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Narrative Experiences of Fathers of Children with Down syndrome

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Graduate School of Education

Lesley University

Ph.D. Educational Studies

Adult Learning and Development

In partial fulfillment of the degree of Ph.D.

Narrative Experiences of Fathers of Children with Down syndrome

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Ph.D. in Educational Studies

Adult Learning and Development Specialization

Approvals

In the judgment of the following signatories, this Dissertation meets the academic standards that have been established for the Doctor of Philosophy degree.

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Abstract

This dissertation explores the narrative experiences of fathers raising children born with Down syndrome. The study joins a recent stratum of research on parents of children with Down syndrome which is grounded in critical disability theory, adheres to a social model of disabilities, and adopts narrative methodology, but which thus far has not investigated fathers' experiences. 22 fathers, recruited by means of snowball sampling, participated in a two-question, semi-structured interview with a follow-up conversation. Findings from question one indicated that, in the initial moment of diagnosis, fathers experienced adverse encounters with medical personnel, intense negative emotions about the diagnosis, distressing episodes of medical complexity in their children, and fruitless and frustrating trials of information-gathering. Findings from question two revealed that fathers, once settled into their lives raising their children with Down syndrome, constructed sound information worlds reinforced by social support and more judicious information-gathering, and became more adept at managing their children's medical complexities. Findings also revealed that fathers experienced changes to their roles, responsibilities, and relationships within their families, but were happy with their lives and proud of their children. Fathers reported that the source of their stress was often attributable to institutional ableism and misunderstandings by others about their lives and about raising children with Down syndrome. The analysis and conclusion sections of this dissertation suggest that a dominant cultural narrative about Down syndrome, which suggests that people with Down syndrome are unwanted and deleterious to their families and society, propagates such institutional ableism and misunderstandings. A final and notable finding from this study is that many participants experienced transformations in

themselves and worldviews, suggesting that their lives were actually made better by raising their children with Down syndrome.

Keywords: Down syndrome, Parents raising children with Down syndrome, Critical disability Studies, Social model of disabilities, Narrative inquiry

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Chapter One - Introduction

Overview

This study explores the narrative experiences of fathers raising children born with Down syndrome. Its specific purpose was to understand fathers' interactions with medical personnel, friends, family, society, and self, as they processed the diagnosis of Down syndrome and adjusted to life thereafter raising their children. The research employed narrative inquiry, a process that included interviewing 22 fathers, transcribing the interviews, re-storying the transcripts, then analyzing for common thematic elements. Analysis was informed by critical disability studies, an approach that problematizes conceptions of disability as medicalized and devoid of sociocultural context, and instead promotes a conception of disability as a social, political, and cultural construction.

Background and Context

Down syndrome, also known genetically as Trisomy 21, is a common chromosomal condition named for John Langdon Down, an English physician who first reported it in 1866. It was later discovered that an extra copy of chromosome 21 causes the most common form of the condition. Individuals with Down syndrome carry increased risk of congenital heart defects (some 40 to 60 percent of individuals), as well increased risk of motor and cognitive delays, gastrointestinal issues, epilepsy, orthopedic conditions, accelerated aging, and Alzheimer's disease (Kozma, 2008; Leshin, 2008). People with Down syndrome have seen meteoric improvement in their quality of life in recent decades. In 1983, life expectancy for an individual with Down syndrome was 25 years. In 2017, life expectancy for an individual with Down syndrome was 60 years (National Down Syndrome Society, 2017). While this definition describes Down syndrome in terms of its medical pathology, other efforts have challenged such deficit-

based meanings in favor of more socially constructed, dialogical definitions (e.g., see Cimini, 2010).

An important distinction that frames the background for this dissertation is a stark difference between a medicalized model of disability and a social model. A medicalized model of disability, with its focus on pathology, begins with assumptions of deficit, loss, abnormality, hardship, and shame, among other mindsets (Lalvani, 2011). It is a dehumanizing model that equates people with their impairments and positions them as a threat or risk to dominant culture (Goodley, 2017). By contrast, a social model of disability holds that disability is socially constructed and therefore apart from bodily or mental impairment. Disability is critically examined as a discourse of exclusion, barriers, and oppression, as well as a term appropriated by individuals with disabilities for purposes of collective identity and advocacy (Linton, 1996; Shakespeare, 2007).

Disability studies, arising from the civil rights movement of the 1960s in America, and drawing from disability rights internationally, has become an area of critical academic exercise, especially after the passage of the Americans with Disabilities Act of 1990 (Davis, 2006). During the 2000s, disability studies, influenced by critical theory and seeking intersectionality among issues of race, socioeconomic status and gender, expanded its critical focus to confront power and resist the dominant cultural narratives of disability. Disability studies—most scholars have taken to using the appellation *critical disability studies*, adhering to critical theory—may now be defined as an interdisciplinary critical tradition (Cole, 2012; Meekosha & Shuttleworth, 2009) which challenges hegemonic assumptions about disability, and problematizes “dominant medicalized and individualized understandings of disability as deficit, disorder, disease,

pathology...as something to fix or cure” (Powers-Albanesi, 2017, p. 2).

An important tenet of critical disability studies is the notion that power and influence are associated with language and narrative in society and culture. The terms *grand narrative* (Roets, Goodley, & Van Hove, 2007); *master narrative* (Lalvani & Polvere, 2013; Connor & Gabel, 2014) *dominant cultural narrative* (Merriam, Caffarella, & Baumgartner, 2007) and *dominant discourse* (Lalvani, 2008) are frequently used in the literature as similar—nearly interchangeable—ideas that exhibit nuanced shades of meaning according to discipline. These terms collectively refer to a series of beliefs, assumptions about reality and normality, and values that society uses to legitimate its institutions and reify its beliefs, and thereby maintain the status quo, with the dominant group maintaining power (Bamberg & Andrews, 2004; Brookfield, 2011; Lyotard, 1987). Dominant cultural narratives “define the sociocultural milieu in which we live; they form the taken-for-granted assumptions on which we live our lives in the way that we do” (Merriam et al., 2007, p. 208). My research concerns cultural narratives about raising children with disability. Lalvani and Polvere (2013) explain, “In cultural narratives about the experience of parenting a child with a disability, notions of profound loss and burden emerge as central themes, and these are upheld in institutional discourses and practices” (p. 3). Much of what we “think we know” about the experiences of parents raising children with Down syndrome, especially from the 1960s through the mid 1990s, has been driven by, and helped to drive, dominant cultural narratives. The effects of medicalized models of disability and research which reifies dominant cultural narratives persist in the present.

Research Problem

A body of research retrospective to the 1960s has examined parent or family experiences raising children with Down syndrome but has been framed by a deficit-based construction of disability and has concentrated on how parents come to “mourn” the “defective” child (Solnit & Stark, 1961), or on pathological grief and “chronic hardship” experienced by families (Olshansky, 1962). Despite three decades’ influence of critical disability studies, and its attempts to frame disability in a sociocultural context, many Americans, including medical professionals, continue to equate disability with tragedy, hardship, loss, and with guilt and shame (Ferguson, Gartner, & Lipsky, 2000; Lalvani & Polvere, 2013).

The notion that disability, in this case Down syndrome, bestows guilt and shame, hardship, and loss of an expected child positions children with Down syndrome, without mincing words, as undesirable. Evidence for the undesired status of children with Down syndrome may be inferred from the fact that in the United States, 67 percent of prenatal diagnoses result in parents choosing to terminate their pregnancies (Natoli, Ackerman, McDermott, & Edwards, 2012). In clinical settings, medical personnel such as doctors, nurses, genetic counselors, and grief counselors are not always trained to deliver diagnoses of Down syndrome or otherwise do not follow best practices for delivering diagnoses (Skotko et al., 2009a, 2009b; Van Riper & Choi, 2011). Thus, medical professionals often emphasize the medicalized model and do little to dispel notions of grief, hardship, and loss, and also do little to provide accurate descriptions of what life raising children with Down syndrome might entail. Most parents describe the diagnosis as a profoundly negative experience (Cuskelly, Hauser-Cram, & Van Riper, 2008; Isgro,

2016; Lalvani, 2008).

Once the intense emotions of diagnosis subside, however, most parents find their lives raising children with Down syndrome to be satisfying, contrary to their expectations upon the initial diagnosis (Lalvani, 2008, 2011). Research has established that most parents do not endure a lifetime of hardship and suffering as a result of raising their children, and in fact often fall into a pattern of stress, coping, and resilience (Ferguson, 2002). While stress is a common theme in the experiences of parents, some studies have revealed positive outcomes in parents' lives, including personal growth, increased satisfaction or well-being, increased confidence in parenting skills, and better family relationships (Cuskelly et al., 2008; King et al., 2006; Neely Barnes et al., 2010; Skotko, 2011).

Research focusing on parents of children with Down syndrome has assumed various approaches. Some approaches have problematized a medical model and promoted a social model of disability, but still have neglected to examine critically sociocultural factors that contribute to stress and oppression (Lalvani & Polvere, 2013). Many of the studies adopting psychosocial approaches have helped to develop a social model of disability by examining the conditions in and around parents, but have relied on survey instruments that contain items with deficit-based assumptions about stress and hardship. Surveys that begin with assumptions may limit the breadth and depth of expression of ideas from parents, thus privileging a dominant discourse of Down syndrome as a problem or medical condition, and dismissing parents' voices and expertise (Bingham, Correa, & Huber, 2012; Gabel & Kotel, 2015; Lalvani & Polvere, 2013).

A stratum of research on parents of children with Down syndrome has, in the last

decade, combined a critical disability theory perspective with narrative methodology (Bingham et al., 2012; Counselman Carpenter, 2015; Driscoll Nugent, 2011; Gabel & Kotell, 2015; Isgro, 2016; Lalvani, 2008, 2011; Lalvani & Polvere, 2013). One way critical disability studies challenges hegemonic power is by means of research highlighting the creation of counter-narratives (Bamberg & Andrews, 2004) or alternative interpretations of the discourse of parenting children with disabilities (Bingham et al., 2012; Lalvani, 2011). Most of the studies in this particular stratum of research have focused on women or families in general, save for two dissertation studies of fathers exclusively (Fleming, 2013; Ridge, 2013). Further research is needed to understand the experiences of fathers of children with Down syndrome as they process the diagnosis and adjust to life raising their children. It may be possible that fathers, as mothers have, provide counter-narratives to dominant cultural narratives.

My study addresses a two-tailed research problem. First, while some efforts have been made toward understanding the experiences of parents raising children with Down syndrome, and have interpreted such experiences through the lens of critical disability studies by using narrative inquiry, those efforts have not yet included exclusively fathers' experiences. Little is known about how fathers process information about Down syndrome or whether their experiences differ from mothers. A second issue my study addresses is that most Americans do not understand what Down syndrome is or what life is like for parents raising children with Down syndrome in the context of a dominant cultural narrative that positions them as abnormal, unwanted, or beset by tragedy. If it can be asserted that academic research ultimately reaches the general society and infiltrates dominant cultural narratives, then further research is needed to help build a

preponderance of evidence concerning the authentic experiences of fathers raising children with Down syndrome.

