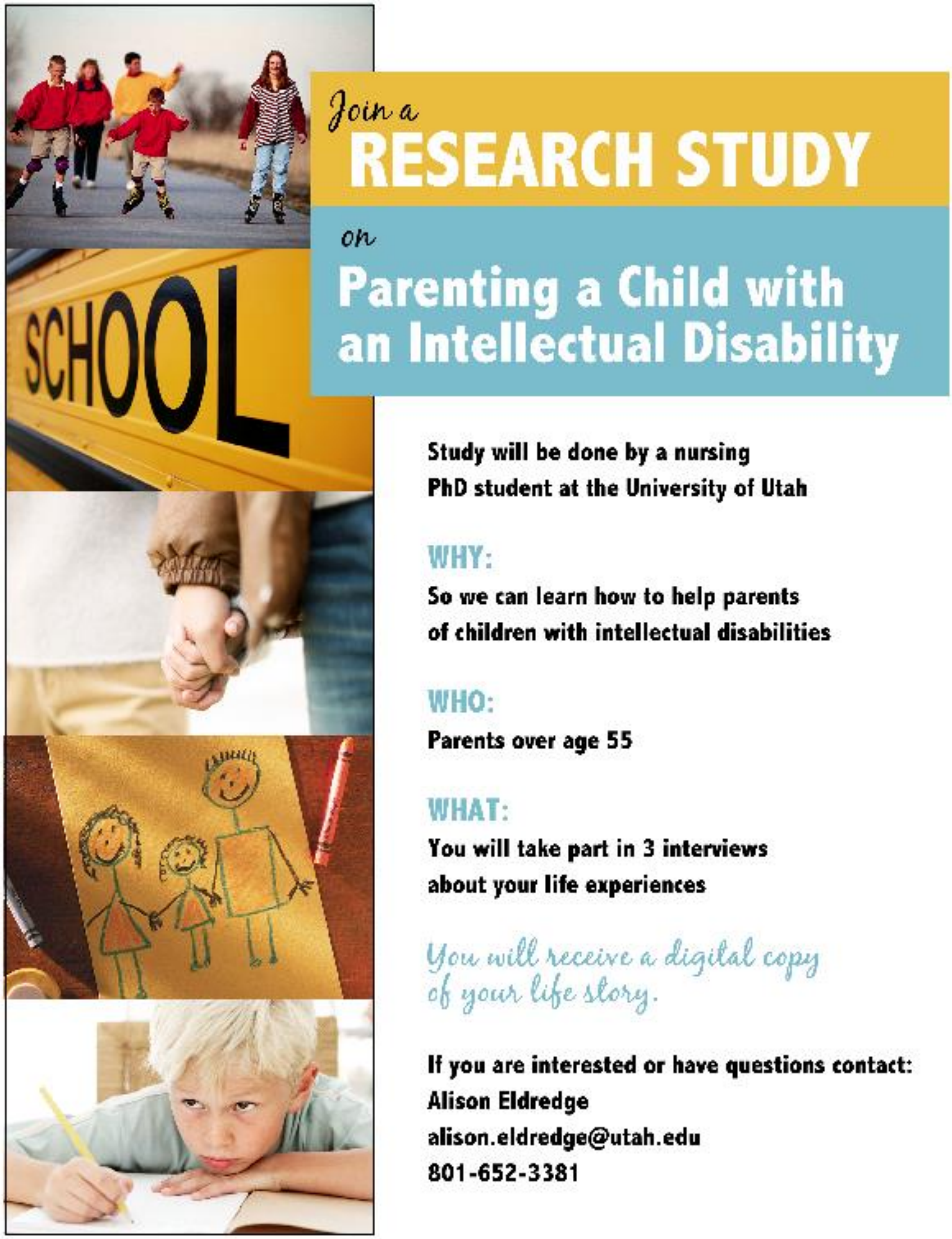
Interview Questions for Interview #3

1. Tell me about your lifeline.
2. What would you say were the ***main*** events you have experienced in your life that changed ***your*** life? Please, describe.
3. What would you say were the ***main*** events you have experienced in your life that changed ***your*** health and well-being? Please, describe.
4. What would you say were the ***main*** events you have experienced in your life that changed ***your*** relationships? Please, describe.
5. What would you say were the ***main*** events you have experienced in your life that changed ***your*** environment? Please, describe.
6. Please, choose one or two of the events you described above and briefly tell me about them from beginning to end.
7. Now, answer the following questions about it.
    h. How long did it last or are is still ongoing?
    i. How were you prepared?
    j. What resources did you use (personal, community, society)?
    k. What were the inhibitors? What kept the tranistion from occuring?
    l. What changed? How are you different?
    m. What lessons did you learn?
    n. Were you successful? Why or why not?
8. Will you tell me about your overall health and well-being (to include your physical, mental, emotional, and spiritual health) over your lifetime?
9. Is this difficult to talk about? In what way is it hard?
10. Were these interviews difficult? What was hard?
11. What have I not asked? Is there something you have been thinking about that I have not asked that you would like to share?
12. Are there things that you wish you could have told someone?
13. Having been through your experience, what would you want to tell other parents? What is the take home message that another mother might need to hear from you? How could you summarize your experience in a way that is truthful and helpful to someone else?
14. What do you wish you could tell nurses, doctors, teachers…? What would have helped you?
15. What would you say is the difference between the mother and father experience?
16. Do you have any advice for me in how to improve the study or the interviews? Would have worded some of the questions differently?
17. Do you have any ideas for future studies?

Inform participant I will e-mail him or her preliminary analyses of all three interviews and would like feedback. Inform participant I will be creating a CD of his or her story and presenting it to him or her at a later date most likely through the mail. Thank the participant.

APPENDIX C

RECRUITMENT FLYER



Join a

RESEARCH STUDY

on

Parenting a Child with an Intellectual Disability

Study will be done by a nursing PhD student at the University of Utah

WHY:

So we can learn how to help parents of children with intellectual disabilities

WHO:

Parents over age 55

WHAT:

You will take part in 3 interviews about your life experiences

You will receive a digital copy of your life story.

If you are interested or have questions contact:
Alison Eldredge
alison.eldredge@utah.edu
801-652-3381

APPENDIX D

RECRUITMENT SCRIPT AND FOLLOW-UP E-MAIL

Script for Informing Parents about the Opportunity for Research Participation

Introduction

Hello, my name is Alison Eldredge. I received your name from…. I am working on a PhD and am looking for parents caring for children with intellectual disabilities to take part in my study. I want to learn more about your health and how healthcare professionals can better support you.