Statement of Purpose and Research Questions

The purpose of this narrative inquiry is to understand fathers' experiences raising their children with Down syndrome in the context of the dominant cultural narrative using narrative inquiry. This addresses a gap in the body of research that assumes a background of critical disability studies and uses narrative inquiry but has not yet produced adequate research exploring fathers' perspectives. My study seeks to understand fathers' experiences within the sociocultural context of the dominant cultural narrative to examine how they narrate their experiences raising children with Down syndrome. The questions that drive this research are 1) How do fathers of children with Down syndrome narrate their experiences concerning their children's diagnosis? And 2) How do fathers of children with Down syndrome narrate their experiences raising children with Down syndrome?

Research Methodology

My research follows a proposition posited by Lalvani and Polvere (2013), who argue that historically research on families with disabilities has been informed by a medicalized model that fails to acknowledge how "deficit-based hegemonic discourses shape the familial experience of having a child with a disability" (p. 1). They argue that research traditionally has begun with assumptions of negative outcomes among families raising children with disabilities and has been oriented around researchers' perspectives. Narrative inquiry, by contrast, does not begin with assumptions, but rather allows participant experiences to preside. Lalvani and Polvere recommend the use of narrative

inquiry as a critical research method informed by critical disability studies as a means of examining sociocultural conditions that create hegemonic discourses. This research began with that premise.

Permission was applied for and granted by Lesley University's IRB, then participants were recruited by means of snowball sampling from social media support groups for fathers of children with Down syndrome, from professional advocacy organizations such as the National Down Syndrome Society, from local support groups, and by word-of-mouth referral. In all, 22 fathers were recruited. Fathers completed an open-ended demographic information template and were then interviewed using a semi-structured interview format. The two research questions were posed to participants, one a generic question about the diagnosis experience and the other about what life is like raising their children. In the design of this study, it was important that no assumptions of stress or hardship influenced fathers, so participants were permitted to narrate their experiences with as little interruption or probing questions as possible. Once fathers addressed the two research questions satisfactorily, the interviews shifted to a conversational format where I asked questions designed to uncover fathers' experiences concerning sociocultural factors and dominant discourses. The interviews were recorded, transcribed, then re-storied, i.e., rewritten and condensed by salient features with a critical focus. Finally, data were analyzed for narrative experience and reported as findings for transferability of understanding. While reproducing the re-storied narratives of all participants would have been prohibitively voluminous, much data as evinced from fathers' voices was retained and presented as findings.

Rationale

The rationale for this research is embedded in a discourse of social justice. Historically, people with Down syndrome have been treated unfairly and inequitably, and the experiences of parents raising them have been and continue to be misunderstood in general society and by medical professionals. Thus, when parents learn of a diagnosis of Down syndrome in their children, they experience shock, grief, loss, and anger, among other intense emotions. Dominant cultural narratives continue to position individuals with Down syndrome as unwanted and their families as beset by grief and tragedy. Goodley (2017) refers to this discourse as “biopolitics as risk politics” (p. 131); that is, people with disabilities are seen as a threat or danger to family structure, to society, and to the power of the dominant culture, which forces thinking about lives as “they should be lived” (p. 131). Similarly, Gabel and Kotel (2015) have provided evidence for the existence of “socio-cultural tropes that position Down syndrome as a dangerous form of the ‘other’ and mothers who give birth to children with Down syndrome as implicated in transgressing cultural norms” (p. 1). Exploring the foundations and implications of the discourses that dehumanize people with Down syndrome and seeking alternative interpretations or counter-narratives of families raising children with Down syndrome may be a first step in dispelling dominant discourses and creating increased awareness of what life is like raising children with Down syndrome among medical personnel and in the general society. If education, awareness, and exposure are the enemies of inequitable dominant culture, then changing cultural norms begins with research that generates understanding and accurate descriptions of the lives of families that have a child with Down syndrome.

Research informed by critical disability studies is beginning to uncover the authentic experiences of parents of children with Down syndrome using narrative inquiry and critical analyses of sociocultural conditions in and around parents. The results have begun to show that parents can dispel features of dominant discourses and illuminate new possibilities of advocacy, visibility, and education, but this relatively new research approach has overwhelmingly featured mothers alone. Much remains to be learned about the experiences of fathers raising children with Down syndrome in the context of a dominant cultural narrative.

Chapter one of this dissertation has outlined the context, background, and conceptual framework of the study. Chapter two will review relevant literature. Chapter three will describe this study's methodology. Chapter four will present findings as garnered from fathers' re-storied narratives. Chapter five will present analysis derived from participant narratives, connecting them to existing literature and revealing new understandings. Finally, chapter six will discuss conclusions, as well as outline limitations and indications.

Chapter Two – Review of the Literature

This review of the literature will present research on parents first experiencing a diagnosis of Down syndrome and research on parents subsequently raising their children with Down syndrome. Beginning with research of the 1960s, which assumed that children with Down syndrome had a deleterious effect on parents and families, and justified the removal of children from their families and placement in institutions, the review will trace the development of the research to the present, outlining literature concerning parents' interactions with medical professionals during the initial moment of diagnosis, as well as their own reactions and intense emotions during this period. The review will then present findings that demonstrate how the initial period of diagnosis is distinct from a period in which parents adjust to life raising their children with Down syndrome.

Historical Understandings

While people with Down syndrome have always existed, and parents have always raised them, this review begins with research from the 1960s on parents raising children with Down syndrome, as ideas from that time period have had an insidious influence on cultural narratives and attitudes of medical professionals in the present. In the mid to late 1960s, research on parents of children with Down syndrome supported the idea that a child with Down syndrome had a deleterious effect on parents and families. Researchers used terms like “pathological grief” and “chronic sorrow” to describe the lives of parents (Olshansky, 1962; Solnit & Stark, 1961). The “defective” child was considered a source of grief and mourning (Solnit & Stark, 1961), bringing crisis to families and threatening the ego capacities of parents. In the 1960s, this deficit-based model of disability was

employed to justify the expulsion of children from their families and their placement in institutions (Farber, 1962, as cited in Ferguson, 2002; Stone & Parnicky, 1966).

In the 1970s and 80s, children with Down syndrome and their parents fared better as more accurate understandings of developmental disability and families living with disability emerged. By the 1980s, early intervention services, educational inclusion models, and family support structures had improved greatly (Krauss, 1993). As parents' lives and experiences changed for the better, reflecting better services and outcomes, the research changed. The relationship was cyclical; that is, research and progress led to better outcomes, which in turn led to different orientations in research (Glidden, Grein, & Ludwig, 2014).

In the 1990s, research on disability more broadly began to organize around two models: medicalized models of disability and social models of disability (Shakespeare, 2007). Ferguson (2002) authored an especially helpful history of how those models emerged, sorting the research from the 1960s through 2000 into a typology of four categories: psychodynamic approaches, functionalist approaches, psychosocial approaches, and interactionist approaches.

Ferguson (2002) draws an important distinction based on assumptions the approaches hold about disability. Research from the psychodynamic and functionalist approaches tends to view disability as an inherent and unrelenting condition linked to pathology, which has obvious groundings in the medical model. On the other hand, the psychosocial and interactionist approaches assume that disability is a social construct. In these latter approaches, "Instead of the disability itself, the crucial factor is the social communication of information and interpretive stances taken by professionals and other

family members” (Ferguson, 2002, p. 127). Understanding this framework provides a way of knowing how research, just as medical professionals, can come to perpetuate a medical model of disability which can impel the dominant cultural narrative forward, or otherwise disrupt or counter it, as Lalvani and Polvere (2013) have shown in their review of historical perspectives on families with children with disabilities.

Influenced by critical disability studies, research from the social sciences on parents raising children with Down syndrome since the 1990s has mostly adhered to a social model of disability and has adopted a psychosocial approach. Importantly, research findings have not supported the notion that parents endure immitigable or chronic grief, neurosis, and lifelong suffering (Farsad, 2005; Ferguson, 2002; Poehlmann, Clements, & Abbeduto). In fact, research has revealed that for parents, life raising children with Down syndrome likely has both negative and positive outcomes (Douglas, 2014; Van Riper & Choi, 2011).

Still, an argument has arisen within the last decade that even the psychosocial approaches, which have examined the themes of stress and coping, have been influenced by the medicalized model of disability, positioning children with Down syndrome as the source of stress in parents. Stress and negative emotions are built-in assumptions in many of the survey instruments that have been employed (Lalvani & Polvere, 2013). Furthermore, while the researchers who have examined stress, coping, and resilience (e.g., see Esbensen & Seltzer, 2011; Hauser-Cram et al., 2001; Poehlmann et al., 2005) have argued for a social model of disability, they may not have not done enough to uncover the sociocultural sources or implications of the effects of dominant discourses of disability (Lalvani, 2008; Song, Mailic, & Greenberg, 2018). Lalvani and Polvere (2013)

in their call for research using narrative inquiry and critical approaches note, “In this extensive body of research that seeks to explore depression and stress among these families, issues pertaining to sociocultural attitudes, values and beliefs about disability are not explored” (p. 5). While Gabel and Kotel (2015); Isgro (2016); Lalvani (2008, 2011), and Piepmeier (2015) have examined mothers’ experiences from critical perspectives using narrative approaches, research adopting a critical disability perspective has not yet endeavored to understand fathers’ experiences.

Parents’ Interactions with Medical Personnel during the Initial Period of a Diagnosis of Down Syndrome

A diagnosis of Down syndrome naturally begins with an interaction between a parent or parents and a medical professional, either prenatally or postnatally. Skotko, Levine, and Goldstein (2011) in a survey of over 2000 parents, and Piepmeier (2015) in in-depth interviews of 32 parents of children with Down syndrome (as well as 14 mothers who elected to terminate their pregnancies) found that interactions with medical personnel are critical, having an effect on parents’ decision to terminate or continue a pregnancy with a prenatal diagnosis.

How medical professionals act around and deliver information to parents matters (Saul & Meredith, 2016). Parent experiences are influenced by the language or the demeanors of medical professionals upon disclosure of a diagnosis (Ferguson et al., 2006; Skotko et al., 2009a, 2009b). Skotko et al. (2009a, 2009b) found that professionals may help parents understand and adjust to sudden and unsettling news of a diagnosis of Down syndrome, or can otherwise further confound parents’ already intense emotions and confusion. Lalvani and Polvere (2013) argue that medical professionals often serve to

corroborate a dominant cultural narrative that associates disability with grief and tragedy. Parents receiving diagnoses of Down syndrome begin their new lives with a deficit-based assumption that their child is somehow a problem.

Skotko (2005), in a survey answered by 985 mothers of children with postnatal diagnoses of Down syndrome, found that physicians and other medical personnel were not providing accurate or updated information about Down syndrome to parents, and in most cases were not discussing potentially *positive* aspects or outcomes of life raising children with Down syndrome. Kleinert et al. (2009) found that many physicians did not feel adequately trained or competent to discuss Down syndrome diagnoses with parents, and such physicians could benefit from training and technology designed to improve their knowledge of and comfort discussing diagnoses.

Because of these and other studies, Edwards and Ferrante (2009) assembled a conference in which professional organizations including the National Down Syndrome Society (NDSS), the National Down Syndrome Congress (NDSC), the American College of Obstetricians and Gynecologists (ACOG), the American College of Medical Genetics (ACMG), and the National Society of Genetic Counselors (NSGC) collectively were called upon to recommend best-practice advice for delivering diagnoses of Down syndrome. An organized statement of their consensual recommendations (as organized by Edwards and Ferrante, 2009) urges, among other helpful suggestions, that physicians provide education about prenatal screening and diagnosis to parents that is “complete, consistent, non-judgmental, and non-coercive” (p. 6). It can be argued that despite best practice recommendations, physicians are not adequately educating parents facing an initial prenatal or postnatal diagnosis.

Accordingly, professional support and advocacy organizations have synthesized and condensed much of the research on recommended practices for delivering diagnoses into “do and don’t” style publications. For example, The Down Syndrome Diagnosis Network (2017) has widely disseminated recommended practices to hospitals, doctors’ offices, and clinical settings. Their recommendations include delivering the news to both parents simultaneously, holding conversations in private settings, providing accurate and timely information, availing parents of opportunities to meet families and connect with support organizations, limiting discussions of possible medical conditions in the child to within one year of age, and avoiding using phrases such as “I’m sorry,” “Unfortunately,” and “I have bad news” (Skotko et al., 2009a, 2009b).

Despite abundant resources that train healthcare professionals on how to discuss new diagnoses of Down syndrome with patients, research findings indicate that many parents are dissatisfied with their interactions with medical professionals. In their survey of 284 parents, Van Riper and Choi (2011) found that 48 % of mothers and 50 % of fathers were dissatisfied with the manner in which a medical professional delivered their diagnosis. The age of the child at the time the parents completed the survey and whether the parent received the diagnosis prenatally or postnatally did not affect parents’ answers. One possible explanation is that parents’ perceptions of diagnosis delivery had not improved in the twenty years prior to 2011, and also that whether the diagnosis was for a fetus or an infant did not have an impact on parents’ perceptions of their interactions with medical professionals during the initial moment of diagnosis.

Van Riper and Choi’s survey (2011) revealed that parents lamented receiving a barrage of medical facts about Down syndrome, and instead preferred information about

what life might be like raising their child. Van Riper and Choi's findings also revealed various reasons why parents were upset with interactions, including medical personnel who coerced parents (in prenatal diagnoses) to terminate pregnancies, and otherwise promoted stereotypes about Down syndrome, were evasive, were void of compassion, lacked forthrightness or honesty, provided lack of support or information, or communicated low expectations about children with Down syndrome.

Nelson Goff et al. (2013), in an online survey of 161 parents, also found little differences between groups of parents who received diagnoses prenatally or postnatally, with both groups evaluating their experiences with medical professionals more often as negative than positive. The manners in which medical personnel delivered their diagnoses mattered to parents in that study, with both groups lamenting a lack of appropriate and current information, as well as a lack of compassion or support.

Isgro (2016), in a focus group study which looked at three groups of seven to 10 women, found that mothers were annoyed when professionals did not use people-first language such as "child with a diagnosis of Down syndrome" instead of "Down's baby" and medical professionals avoiding contact with them or being evasive. The themes emerging from mothers' narratives in these groups were "silence, shame, and secrecy" (p. 70). A complaint appearing frequently in research findings, one that bespeaks the dissonance between best practice recommendations and actual practices is that professionals delivered the diagnosis as if were bad news or tragedy (Skotko et al., 2009a, 2009b; Van Riper & Choi, 2011).

Gabel and Kotel (2015), conducting a narrative inquiry of three mothers who had given birth to children with Down syndrome, but analyzed other studies in which mothers

experienced traumatic birth circumstances, found that medical personnel served to position parents in a “normative discourse” (p. 13), in which their children were seen as “other,” as unwanted. Mothers in that study spoke of a “lack of eye contact, congratulations, or happiness [and of] medicalized identity formations and avoidance” (p. 7).

Counselman Carpenter (2015), in a dissertation study in which the investigator interviewed 18 mothers who experienced an unexpected diagnosis of Down syndrome in their children shortly after birth, reported that half of the participants experienced a negative reaction from medical personnel. Factors that influenced participants in that study included the person delivering the diagnosis, the timing of when it was delivered, language used by medical personnel, the emotions (or absence thereof) of the news bearer, the certitude of the diagnosis, and other persons present when it was delivered.

Research has begun to uncover what parents want (or would have wanted) from their interactions with medical professionals at the time of the initial diagnosis. Sheets et al. (2011) surveyed over 900 parents of children with Down syndrome. Their findings suggest that parents’ needs and priorities tend to strike a balance between clinical information and information about the potentials and abilities of people with Down syndrome. Parents wanted accurate and relevant information about what their family might experience. Van Riper and Choi (2011) revealed that parents wanted an unbiased stance from medical professionals, positive information about what their child might accomplish, emotional support, and up-to-date resources delivered shortly after the diagnosis. Fleming (2013), in a phenomenological dissertation study of 10 fathers of children diagnosed postnatally with Down syndrome agreed with mothers concerning

their interactions with medical personnel. Fathers appreciated medical personnel who delivered upfront, honest, and supportive information. They also appreciated the supportive literature, as well as the pragmatic next steps: the contact information for therapists, early intervention specialists, and opportunities to meet other families.

Parents' Emotions and Experiences during the Initial Period of a Diagnosis of Down Syndrome

The sudden diagnosis of Down syndrome is for most parents associated with intense emotions. Hodapp (2007) notes, "Almost by definition, the offspring with disabilities [is] thought to cause 'bad things' to happen to families and to individual family members" (p. 279). Regardless of the source of such emotions, or the duration of their effects and impacts, which will be discussed elsewhere in this literature review, intense emotions of doom are often present in the moment of diagnosis. Ellis (1989), in a review of research dating to the 1960s, described a loss of an expected child spurring a family crisis, with grieving as a natural process. Eakes, Burke, and Hainsworth (1998) in a later defense of models of chronic sorrow demonstrated that grieving is a natural response to the initial loss of the "perfect" child (p. 181). Those authors argued that chronic sorrow is a lifelong process.

Nelson Goff et al. (2013) found that both mothers and fathers experienced a "violation of expectations" (p. 1133) causing grief, stress, and shock. In fact, grief was the most common theme in Nelson Goff et al.'s findings, suggesting that parents experienced strong feelings, Described by Poehlmann et al. as "loss and mourning for the 'hoped-for child,' similar to [Kubler-Ross's model concerning] bereavement associated with the death of a family member" (p. 255). Fleming (2013) also found that fathers

revealed all of the stages of grief described by Kubler-Ross except for bargaining. Ridge (2013) in his study of fathers with prenatal diagnoses reported that all 10 participants experienced grief and loss, but six out of 10 fathers felt acceptance quickly after some “turning point” in the pregnancy (see p. 121). Turning points included meeting families with children with Down syndrome and having intense, in-depth conversations with their partners.

Lalvani (2008), in a narrative inquiry of nine mothers, found that those mothers experienced shock, distress, and depression upon diagnosis. Lalvani (2011) repeated a similar narrative inquiry in another study and found similar experiences, with expanded descriptions of anger, fear, guilt, rage, and devastation. Gabel and Kotel (2015), and Isgro (2016) reported mothers experiencing similar themes of shock, sadness, stress, and grief.

Ridge (2013), in a doctoral study featuring a phenomenological approach examining 10 fathers receiving a prenatal diagnosis of Down syndrome in their children, found that the participants experienced grief, fear, mourning, denial, anger, shock, devastation, and being overwhelmed. Fathers in that study used colorful and illustrative metaphors such as feeling “crushed,” or being in “emotional tailspin” (p. 122), or the picture of a happy family being “thrown away” (p. 87) upon the news of a prenatal diagnosis.

An interesting and unique perspective comes from the autoethnographic account of Kaposy (2013), a bioethicist whose own dissertation concerned disabilities and a stance against infanticide, and who later became a father of a child with Down syndrome. Kaposy reported “panic and dread” (p. 19) upon suspecting a Down syndrome diagnosis in the case of his would-be child; this, as Kaposy points out, despite the understandings

carried by his professional self that life with children with disability need not be a cause for dismay. Even Kaposy's professional understandings did not mitigate his personal feelings of panic and dread, which serves as evidence of an insidious and hegemonic dominant cultural narrative at work. Even the professional who understands developmental disability, and empathizes with the parent experiencing a new diagnosis feels the sting of the dominant cultural narrative, as "panic and dread" set in.

Lalvani (2008, 2011), Gabel & Kotel (2015), and Piepmeier (2015) all found that mothers receiving a prenatal diagnosis of Down syndrome come to a crossroads of discourses concerning women's reproductive rights, spirituality, life raising children with Down syndrome, and responsibility to society. Piepmeier found that mothers felt a great uncertainty amid a decision-making process involving their reproductive rights as defined by, "confusion, grief, struggle, and paradox" (p. 2), the paradox being that they felt overwhelming love and desire to protect the fetus, even if that meant termination. The mothers in Peipmeier's interviews all shared similar understandings of social stigma against persons with Down syndrome and the effect (or projected effect) of stigma on themselves.

Gabel & Kotel (2015) similarly found that mothers may have a sense, which they garner from dominant discourses of disability, that they are "transgressing cultural norms," causing their experiences to be "fraught with confusion, isolation, degradation, and feelings of invisibility" (p. 1). Similarly, Lalvani (2011) found that many mothers may become aware of the "embeddedness of this initial reaction in a sociocultural, historical, and political context" (p. 282) as they reflected on and relayed diagnosis narratives. Lalvani reported that mothers heard expressions of sympathy and

prognostications of burden and hardship from medical personnel, had doctors question them about terminating the pregnancy and asking why they had forgone prenatal testing, and heard expressions that they were having a “special child” (p. 283).

Ridge (2013) examined fathers’ prenatal experiences and found that most fathers had “strikingly affirmative perspectives” (p. 121). All nine participants told of intense emotions upon diagnosis, which included disappointment, upset, and feeling crushed. All nine participants also had conversations with their partners about terminating the pregnancy. Some cited religious precept or faith as a deciding factor to continue the pregnancy, while others cited more earthly ethical and values-related matters. Some fathers reported serious, drawn-out (in one case ‘heated’ [p. 92]) discussions with their partners, while others described unspoken understandings. Most fathers were deferential to their partners (“Obviously, it is her body” [p. 91]), while others came at odds with their partners, but in all cases in that study, participants came to accept the pregnancy and later view their decision favorably.