Eligibility Criteria

I'm calling because you might qualify for the study. I am looking for parents who are 55 years of age or older who are the birth parents or spouse/partner to the birth parent of a child with mild to moderate ID. ID= diagnosis of ID, been told child has a lower intelligence, or child attended a special education class. I am also requiring the parent to report having primary responsibility for the care and well-being of the child with ID for the majority of the child's life. Would you qualify? May I tell you more about the study?

Request

For this study, I want to interview you 3 times and record the interviews. The interviews can be done at your home or in a private room in a public building, like a library or recreation center. A quiet place where you would not get distracted would be ideal. The interviews will last between 1 and 1 ½ hours each. I will ask you to share your story about raising a child with an intellectual disability. I will also ask you to draw a lifeline or timeline to help me understand your experience. This is a chronological representation of your life. You include all of the major events in your life starting when you were born and going until the present. I will ask you to explain the lifeline to me during the last interview. After we finish all of the interviews, I will put together your story on a CD and present it to you.

You can decide to take part in the study if you want to. Nothing will change with your relationship with your doctors or nurses if you choose to be in the study or decide not to be in the study. No one will share your name or information about you if you take part in the study. It is up to you to decide whether to take part in this study. If you decide to take part in the study you can change your mind. You can quit being in the study or decide not to take part and you will not lose benefits or have any penalty.

Invitation

Would you like me to e-mail you the consent papers to read and think about?

<u>If yes,</u>

May I get some contact information from you? Phone number and e-mail address of participant. Would you like to set up an appointment for the first interview or wait until after you have read the consent form? Would you like to meet at your home or another location? What is your home address? Do you have any questions for me? If you think of any, feel free to call me or respond to my e-mail to you. My phone number is 801-652-3381. You can also ask more questions about the study when we meet in person.

Participant's name:____
Participant's home telephone #:______________
Participant's cell phone #:________________

Participant's E-mail: _______________________________________

Address for interview:____
____

If no,
It is fine if you don't want to learn any more about the study. No one will contact you about it again. Do you know of anyone else who may be interested in participating? Thank you, though for listening.

Final remarks
One last thing, I want to make sure you know that I received Institutional Review Board approval to conduct this study. Their goal is to insure that any research study that is conducted protects human rights. This study is designed with high standards of confidentiality; your name and contact information will not be used in any way except to let you know about this study.