Ridge (2013), as mentioned above, reported fathers describing a “turning point” after the prenatal diagnosis. These turning points were spurred by religious beliefs in some cases, but also encounters with other families of children with Down syndrome who offered social support. One father remarked that the kid with Down syndrome whom he met convinced him that the diagnosis “was not quite dooming all of us into a life of institutions” (p. 93). It is possible that the “turning points” described by Ridge offer some evidence that fathers do consider the dominant cultural narrative and view their own experiences as counter to it, as Lalvani (2008, 2011) found mothers may do.

Disclosing the fact that their child (or fetus) has Down syndrome to families and friends may be difficult for both mothers and fathers. Gabel and Kotel (2015) relayed in their findings the difficulty mothers experienced concerning how family, friends, and strangers viewed their children and their decision to continue a pregnancy of a fetus with Down syndrome. Ridge (2013) found that fathers may have a difficult time telling their family members and friends about the diagnosis. Family members' lack of knowledge of Down syndrome made relaying the diagnosis all the more difficult, and cultural differences had an effect on fathers' comfort levels. One American participant, for example, reported difficulty discussing the diagnosis with his Muslim mother in Morocco. That father attributed a lack of awareness of disability in Moroccan society to his mother's advice for his partner to terminate the pregnancy.

It is important to note that not all parents view the diagnosis of Down syndrome as a profoundly negative experience. Nelson Goff et al. (2013) found that many parents with prenatal diagnoses had adjusted to the idea of raising a child with Down syndrome, as a prenatal diagnosis allowed them time to process and prepare. The act of becoming aware of a diagnosis may begin the process of coping and adaptation. Bingham et al. (2012), in in-depth interviews of six mothers, reported that the greater the amount of time spent in uncertainty of a diagnosis was associated with greater stress for mothers.

Some factors may attenuate the effect of a sudden diagnosis of Down syndrome. Nelson Goff et al. (2013) found that mothers who held their babies prior to diagnosis (this would of course be exclusive of postnatal diagnoses) adjusted more quickly than mothers who did not. Nelson Goff et al. also found that mothers who had more prior knowledge and awareness of Down syndrome adjusted more quickly. Other factors seem to have a

reductive impact on the parents' intense emotions. Humphreys et al. (2008) found that for mothers, support from their partners was a factor in easing the emotional strain.

Counselman Carpenter (2015) found that informal social support from family, friends, religious leaders, and neighbors; as well as formal social support from medical personnel, social workers, and interventionists considerably changed the nature of their initial diagnosis experiences, often for the better.

The presence of medical complications in the fetus or child may create new emotions and concerns that supplant the initial emotions of the diagnosis. Counselman Carpenter (2015) and Driscoll Nugent (2011) reported that mothers whose children experienced feeding difficulties, required extended NICU stays, or had heart conditions presented challenges that changed the nature of parents' experiences of their children's Down syndrome diagnosis by posing newer and more exigent concerns. Nelson Goff et al. (2013) found that 26 % of their prenatal group and 23 % of their postnatal group reported medical complications, suggesting that the issue of medical problems complicating diagnosis runs in both groups.

The initial emotions and reactions of receiving a diagnosis of Down syndrome vary in intensity and duration (Bingham et al., 2012; Counselman Carpenter, 2015; Driscoll Nugent, 2011; Nelson Goff et al., 2013), but a consensus in the research seems to be that most parents consider the moment of diagnosis to be characterized by intense emotions, stress, and uncertainty. A dramatic statement emblemizes the parent experience encountering a dominant cultural narrative of Down syndrome during the moment of diagnosis: "In many cases, the infant with Down syndrome enters this world surrounded by hope and love that can be stripped immediately away and replaced with

disappointment and fear. The joy of a new life is tainted by the unexamined, misunderstood, and imposed assumptions of others” (Gabel & Kotel, 2015, p. 3).

Parents cope with the stress of the initial period of diagnosis in different ways depending on context (Cuskelly et al., 2008). Poehlmann et al. (2005), interviewing 21 mothers, differentiated between negative or emotion-based coping strategies and positive or problem-solving strategies. Mothers in this study benefitted during the initial period of diagnosis by support from friends, family, and especially partners. Similarly, Bingham et al. (2012), by using a model that distinguishes between palliative strategies and problem-solving strategies, found that coping begins soon after the initial diagnosis. Palliative strategies do not have remedial or action-oriented outcomes, and include denying, questioning, and wishful thinking. Problem-solving strategies actively seek corrective or therapeutic measures and may include information-seeking, finding social support, reframing experience, and relying on spirituality. Bingham et al. found that palliative strategies were effective during the initial moment of diagnosis, especially when mothers experienced a delay between a suspicion of Down syndrome and a verified diagnosis, but that problem-solving strategies helped them to adjust to the diagnosis in their lives thereafter.

Again, there exists no consensus as to how long the “initial” period of diagnosis lasts; however, it is clear that a separation exists between the initial moment of diagnosis and some later point after, which for the purposes of my research may be described in variations of “life raising children with Down syndrome.” Findings in Poehlmann et al. (2005) and Bingham et al. (2012) suggest that as parents transition from the initial diagnosis period to their lives thereafter, their coping strategies change from palliative to

problem-solving. While no research has yet attempted explicitly to partition or demarcate the parents' initial reactions to diagnoses versus life thereafter, research designs and findings of research results across the corpus of literature have propitiously organized around the idea that the initial intense emotions subside in most parents as they settle into their lives raising children. Thus, one of the organizing principles in my study's design was to interview fathers first about their initial reactions and experiences concerning diagnosis and second about their lives raising children. The next section of this review of the literature examines research findings about parents' lives raising children with Down syndrome.

Research on the Experiences of Parents Raising Children with Down Syndrome

Studies once routinely examined the experiences of parents of children with Down syndrome combined with parents of children with other intellectual disabilities, including studies exclusively with fathers (Ricci & Hodapp, 2003; Stoneman, 2007). The culmination of much of this research resulted in something researchers termed "The Down syndrome Advantage" (Corrice & Glidden, 2009). Children with Down syndrome, results suggested, are easier to raise and create less stress on families than children with other intellectual disability. Findings comparing parents' experiences along lines of their children's varying diagnoses exceed the scope and focus of this dissertation; an interested person might find a review in Esbensen & Seltzer (2011). However, some findings from those studies are relevant to this dissertation insofar as much of the learning about parents of children with Down syndrome emerged from those studies, particularly in the years between 1999 and 2011.

As for parents of children with Down syndrome, the emotions associated with the initial diagnosis most often give way to a pattern of stress and coping. Nelson Goff et al. (2016), in a survey of 445 parents of children with Down syndrome of various ages, found that the common and expected themes of shock, anger, distress, grief and loss eventually receded and were followed by experiences mostly understood as stressful, but simultaneously occurring with coping, adaptability, resilience, acceptance, growth, and in many cases transformation.

Stress

The sources of the stress on parents raising a child with Down syndrome have been identified in the research as deriving from child-based characteristics, parent-related stressors, and mental health and psychological well-being of the parent (Cuskelly et al., 2008). Child-based characteristics that cause stress in parents include demandingness and inadaptability (Hauser-Cram et al., 2001) as well as aggression, stubbornness, and moodiness (Poehlmann et al., 2005). Parent-related stress derives from aspects of experiences raising a child with Down syndrome, including depression, social isolation, strain on partner relationships, frustrations with developmental delays, and demands related to the health of the child (Esbensen & Seltzer, 2011; Hauser-Cram et al., 2001).

Krauss (1993), in a survey of 141 parents of children with Down syndrome, found that mothers reported more difficulty adjusting to parent related stressors than fathers did, and fathers reported more difficulty adjusting to child-related stressors than mothers did. Hauser-Cram et al. (2001), in a landmark longitudinal study which began focusing on 183 parents whose children were <12 months of age and followed those parents until their children were age 10, found that both mothers and fathers experienced child-related

stress increasingly until their children reached age ten (when data collection stopped), but stress had significantly increased for fathers during the child's infant and toddler years (0-3), suggesting that this may be an age in which fathers' experiences differ from mothers'. Hauser-Cram et al. also found that fathers and mothers' parent-related stress was comparable, and not appreciably higher than that of typically-developing parents, when their children were age ten, suggesting that stress raising children with Down syndrome most often does not raise to clinical levels.

Meeting the therapeutic and medical needs for children with Down syndrome is a source of stress for parents frequently identified in the research. Farkas et al. (2019), in an online survey of 435 parents of children with Down syndrome, found that those demands were responses to both serious medical conditions and persistent chronic health conditions. Skotko et al. (2011) found that high levels stress due to medical complications were associated with lingering regret among parents. Ridge (2013) found that fathers, as their own involvement in raising their children increases, reported experiencing stress due to time constraints and frequent appointments.

Raising children with Down syndrome can result in stress that affects partner and family relationships. Risdall and Singer (2004), who conducted a meta-analysis of 13 studies on marital relationships in parents of children with disabilities, Kersch et al. (2006), who gathered data from 67 families participating in an early intervention survey, and Hartley et al. (2011), in an extensive literature review, found that stress has an impact on family and parent inter-relationships. Ridge (2013) found that as fathers increase their involvement with their child with Down syndrome, they have better relationships with everyone in the family. Norton et al. (2016), in their survey of 112 couples who were

parents of children with Down syndrome, found that as fathers become more involved in the care of their children with Down syndrome, and their attachment to their children increases, their stress own decreases, and their partners' stress decreases. Cuskelly et al. (2008), in a comprehensive article assessing information about families with Down syndrome, found that mothers' satisfaction with fathers' involvement helped both parents to adjust to stress. Urbano and Hodapp (2007), in a records review of hundreds of thousands of families, found that, in spite of stress, parents with a child with Down syndrome are slightly less likely to divorce as compared to parents in the general population.

A number of correlates to stress have been identified in the literature. Hornby (1995), in a questionnaire survey of 127 fathers, found that fathers' stress was lower with higher levels of their education and perceived financial adequacy, but not impacted by their socioeconomic class. Hornby also found that most fathers did not demonstrate depression or "personality difficulties" (p. 251) as a result of raising children with Down syndrome. Phillips, Connors, and Curtner-Smith (2017), who surveyed 35 mothers of children with Down syndrome and 47 mothers of typically-developing children found that lower levels of authoritative parenting styles (and higher levels of permissive parenting styles) were associated with higher levels of stress in parents of children with Down syndrome.

Some researchers adhering to a psychodynamic approach assume that "chronic sorrow" and "ambiguous loss" remain a part of the parents' experiences as those parents mourn "their own lost dreams but also the loss of opportunities for their child" (Patrick-Ott & Ladd, 2010, p. 76). Eakes et al. (1998) maintain that chronic sorrow is a repeating

phenomenon in which people with disabilities and their families experience loss or grief when they find disparities between their own situations and societal, developmental, or personal norms. Research in the psychodynamic tradition has begun to explore ambiguous loss as a non-deficit, person-oriented approach. For example, in an online survey of 50 fathers, Bentley et al. (2015) found that fathers while coping with ambiguous loss fell into one of three categories: mastering, connecting, or thriving, suggesting that ambiguous loss as a construct may not be a fatalistic and irreconcilable sentence (as chronic sorrow) for parents raising children with disabilities. In fact, fathers in the thriving category had the highest levels of life satisfaction, marital satisfaction, and hope, akin to conditions described in the coping and resilience literature.

Coping

The stressors of raising a child with Down syndrome do not go unchecked by parents and are not immitigable and interminable, as research from the 1960s once suggested. Coping strategies that parents use to improve their experiences raising children with Down syndrome have emerged from the research. And while during the initial period of diagnosis, parents may rely on palliative strategies (Poehlmann et al., 2005; Bingham et al., 2012), research has shown that parents mostly rely on problem-solving strategies to cope with the stressors of raising children with Down syndrome. In fact, Ridge (2013) reported a majority of fathers establishing a forward-looking, affirmative approach after a prenatal diagnosis.

Hornby (1995), who was among the first investigators to examine the experiences of exclusively fathers (n = 127) of children in particular with Down syndrome, found that fathers did not cope or adapt differently according to child-related factors such as gender,

IQ, or age. Rather, fathers' coping and adaptation was related to their satisfaction with the social support they received and their own personality; i.e., fathers who showed "low levels of neuroticism and high levels of social desirability" adapted well (pp. 249-250). Hornby concluded, "It is important for practitioners not to project onto these fathers the sort of negative expectations which are found in the literature" (p. 252).

Poehlmann et al. (2005) found that parents employ a number of positive coping strategies such as finding faith or spirituality, finding support in family, and advocating for their children. Phillips et al. (2017) found that parents of children with Down syndrome adjust their parenting styles, often to reflect more permissive versus authoritative styles but could benefit from training and support to parent under stressful conditions. Norton et al. (2016) found that parents who sought respite care were coping with stress better than those who did not. Two prominently identified coping strategies that parents rely on have emerged from the literature. They are information-seeking and finding social support.

Information Seeking

One of the most common coping strategies employed by parents is information seeking. Gibson (2016), using a grounded theory design in which 35 parents of children with Down syndrome were interviewed, argues that most parents who are not mired in denial or dismissive orientations enter into an "information world" of Down syndrome (Jaeger & Burnett, 2010 in Gibson, 2016). The information world is a framework for understanding how parents engage in information seeking in terms of understanding the self and where and how it interacts with other people and information in society and on the internet and in media. Skotko et al. (2009a,b) found that parents may benefit from

guided assistance as they seek information about raising children with Down syndrome. Douglas (2014) in an article addressing grief counselors argued that parents benefited by counselors encouraging them to engage in identity reconstruction and meaning-making after feelings of shock and loss have subsided. Gibson (2016) found that parents progress in somewhat predictable patterns from information-avoidance to active information-seeking, and thus may benefit from a progressive plan of assistance with information gathering from counselors and therapists.

Social Support

Parents of children with Down syndrome and theorists generally cite the need for or value of social support and belonging (King et al., 2006; Nelson Goff et al., 2013; Skotko et al., 2009a, 2009b). Ridge (2013) found that fathers benefited from social support and enjoyed being part of a Down syndrome community, which they found to be especially close. Fathers in that study reported “satisfaction, support, and affection” (p. 132). Farkas et al. (2019) found that fathers, like mothers, reported a reduction of stress and increased satisfaction when their perceptions of social support are high. Negative encounters in situations of social support, however, can increase stress. This may be true especially in encounters with larger, more formal institutions than smaller support groups. Sauer (2013) demonstrated frustration with this in an autoethnographic account, and Neely Barnes et al. (2010) in a focus group study of 45 parents of children with various intellectual disabilities found that institutional ableism in educational and medical settings can be a significant source of stress.

Resilience and Positive Outcomes

Regardless of the coping model, the literature suggests generally that parents find

life raising their child with Down syndrome is not as bad or tragic as they might have imagined or projected during the initial period of diagnosis (Nelson Goff et al., 2016). In fact, research has found that parents and families demonstrate resilience, or the ability to endure and move on from major challenges and to tolerate stress (Cuskelly et al., 2008; Myers-Walls, 2017; Van Riper, 2007; Walsh, 2003).

Positive themes have emerged from research on parent experiences of raising a child with Down syndrome. In a case study design with 19 parents of children with Down syndrome, Kausar, Jevne, and Sobsey (2003) found that hope was a strong predictor of positive transformation in parents. King et al. (2006), from three focus groups of 19 total participants, found that parents adjust to lost dreams and create new belief systems and worldviews that accommodate positive contributions of people with disabilities to their families and society on the whole. Constantino (2010) in an autoethnographic account aimed at counselors found that healthy relationships and a sense of connectedness helped mothers demonstrate resilience, growth, and healing. Gilmore and Cuskelly (2007) surveying and presenting research in a conference paper, found that parents of children with Down syndrome had high levels of satisfaction and perceived parenting efficacy, on par with parents of typically-developing children when their children were age four to six.

Farkas et al. (2019) found increased pride, social connections and perceived positive contributions to the family a child with Down syndrome makes. Norton et al. (2016) found Contributions from children include “daily uplifts” from personality. And Douglas (2014) found parents discover “silver linings” (p. 697) in their lives that help them forge meaning. Isgro (2016) found that many mothers described raising their

children with Down syndrome as a joy and that they provided “unexpected benefits” (p. 69). Skotko et al. (2011) found that 99 % of parents love their son or daughter with Down syndrome and 97 % of parents were proud of their children. Only five percent of parents reported being embarrassed of their son or daughter with Down syndrome and only four percent regretted having their son or daughter. Scorgie, Wilgosh, and Sobsey (2004) and Scorgie and Wilgosh (2008) have established that parents raising children with Down syndrome develop effective life management strategies that hold over time and eventually may lead to positive substantial transformations.

These general conclusions about life raising children with Down syndrome are serviceable towards helping parents with new diagnoses realize that the important aspects of parenting life, such as love and pride, are overwhelmingly present in life raising children with Down syndrome and are especially helpful in understanding a big picture (Skotko et al., 2011). More critical research studies, however, have cautioned against an exclusive inquiry for positive experiences raising children with Down syndrome in favor of more accurate and balanced accounts (Farkas et al., 2019; Ferguson, 2002; Isgro, 2016).

Accurate and Balanced Accounts of Life with Down syndrome

Outside of academia, a flourishing stream of parent memoirs exist. While such memoirs purport to promote visibility of children with disabilities, they may be problematic in that by sensationalizing narratives, they depict raising children with disabilities as a heroic act, or otherwise depict persons with disabilities as heroic other. Worse still, they may portray people with disabilities as problems their parents have overcome (Piepmeier, 2012; Sauer & Ferguson, 2013). In academia, Krauss (1993) and

others (Ferguson 2002; Linton, 1998) have suggested a need to focus on power structures and sociocultural factors as sources of grief and stress in parents of children with disabilities, which presaged the need for a more critical and culturally-embedded focus on the experiences of parents of children with Down syndrome. Research framed by critical disability studies, particularly in the last decade, has problematized not only the medicalized model of disability and its intransigent linkage of disability with pathology, but also the psychosocial approaches and their emphasis on stress, coping, and resilience as being deficit-based, relying on assumptions that equate disability with loss.

Hodapp (2007) and Cuskelly et al. (2008) have observed that investigators once tended to focus on the negative aspects of raising children with Down syndrome. A number of studies in the last decade have encouraged a balanced approach that seeks both negative and positive experiences (Farkas et al., 2019). In fact, raising children with Down syndrome, just as raising children in general, has negative and positive aspects. King et al. (2000) found that stress and growth may in fact occur simultaneously. Lalvani (2008), notes, “Although many parents of children with developmental disabilities report increased demands, higher levels of stress, or negative feelings, they simultaneously report positive perceptions, increased familial closeness, personal growth, and enrichment in their lives as a result of their experiences” (p. 436). Psychosocial and interactionist approaches have demonstrated that life raising children with Down syndrome is contextual, where many internal and external factors around the parent are brought to bear (Ferguson, 2002). In an important, somewhat recent addition, Marshak, Lasinsky, and Williams (2019) in a survey of 311 fathers of children with Down syndrome found that fathers experienced positive changes and personal growth as a result of raising their

children, but those positive changes coexisted with stress and anxiety.

Counselman Carpenter (2015) found that stress may actually spur growth. This study ascribed eventual positive outcomes following a difficult initial period of diagnoses to posttraumatic growth in mothers. Mothers found strength previously unknown to them, which lead to various transformations, including reformed perspectives of Down syndrome, leadership, and advocacy. Counselman Carpenter also reported that mothers experienced a greater appreciation of small things as well as changed priorities.

Ridge (2013) found that fathers experienced personal growth in levels of tolerance, acceptance, appreciation, and patience. Kaposy (2013) reported that he and other fathers showed increased open-mindedness and being less judgmental. King et al. (2006) found that fathers experience important changes to values and belief systems and world views. Fathers gained a sense of self-efficacy and control as they spent more time with their children and demonstrated adaptability and resilience. Their world views became broader and more resolved, and they reassessed their values in terms of “what is important in life” (p. 361). Participants in several studies have described reported transformations that go beyond changes to routine and daily life and enter into changes to belief systems and world views (King et al., 2006; Ridge, 2013; Scorgie et al., 2001).

Awareness of Positioning in a Down syndrome Discourse

Having a child with Down syndrome is for most parents a life-changing experience. Quotidian factors such as daily schedules, medical appointments, and family roles change, as do personal factors (Skotko, 2011). As mentioned, research has revealed a contrast between parents’ expectations during the initial diagnosis period and their actual lived experiences some time after. Nelson Goff et al. (2016) found that parents

demonstrated acute awareness that stress over society's reaction and acceptance of their children was more impactful than factors related to the child, Down syndrome, or to themselves.

Other studies have revealed parents' frustrations with issues in society. Several common themes have emerged from these frustrations. Counselman Carpenter (2015) found that mothers experience frustration with developmental delays as they compared their children to typically-developing peers. Those frustrations gave way to increased satisfaction when children achieved milestones. Hodapp et al. (2003) and Isgro (2016) found that parents experienced frustration with societal stereotypes of children with Down syndrome as happy or good-natured. Driscoll Nugent (2011) found that mothers experienced a sense of social isolation, and that they lost friends even as they made new friends with common interests. Isgro (2016) reported mothers' frustration with expressions of burden, sorrow, and sympathy from others. Isgro (2016) and Lalvani (2011) also found that mothers were frustrated with the myth of the super parent, the idea that parents of children with Down syndrome are somehow special, other than normal, heroically equipped, or chosen by God.

Lalvani (2008, 2011) found that many mothers, upon retrospective reinterpretation, became aware of the dominant cultural narrative and its hegemonic discourses and opposed it by means of creating counter-narratives, engaging in advocacy, promoting policy change, and supporting others. Lalvani also found that mothers engaged in a search for meaning that included social and interpersonal ramifications of life raising a child with Down syndrome, in effect, becoming aware of their positioning in a discourse. With that knowledge, they were able to stage a resistance to the medicalized

model of Down syndrome and a resistance to the idea of their children's "otherness" implied in the messages and behaviors of others. Many mothers reported transformations in their views of raising children with Down syndrome, and made concerted efforts to educate others about how "normal" their lives were. Faced with expressions of burden, sorrow, or sympathy, mothers in Lalvani's (2011) study found themselves emboldened to dispel such expressions. Overwhelmingly, mothers found themselves "just being a parent" (p. 285) and leading lives that they characterized as ordinary.