If you have complaints, questions, or concerns about this study, you can contact me at 801-652-3381 or Alison.eldredge@utah.edu; Lauren Clark at 801-581-8576 or lauren.clark@nurs.utah.edu, or the Institutional Review Board at (801) 581-3655 or by e-mail at irb@hsc.utah.edu

E-mail to Parents Containing Consent Form and Invitation to Participate in Study

Dear (participant's name),
Thank you for being willing to participate in a research study for my dissertation. I have attached the consent form for you to read over. Please, feel free to e-mail or call me with any questions you may have about the consent form or the study.

If you would like to participate, please, e-mail or call me with some dates and times that you are available. I will call you in a couple days if I have not heard from you.

Thank you again for considering participation. If you choose to take part in the study, I look forward to hearing your stories and learning more about your experience raising a child with an intellectual disability. Take care.

Alison Eldredge, PhD Candidate
University of Utah, College of Nursing
Alison.eldredge@utah.edu
801-652-3381

APPENDIX E

CONSENT AND AUTHORIZATION DOCUMENT

Consent and Authorization Document
for Minimal Risk Research

BACKGROUND

You are being asked to take part in a research study being undertaken by a doctoral student at the University of Utah College of Nursing. Before you decide to take part, it is important for you to understand why the research is being done and what you will be asked to do. Please take time to read the following information carefully and discuss it with your friends or relatives if you wish. Ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not to volunteer to take part in this research study.

The purpose of the study is to explore and describe the transitions and overall health trajectories of parents caring for children with intellectual disabilities (ID). This study will lay a foundation for future research. For example, with an understanding of parents' experiences, researchers could test interventions to better support parents with ID through transitions in their lives.

STUDY PROCEDURES

You will take part in 3 interviews that will each last between 1 and 1 ½ hours. The interviews can take place in your home or in a private room of a public building (i.e. library, recreation center), whichever is more convenient for you. A quiet place as free from distractions as possible would be the best. The interviews will be digitally recorded. During the first and second interviews we will talk about your experience raising a child with ID. Before the third interview you will be asked to complete a lifeline. A lifeline is a chronological representation of your life. It includes all of the major events/transitions/turning points in your life starting when you were born and going to the present. We will discuss your lifeline during the last interview.

Interview	Topic
1	Tell about your experience raising a child with ID
2	Finish story from interview #1, answer any follow up questions
3	Explain and answer questions about your lifeline

RISKS

The risks of this study are minimal. You may feel upset thinking about or talking about personal information related to raising a child with ID. These risks are similar to those you experience when discussing personal information with others. If you feel upset from this experience, you can tell the researcher, and she will tell you about resources available to help.

BENEFITS

There are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of parents of children with ID and their transitions in the future.

CONFIDENTIALITY

I will keep all research records that identify you private to the extent allowed by law. Records about you will be kept on a password protected computer in a locked office. I will be the only person allowed access to your information. Your name will not be kept with your responses from the interviews. In publications, your name will be removed.

You will be anonymous except in cases where the researcher is legally obligated to report specific incidents. However, if you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher will report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact Alison Eldredge at 801-652-3381 or Alison.eldredge@utah.edu. If you feel you have been harmed as a result of participation, please call me; I will return your call within 24 hours.

Institutional Review Board: Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Research Participant Advocate: You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

VOLUNTARY PARTICIPATION

It is up to you to decide whether to take part in this study. Refusal to participate or the decision to withdraw from this research will involve no penalty or loss of benefits to which you are otherwise entitled. This will not affect your relationship with the investigator.

COSTS AND COMPENSATION TO PARTICIPANTS

There is no cost to you to be in this study. However, you will need to need to commit to participating in three interviews each lasting 1 to 1 ½ hours. Following the final interview, I will present to you a CD of your story.

AUTHORIZATION FOR USE OF YOUR PROTECTED HEALTH INFORMATION

Signing this document means you allow me, the researcher in this study, and others working with me to use information about your health for this research study. You can choose whether or not you will participate in this research study. However, in order to participate you have to sign this consent and authorization form. This is the information we will use:

Name

Address
Phone Number
E-mail address

Others who will have access to your information for this research project are the University's Institutional Review Board (the committee that oversees research studying people) and authorized members of the University of Utah Health Sciences Center who need the information to perform their duties (for example: to provide treatment, to ensure integrity of the research, and for accounting or billing matters).

If we share your information with anyone outside the University of Utah Health Sciences Center you will not be identified by name, social security number, address, telephone number, or any other information that would directly identify you, unless required by law.

You may revoke this authorization. This must be done in writing. You must either give your revocation in person to the Principal Investigator or the Principal Investigator's staff, or mail it to Alison Eldredge at 8465 Meadow Green Way, West Jordan, Utah 84088. If you revoke this authorization, we will not be able to collect new information about you, and you will be withdrawn from the research study. However, we can continue to use information we have already started to use in our research, as needed to maintain the integrity of the research.