Fleming (2013) observed that fathers created "a new vision for their child, focusing on the child and not the disability" (p. 140) but did not examine how fathers engage with sociocultural issues that caused them to have to distinguish between the child and the disability. Missing from the literature on fathers of children with Down syndrome is any inquiry regarding fathers' views of the sociocultural source of stress in their lives and the dominant cultural narrative. It is clear that fathers sense a disconnect between their initial reactions, conceptions, and experiences of the moment of diagnosis and their later experiences raising their children (Fleming, 2013; Ridge, 2013). Research reveals that fathers are aware of the contrast, but no study has inquired of fathers why they believe it exists; nor have any studies analyzed their experiences with a view towards the effect of discourses or the creation of counter narratives. My research endeavors to examine fathers' experiences with this gap in mind.

Chapter Three - Methodology

Overview

This research study was a narrative inquiry into fathers' experiences upon learning of a diagnosis of Down syndrome in their children and subsequently into raising children with Down syndrome. While research historically has positioned children with Down syndrome as unwanted and as a source of immitigable grief and stress in their families, research in the previous three decades has determined that mothers and fathers raising children with Down syndrome demonstrate coping and resiliency.

Recent research using narrative methods and informed by critical disability studies has revealed that mothers have established counter narratives that contest and repudiate dominant discourses about raising children with Down syndrome. As mentioned in the previous chapter, mothers have increasingly become aware of their positioning in a dominant discourse and have begun to create a narrative that their lives are "normal," and that the stress of raising a child with Down syndrome may be understood in sociocultural contexts and not medical ones.

As the corpus of research contains fewer studies attempting to learn of fathers' experiences raising children with Down syndrome generally, and as few studies have assumed a critical disability studies approach which might look at fathers' positioning in the context of dominant discourses, my research attempted to address both of those gaps.

Rationale for Narrative Inquiry

The decision to use narrative inquiry for my research was primarily informed by the recommendations of Lalvani and Polvere (2013), who, reviewing the history of research done on parents of children with Down syndrome, argue that many studies

purporting to examine “objectively” families’ experiences are predicated on instruments such as the Parenting Stress Index (PSI), the Parenting Stress Scale (PSS), or the Global Inventory of Stress (GIS), in which “inordinate levels of stress among families of children with disabilities [are] the starting points for inquiry”(pp. 7-8). Such instruments examine parents’ experiences as interpreted by a set of questions that make assumptions about their lives, creating an understanding that “shapes certain realities and silences others” (p. 8). Narrative inquiries, on the other hand, “draw critical attention to the ways in which parents’ responses to their children’s disabilities are situated in cultural interpretations of disability labels and of the parameters of ‘normalcy’” (p. 14). As indicated in the literature review, studies which have used narrative inquiry informed by critical disability studies have created narratives of parents’ experiences that are counter or alternative to the dominant cultural narrative about raising children with Down syndrome. They provide more accurate accounts of parents’ experiences (Bingham et al., 2012; Counselman Carpenter, 2015; Driscoll Nugent, 2011; Gabel & Kotel, 2015; Isgro, 2016; Lalvani, 2008, 2011).

These extant narrative inquiries collectively demonstrate how narrative inquiry has the unique ability to relay, not merely descriptions of events or purported documentation of experiences, but rather *interpretations* of experiences, replete with enlightening internal and external dialogs and narrative choices participants make. The meaning inherent in experience is not only in content, but is influenced by the manners in which interpretations are related (Elliott, 2005).

Narrative inquiry is also an effective method for uncovering injustices inherent in dominant discourses. Clandinin and Rosiek (2007) note that, “Inequality and injustice

are sustained, in part, by the ways in which privileged members of society insulate themselves from the suffering of others. Attending to the narratives of marginalized groups can disrupt this insularity” (p. 62). Narrative inquiry is an optimal design and method for this study, as it adds to a small but growing body of literature that privileges the authentic voices of parents of individuals with Down syndrome and can help to uncover the way they interpret their experiences in the socially constructed context of the dominant cultural narrative. Narrative inquiry is a feasible method for reconstructing individuals’ experiences with self and others and situating them in a sociocultural context (Pinnegar & Daynes, 2007), as well as making meaning of those experiences (Clandinin & Connelly, 2000).

Narrative inquiry thus was thus selected as a sensible method for my research. As for guidance as to how a narrative inquiry might be conducted, Clandinin and Connelly (2000), Elliott (2005), Clandinin and Rosiek (2007), Polkinghorne (1988), and Josselson (2007) were reviewed. Clandinin and Connelly (2000) is a seminal text, often referred to in research using narrative methods to learn of the experiences of parents of children with Down syndrome (Driscoll Nugent, 2011). It also appears to be a standard bearer in the narrative inquiry chapters of textbooks on qualitative methodology and approaches (Marshall & Rossman, 2006; Creswell, 2012; Bloomberg & Volpe, 2008).

Recruitment and Sample

Participants in my study were recruited by means of snowball sampling with assistance from authors of blogs including *The Mighty* and *Inclusion Evolution*; from support groups on social media; from sources local to the author, including Southwest Florida BUDS; from word-of-mouth referral; and from political advocacy groups

including The ARC, The National Down Syndrome Society (NDSS), and The National Down Syndrome Congress (NDSC). Individuals calling themselves fathers and having at least part-time custody of a child with Down syndrome were invited to participate. IRB approval was obtained from Lesley University and general permissions were obtained from institutions assisting with recruitment mentioned above. Informed consent was obtained from all participants, including consent to be audio recorded. Participants were given the option of interview via phone or video conference. The written invitation to participate in the research returned over a hundred interested queries. Mothers, siblings, caretakers, and international participants were politely dismissed, apart from one Canadian father who had spent time in the United States. Some fathers expressed interest and later did not return calls or emails. In the end, 22 fathers were interviewed. Interviews ranged from 35 to 118 minutes in length, but averaged around 55 minutes.

Data Collection

All participants were asked beforehand to complete a brief survey collecting data regarding age, gender, socioeconomic status, racial and ethnic identity, and religious beliefs. Responses were open-ended. Participants, all of whom identified as male, ranged in age from 28 – 55 years ($\mu=41.4$ years). Their children, 12 boys and 10 girls, ranged in age from <1- 18 years ($\mu=5.7$ years). Most participants identified as white or Caucasian (17), with two identifying as Hispanic, one identifying as biracial, one identifying as ethnic Jewish, and one response left blank. Descriptions of socioeconomic class included the terms: working class (1), lower middle class (1), middle class (11), and upper-middle class (6). Other variances (3) were “below average,” “high,” and “comfortable.” Religious beliefs were mostly described on survey responses as some variation or

denomination of Christianity (17), in addition to two participants using the term “atheist,” one self-describing as “non-practicing,” one participant identifying as “Modern Orthodox Jewish,” and one participant describing his religion as “worldly.” A geographic diversity was established in the population sample of this study, with participants ranging from: California (3), Arizona (1), Oklahoma (1), Texas (2), Louisiana (1), Arkansas (1), Florida (2), North Carolina, Virginia (2), New Jersey (1) New York (1), Massachusetts (1), Indiana (1), Michigan (2), Minnesota (1), Illinois (1), and Vancouver, British Columbia (1).

After being provided verbally a brief overview description of the study, which emphasized that fathers’ perspectives were needed, but was careful to avoid declaring assumptions or biases, fathers were asked if they had any questions and to introduce themselves generally. They were then asked to begin their narratives by describing their experiences receiving the diagnosis of Down syndrome. Once that portion of their narrative seemed to be concluded, fathers were asked to describe what life is like raising a child with Down syndrome. Interruptions and probing questions were avoided whenever possible. The design of this study called for maintaining the integrity of participant-driven narratives, and required not asking probing or leading questions that might betray biases or assumptions. Once fathers seemed to complete their narratives concerning diagnosis and life thereafter, a third portion of the interview was initiated in which I asked follow-up questions, particularly critical questions pertaining to dominant discourses about Down syndrome. The spirit of narrative inquiry holds that the researcher and participants co-author the generation of field texts (Clandinin & Connelly, 2000), so this segment of the interview grew more conversational in nature, allowing for

candidness and increased disclosure about the theoretical underpinnings of my research.

Hollingsworth and Dybdahl (2007) note that the more the epistemological grounding in a research study moves away from positivism and towards constructivist and critical outlooks, the more a study's theoretical position on power, relationship, and identity, relies on the direction of narrative shifting back and forth between narrators and researchers. Clandinin and Connelly (2000), noting the potential of conversation, remark, "The listener's response may constitute a probe into experience that takes the representation of experience far beyond what is possible in an interview" (p. 109). My desire was to understand if fathers narrated their awareness of dominant cultural narratives upon diagnosis, and then, after diagnosis, if they offered counter-narratives or alternative interpretations of the discourse of raising children with Down syndrome. As I did not wish to make any putative claims about fathers' experiences with dominant cultural narratives that did not derive from their own narrated experiences, I ensured that every conversation at least once broached the subject.

Some fathers provided pictures, invitations to view Facebook pages, links to videos, and other artifacts. One father provided a video tour of his property. Three fathers introduced their children to me via video conference at the end of their interviews. It should be noted that this occurred at the end of the interviews and that, because the presence of children was not called for by the research design, these were informal and unexpected encounters. No children were present during the main conveyance of the interviews. Many fathers provided book recommendations, movie suggestions, and accolades for professional organizations. These field texts were collected and incorporated, as well as the extensive notes I took during interviews.

Data Analysis

In narrative inquiry, the bridge between data collection and data analysis occurs in the conversion of field texts to research texts. Clandinin and Connelly (2000) note, “As we move from field texts to research texts, our field texts are the texts of which we ask questions of meaning and social significance” (p. 130). Analytical and interpretive actions by the researcher convert the field texts into research texts. The meaning inherent in the transcripts, audio recordings, notes, artifacts, and in the researcher’s natural memory of interacting with participant become transmogrified into restoried narratives. Questions of meaning are rendered “more complex as we ask them in the midst of trying to negotiate a new way of being in relation with our participants” (p. 130). Audio recordings were transcribed manually by me, and reviewed a second time with thorough note-taking and narrative planning.

Finally, all field texts were converted to research texts through a restorying process that culled the salient features of participant narratives and reconstructed them with descriptions of the interview process. What qualified as salient features was determined by the participants and by me. Participants addressed the two open-ended questions during the interviews, and many specific themes, experiences, and emphasized details driven by the participants, some anticipated and others not, were relayed. During the second, more conversational phase of the interviews, I asked many directed questions that revealed further themes, experiences, and details that this study was interested in, especially as they concerned experiences with the dominant cultural narrative of Down syndrome. In this way, plot details of narratives were synthesized with descriptions of the way participants relayed them, the order in which they were relayed, the metaphors and

mannerisms participants adopted, the valuation of certain details over others, and additional features of emotion, appearance, voice, tempo, and emphasis. These restored narratives, which tended to be five to seven pages, represented the narrative experiences the fathers relayed during the interviews, as interpreted by me, in a three-dimensional inquiry space.

In narrative inquiry, the shift between data collection and analysis, between field text and research text, are not seen as a singular transition. Just as in other qualitative methods, member checking is a form of verifying authenticity and trustworthiness that can help validate the accuracy of findings (Creswell, 2012). With this in mind, the design of my study called for me to return all restored narratives to participants. Participants were asked to review their restored narratives in terms of characterizations, important features, accuracy of details, any missed details or opinions, and even the plausibility of the pseudonyms I generated. While I asked participants to review and comment on their narratives within two weeks, most did so within a day or two. All desired changes from participants were immediately incorporated without debate. Mostly, changes came in form of ages and timeline matters, or details about location. In one case, a father's name was representative of a US president, and when I changed it to a name of another president, he requested the use of a different pseudonym. In another case, the participant and the mother of the child with Down syndrome were no longer married, a detail that was rewritten into the narrative in a manner which was agreed upon with the participant. In no cases were changes so impactful that they created disagreement between the participant and me. I was able to incorporate them and proceed without further discussion.

The final process was to reread the restored narratives through again and to conduct a final thematic analysis. In all, 11 major findings coalesced.

Presentation of Findings

The value of narrative inquiry is in experience. Clandinin and Connelly (2000) note, “We keep in the foreground of our writing a narrative view of experience, with the participants’ and researchers’ narratives of experience situated and lived out on storied landscapes as our theoretical methodological frame” (p. 128). Unfortunately, it was not feasible to include as findings the entire restored narratives from all 22 participants in this study, as this would have made for a chapter nearly two hundred pages long. Clandinin and Connelly note, “The container establishes the form for us, and we work within that form to write our narrative inquiry text” (p. 155). Therefore, an effort was made to strike a balance between allowing the fathers’ voices (and thus experiences) to be heard and a movement towards thematic learning. Clandinin and Connelly refer to this as a tension between narrative form/experience and the “reductionistic boundary” (p. 140). People, after all, are not categorical monoliths, and in narrative inquiry, participants are enlisted to enrich an understanding of a research problem by means of their stories, not their classifiable characteristics. Their experiences are for the telling.

Still, as Clandinin and Connelly (2000) point out, narrative inquiry can be a method to “make sense of life as lived...by trying to figure out the taken-for-grantedness” (p. 78). Therefore, the purpose of data analysis for my study was not to distil themes by cycling through data, but rather to allow themes to emerge from stories. A great deal of taken-for-grantedness exists concerning the experiences of fathers raising children with Down syndrome. Taken for granted in society and the medical field is that

their lives will be in accordance with the medicalized model of Down syndrome, i.e., beset by grief, loss, tragedy, and hardship. Taken for granted in academia once was the notion that raising children with Down syndrome is comparable to raising children with other developmental and intellectual disabilities. Taken for granted in many studies which featured parents as a homogeneous group was the notion that fathers' experiences are the same as mothers'. Situated in a research area with a small basis of understanding experience, the task of analysis in my study is to discover if the themes present in the studies on mothers and parents in general emerge from fathers' experiences, but also to discover what other themes emerge, and what other experiences fathers report as salient features. The findings in my study are therefore presented in the next chapter thematically while maintaining as much of the participants' original expression as possible. The findings chapter will be followed by a more traditional interpretations section in chapter five.

Chapter Four – Presentation of Findings

The purpose of this research was to conduct a narrative inquiry into fathers' experiences upon the diagnosis of Down syndrome and about life raising children with Down syndrome. The design of my research study prohibited defining either of those conditions with precision because I wanted fathers to narrate their experiences in their own terms and through their own interpretations. This was to avoid the suggestion of assumptions that their experiences were negative, medicalized, stressful, or deficit-based, assumptions that can be found in survey-based research on parents of children with Down syndrome. I present the findings in this chapter in accordance with the order I presented questions to participants. In question one, I asked fathers about their reactions to and experiences upon the initial diagnosis of Down syndrome in their children, what I have referred to throughout as the "initial period of diagnosis." In question two I asked fathers about their experiences raising children with Down syndrome. Then fathers and I engaged in a third conversational phase. I incorporated some data from the conversational phase into the final thematic section about life raising children with Down syndrome, as will be clear below.

Question One

I presented Question One to all 22 participants as such: "What were your experiences during the initial period of diagnosis of Down syndrome?" I present the findings in this chapter as thematically organized subheadings, which I culled from the restoried narratives of the participants. Each subheading is followed by an amalgamation of my observations and many illustrative examples rendered in participants' original voices. Where applicable, I have made sub-findings as clear as possible. Although the

findings in this chapter are not presented in a pure narrative format, I made an earnest effort to allow fathers' voices to illustrate the findings.

Finding One: Of 22 total participants, 18 participants narrated interactions with medical personnel while four participants did not mention interactions with medical personnel. 13 participants reported negative interactions with medical personnel, while five participants reported exclusively positive interactions. Three participants narrated a combination of positive and negative interactions.

Eight of 22 participants received prenatal diagnoses, and of those, seven complained that medical personnel delivered the diagnosis as if it was bad news. Ryan said, "The demeanor of the ultrasound tech went from 'normal' to 'we have an issue.'" And later, delivering the diagnosis, the doctor immediately presented the option of aborting the pregnancy before attempting to explain what Down syndrome was. Branson reported that a genetic counselor, shortly after their diagnosis, bombarded him and his partner with "the bad things that [their family] were going to experience." He remembered thinking that there was no "silver lining in the cloud of negativity" cast by the geneticist.

Ryan, having experienced a chilling change in the ultrasound tech, lamented the icy manner of the physician, who next saw him and his partner, saying, "it just felt so, not human, I guess; it just felt like, do you want to buy this car or not?" Similarly, Samson recalled the diagnosing doctor's delivery as, "just so cold. It was very mechanical, without any concern for how the parents were going to take it." Paul disclosed that a substitute doctor (the OBGYN being away) left a nervous voicemail for his partner confirming a diagnosis, sounding as though he were grateful they did not pick up the call.

Wolfgang admitted the diagnosis was mournful, and said that medical personnel did little to “change the feeling of gloom.”

Wes reported that after he and his partner were delivered a prenatal diagnosis, various doctors, counselors, and medical support personnel at the large university hospital they visited “pressured” them regularly to terminate the pregnancy. Wes believed it was seven or eight times. He sounded disappointed when he intoned, “You’d expect them to be a bit progressive when it comes to quality of life for people with disabilities, but they weren’t.” He and his partner became so angry that they insisted the nurses prominently note in their chart that terminating the pregnancy was not an option.

Fathers receiving postnatal diagnoses in this study seemed to fare better with medical personnel, with only five of 14 participants reporting negative interactions. The five fathers who reported negative interactions with medical personnel narrated that medical personnel treated them and their spouses rudely and that they sensed or felt like there was something “wrong” with their children.

Howard remembered thinking that the medical personnel in the delivery room were quiet and evasive with information. He noted thinking, “We just had a baby; can't someone be happy?” He described the doctors’ bedside manners as “atrocious” in terms of their unwillingness to talk or even provide comfort. Howard and his partner were in the recovery ward by the time another doctor, who only identified himself as a “specialist,” entered to deliver the diagnosis. Howard angrily said, “The doctor pretty much told us all the things that our child would *never* do; he even used the term ‘these kids’ to describe what my son would never be able to do.”

When Trek's daughter was born after an emergency C-section, his partner was removed to a recovery room and his daughter was sent in another direction. A doctor curtly explained to him that his daughter needed "heart testing and chromosome testing" as she was carted away. He remembered asking of another doctor, "Does she have Down syndrome or something?" He described his interactions with that doctor as such: "I felt like she was being very arrogant, as if I couldn't take any news that she was going to give me." Because the doctor was so evasive, Trek assumed the worst, thinking, "Whoa! Is she going to pass away?" Trek had to find his partner's recovery room without anyone conducting him there. Then, he and his partner spent eight hours being told that they could not see their daughter. Trek spent this time on the internet, searching for symptoms of Down syndrome. He said he confirmed the diagnosis on his own, noting, "Features of Down syndrome, check; big fold on the back of the neck, check; eyes, check... you know what I mean? Everything. I got it." Trek reflected, "Obviously [Down syndrome] isn't 'nothing,' but it could have been far worse. We were definitely not happy with the way the hospital treated us. We felt like they couldn't give us the dignity to tell us their suspicions." Eventually a "Grief Counselor" came to deliver the diagnosis. Trek said, "I already figured it out myself."

Five participants reported exclusively positive interactions with medical personnel. Mark was more than satisfied with his experiences at Massachusetts General Hospital. He noted, "This is one of the great things about Massachusetts General. The head geneticist...told us about the program at Mass General for Down syndrome and autism. He got us signed up for that." Doctors in that program are tracking patients for longitudinal data, but they are also giving patients a comprehensive continuity of care

that includes medicine and therapies. Mark said, “They offer every service you could think of: social, physical therapy, speech, occupational, cardiology, dentistry, neuro; you name it, they have it.”

Chris said that he appreciated two things about the diagnosis, honesty and encouragement. A doctor of 35 years in practice told Chris and his partner that they could wait for the official genetic testing, but that he was *sure* their son Jake had Down syndrome. He also reassured them that they were “going to be fine.” Chris said the doctor was “kind... and very strong with his words, and that helped.” Paul similarly appreciated the matter-of-factness of his doctor’s diagnosis delivery, claiming that as an engineer and a man with a science background himself, he understood the need for directness. The clarity and precision of the doctor’s words helped him to overcome the shock of the information.

Barry’s partner June was employed as a midwife in the very hospital in which their son Rory was born. When she and Barry arrived by ambulance, several of her colleagues, nurses and midwives, were gathered about her supportively. Barry noted that as a source of familiarity that helped ease the pressure. Matt had the fortuitous and unexpected experience of a chance encounter with an old source of comfort. Their attending pediatrician was unavailable at the time of his son Andy’s birth, and Matt explained, “the one that we were assigned was the doctor I had when I was a kid, so it was kind of funny how it went around in a circle like that. It made me feel good.”

Three fathers narrated their interactions with medical personnel as a combination of both positive and negative experiences. Scott, who spent almost 24 hours in helicopters, ambulances, and multiple emergency rooms, was in a persistent state of

concern about his daughter's well-being, related the detail of a genetic counselor who delivered the diagnosis to him and his partner. Scott said, "There was this relief, at this point, because we finally got an answer, because we'd been asking at that point for almost a day." The genetic counselor gave them an honest diagnosis and an honest account of what life raising a child with Down syndrome might be like. The counselor was, "one of the coolest people" Scott ever met, and even became friends with the family, a friendship that has lasted. The hospital in which his daughter eventually recovered provided accurate information and education. Scott relayed, "We watched a video, read pamphlets; and I think even their story was, this isn't the end of the world, you know?" He felt pretty confident about his new life raising a child with Down syndrome as he left the hospital.