This authorization lasts until this study is finished.

CONSENT

I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. I will be given a signed copy of the consent and authorization form to keep.

I agree to participate in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.

____
Participant's Name

__________________________ _____________
Participant's Signature Date

____
Name of Person Obtaining Authorization and Consent

__________________________ _____________
Signature of Person Obtaining Authorization and Consent Date

APPENDIX F

DEMOGRAPHIC FORM

Demographic Form
Transitions and Health Trajectories of Parents Caring for Children with Intellectual Disabilities

What is your name?		
What is your home address		
What is your home telephone #?		
What is your cell phone #?		
What is your e-mail address?		
What is your date of birth?		
What is your gender?	☐ Male	☐ Female
What is your race?	☐ American Indian/Alaskan Native ☐ Asian ☐ Native Hawaiian or Other Pacific Islander	☐ Black or African American ☐ White
What is your ethnicity?	☐ Hispanic or Latino	☐ Not Hispanic or Latino
What is the highest level of formal education you have completed? (Check one)	☐ Less than high school ☐ Less than 7th grade ☐ Junior high school ☐ Partial high school ☐ High school graduate (whether private preparatory, parochial, trade, or public school)	☐ Partial college (at least one year) or specialized training ☐ Standard college or university graduation (e.g., B.S.) ☐ Graduate professional training (graduate degree)
Are you currently employed?	☐ Yes, employed full time ☐ Yes, employed part time ☐ No, retired	☐ No, fulltime homemaker ☐ No, looking for work ☐ Other __________________________
What kind of work do you do?		
If you are now employed outside the home, how many hours per	☐ 1-5 hours/week ☐ 6-10 hours/week ☐ 11-20 hours/week ☐ 21-30 hours/week	☐ 31-40 hours/week ☐ 41-50 hours/week ☐ 51-60 hours/week ☐ 61+ hours/week

week do you work on average?							
What is your approximate household (total) annual family income before taxes?	☐ Under $15,000 ☐ $15,000 to $29,999 ☐ $30,000 to $44,999			☐ $45,000 to $59,999 ☐ $60,000 to $74,999		☐ $75,000 to $89,999 ☐ $90,000 or above	
On a scale of 1-7 (1=Very confident to 7=Not at all unconfident) how confident do you feel with regard to your ability to meet your financial obligations right now?	1	2	3	4	5	6	7
	Very confident						Not at all confident
What is your current marital status?	☐ Single ☐ Married ☐ Divorced				☐ Cohabitating ☐ Other ___________________		
Are you currently living with a spouse/partner	☐ Yes ☐ No						
What is the date of birth of your SPOUSE?							
What race is your SPOUSE?	☐ American Indian/Alaskan Native ☐ Asian ☐ Native Hawaiian or Other Pacific Islander				☐ Black or African American ☐ White		
What ethnicity is your SPOUSE?	☐ Hispanic or Latino				☐ Not Hispanic or Latino		
What is the highest level of formal education your SPOUSE has completed? (Check one)	☐ Less than high school ☐ Less than 7th grade ☐ Junior high school ☐ Partial high school ☐ High school graduate (whether private preparatory, parochial, trade, or public school)				☐ Partial college (at least one year) or specialized training ☐ Standard college or university graduation (e.g., B.S.) ☐ Graduate professional training (graduate degree)		

Is your SPOUSE currently employed?	☐ Yes, employed full time ☐ Yes, employed part time ☐ No, retired	☐ No, fulltime homemaker ☐ No, looking for work ☐ Other ____________________	
What kind of work does your SPOUSE do?			
If your SPOUSE is now employed outside the home, how many hours per week does s/he work on average?	☐ 1-5 hours/week ☐ 6-10 hours/week ☐ 11-20 hours/week ☐ 21-30 hours/week	☐ 31-40 hours/week ☐ 41-50 hours/week ☐ 51-60 hours/week ☐ 61+ hours/week	
How many children do you have?			
What are the birthdays of your children?			
Which of those children have ID?			
How many grandchildren do you have?			
Who currently lives at your home?			
What are the approximate ages of those who live in your home?			
Child #1 with ID			
What is your relationship to your child with ID?	☐ Birth Father ☐ Birth Mother	☐ Adopted Father ☐ Adopted Mother	☐ Foster Father ☐ Foster Mother ☐ Other ______________
Is your child with ID living at home with you?	☐ Lives at home with me ☐ Lives elsewhere ______________________________		
What is the gender of your	☐ Male ☐ Female		

child with ID?	
What is the diagnosis of your child with ID?	

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