Howard describes the thoughtful act of a lactation nurse which helped to "break the spell of negativity" after a doctor told Howard's partner Jeanne that babies with Down syndrome could not breastfeed. The nurse scoffed at the doctor and said, "Let's give it a try." By the end of the day Howard and Jeanne's son Jack was "latching on like a champ." He breastfed just fine until he was nearly two years-old.

Brian said that the medical personnel were supportive of him and his partner, but he added, "There definitely wasn't the same happiness in their voice as when our first two kids were born." Brian delivered this idea with a big shrug and a frown. It was as if the reactions from the medical personnel were expected. Still, he added this final thought: "no negativity though."

On the subject of what fathers want from medical professionals during a diagnosis, three themes emerged in the narratives of fathers in my study: forthright

honesty, compassion, and accurate information. Eight participants lamented of doctors who were evasive with information. Three participants specifically said that they appreciated the forthrightness of medical professionals. Four participants specifically complained about the manner in which the diagnosis was delivered. Three participants indicated that they wanted the diagnosis delivered in a more compassionate or empathetic way. Four participants reported that they were given accurate and supportive information about Down syndrome and what might be in store for their family, while 20 participants resorted to independent information seeking, often because of the lack of information or support provided to them (see finding five a).

Finding Two: 20 of 22 participants reported experiencing intense negative emotions at the initial moment of a diagnosis of Down syndrome in their children. Participants reported shock and devastation, being scared or nervous, or expressing sorrow or loss of an expected child. Two participants did not report experiencing intense negative emotions, both of whom were personally familiar with people with Down syndrome.

Two participants did not describe any kind of negative thought when narrating their reactions to the diagnosis. Wes said that his primary reaction to the diagnosis was acceptance. He reported thinking, “Okay, at least it’s not Trisomy 13 or Trisomy 18, which are conditions not compatible with life... but Down syndrome? Cool.” Wes has had multiple jobs over 20 years working in various capacities with people with disabilities. He also has an older daughter with a rare genetic condition (fewer than 300 cases known worldwide). Down syndrome simply was not a cause for intense emotions for Wes. He intoned, “Some of my favorite people in the world have Down syndrome, people I’ve known for a long time.” Walter, too, narrated that he accepted the diagnosis

somewhat readily. He said, “To me it was like, okay that’s all it is? In terms of disabilities, this is something I can work with. We can get somewhere with her. It’s not going to be the end of the world.” Walter is the director of a home for adults with intellectual disabilities. He concluded by saying, “I’m a little bit more prepared than most people for this type of diagnosis.” Experience and occupation prepared these fathers uniquely for the diagnosis in their children.

For all other participants, the unexpected diagnosis caused intense negative emotions. Ten of 22 participants used the word “shock” when narrating their initial reaction to the diagnosis. Other similar words connoting the theme of the unexpected diagnosis and its effects on emotions ranged from the understated “concerned” to the dramatic “devastated.” Fathers who described shock seemed to use it to express being stunned or blindsided by the news. Fathers with stronger associated feelings of anger or depression used “devastated.” Harrison, whose narrative in general struck a harsher and cynical tone, said of the diagnosis, “I was devastated. Devastated. Oh my gosh I was... I never even thought about this happening.” Wayne, fighting back tears, related that he and his partner “were devastated. It was a huge blow. We were just crying. No, no, no.” Howard likened the first moment of diagnosis to a “death sentence.” He admitted knowing the feeling was wrong but noted that no one in the delivery room tried to dispel it. Bill described the diagnosis as a “crushing blow.”

Harrison thought of his future plans and peered ahead into a crystal ball of what life raising a child with Down syndrome might mean. He declared, “I love the idea of travel. I’m not going to get to travel as much as I want. I thought this is going to ruin my whole travel plans. We’re never going to be empty nesters.”

Harrison divulged this revelatory detail later: “My mother was a drug addict. I had to take care of her.” In the subtleties in his narrative, Harrison intimated that he may have been neglected, forced to grow up early, and lied to many times over. This cycle of mistrust occurred several times. He recounted, “You’re talking about a grown person that I had to take care of all the time. Of course, she wasn’t really sick, she was a drug addict. She was faking all the time.” Finally Harrison broke away from their toxic relationship, but he has projected on the idea of raising a child with Down syndrome elements of his past. He added, “Maybe I’m a selfish person,” but concluded, “I’m just not the kind of person who is good with the idea of having to take care of someone in perpetuity. It’s frightening to me.” Of his son Watson, Harrison said, “He represented to me the idea of having chains. I had this massive burden again. I wasn’t free.” This was a tender subject. Harrison admitted, “I haven’t talked or thought about that a whole lot, like, unpacked that.”

Ten of 22 participants reported feeling scared, nervous, or worried about the future upon the initial period of diagnosis. Samson wondered, “How are we going to deal with this?” Ollie said, “I assumed Reid could be chronically ill, in and out of medical appointments and surgeries.” When asked about his early moments during the diagnosis, Garth, who admitted to being prideful, said he was “scared.” That was the only thing he would relate about that moment. And even Chris, a man with an effusively positive personality, admitted that he was “a little scared. Nervous, I guess.” Branson, who had a cousin with Down syndrome who died young in the 1980s, acknowledged that he was “worried about what the long-term medical implications would be.” Trek, Bill, and Ollie all told of experiencing misgivings about the future financial security of their families.

Six of 22 participants revealed themes of sorrow, mourning, or loss of an “expected child” during the initial period of diagnosis. Scott was the only participant to report denial as an intense emotion, but he said it was quickly followed by sorrow. He said, “We had the ‘this wouldn’t happen to us; this happens to other people’ kind of moment. It was a little bit heart-wrenching I suppose.” Scott described how this was followed by sorrow and a sense of unfairness. He said that he and his partner Lilly had a “pity party,” one that only continued, “for that day at least, or for the next day or two.”

Ryan admitted, “I felt sorry for myself. And I felt sorry for my wife, and I felt sorry for my, you know, future son.” The sorrow was attended by a sense that the quality life for Ryan’s family would be compromised. “This is going to take away from our family,” Ryan admitted to feeling. He added, “My son, you know, unborn son, his life is going to be compromised, and you know, we’re going to be so busy with our other kids, what’s he gonna get from us?” Brian remembered a similar thought, as he reported saying to his partner, “We have two children already; what is this child going to add to our lives?” Howard recalled, “I was sad for my older son because he didn’t get the brother that he was supposed to have.” He described the diagnosis in general as giving him a “sense of loss” and he recalled a wise friend who gave him “permission to mourn.” Bill described the diagnosis as “really hard,” adding, “because in our minds, we had a scenario of what was going to be...a perfect little boy laid out in our minds, what his life was going to be...and that wasn’t to be.”

Finding Three (a): 17 of 22 participants narrated issues of medical complexity in their children during the initial period of diagnosis. As the severity of the medical condition increased, participants were more likely to focus on the details of their

children's health than any other narrative detail, including their own feelings. Five participants did not narrate issues of medical complexity at the time of diagnosis.

I define medical complexity here as a serious health concern in the child that a father disclosed, whether that health concern was resolved within a few hours, days, or months; or that health concern persisted for years or never resolved. The findings in this section concern fathers' experiences upon the time of diagnosis, and health concerns which may not have persisted across the narrative landscape of time certainly did affect fathers' experiences at the moment of birth or diagnosis shortly thereafter.

Four of 22 participants reported that their children were born by emergency C-sections; seven of 22 participants reported diagnoses of heart conditions in their children upon birth; eight of 22 participants reported severe respiratory distress in their children, including Matt, whose child was born "not breathing." Four of 22 participants reported feeding difficulties in their children.

Samson revealed that his son had a rare blood disorder discovered only hours after his son's birth, which would later prove to be a form of leukemia. Both Matt and Ollie's sons were born with acute kidney distress, and Bill disclosed that his daughter was born with a dual diagnosis of Down syndrome and deafness.

In cases of prenatal diagnoses of medical concerns, medical professionals may take precautions to minimize the tenuous and exigent risks that create traumatic stress and tumult when the child is born. In Branson's case, for example, his daughter Sarah was diagnosed with an Atrial Septal Defect, a heart condition, before she was born. A team of cardiologists attended the delivery to ensure her heart health. Paul, who was also given a prenatal diagnosis, said that his daughter's birth was attended by many

specialists. He said, they “wooshed” her in several directions shortly after birth, where she was apparently examined by different specialists. Paul chuckled as he said with irony, “They came back like ten minutes later and said everything was cool.”

Among 14 participants relating narratives of postnatal diagnoses, 12 also included unexpected medical concerns and traumatic birth circumstances. These fathers tended to focus less on the demeanors of medical personnel and more on the tenuous moments of their children’s first moments in the world. Matt, for example, received a diagnosis of Down syndrome in his son along with kidney distress and severe respiratory distress. He said, “I didn’t have time to process anything about Down syndrome. Ensuring that Andy was stable and healthy came first.”

Franco choked back tears as he told me that after his child was born by emergency C-section, his partner was taken by stretcher in one direction and his daughter in another stretcher over a bridge to an adjoining hospital. Not knowing what to do, he followed the team spiriting his daughter away. The confusion “was like a scene in a movie,” Franco said. “They had my daughter on the little stretcher, hooked up to all these machines, and they were running with her, and a machine was breathing for her. I was stunned.”

Mark told of his daughter who was diagnosed with a heart condition at birth. He, his partner, and his daughter, after a long day, were sleeping in the hospital the same night she was born when, amid a pandemonium of buzzers and alarms, a trauma team rushed in and brought his daughter to the NICU because her vital signs had become critical. Mark and his partner were not allowed to visit their daughter over five hours as doctors stabilized her condition. In another intense narrative, Scott related a whirlwind

sequence of events that spanned three hospitals and two states, including transports by ambulance and helicopter, all the while fielding phone calls from concerned family members. His daughter was having trouble breathing during her first two days, and his narrative focused understandably on those concerns.

Finding Four: Of eight participants with prenatal diagnoses, all discussed the theme of women's reproductive rights and abortion in their narratives. Six participants agreed uniformly with their spouses to keep the pregnancy, while two participants reported conflicts with their partners. 14 participants reported postnatal diagnoses, and thus did not narrate the theme as a part of their experiences.

As a finding, the theme was important, as it represented an important but temporary, and not lingering conflict in most cases. In some cases, participants disclosed a brief decision they and their spouses reached about termination. Orlando stated, "I don't want to say we rebounded quick, but there was never an instance of [discussing] ending the pregnancy." Three fathers reported arriving at an amenable decision with their spouses from the moment of diagnosis. Andrew, for example, asked his partner upon diagnosis, "what are we going to do?" and she replied, "We're going to do this!" His immediate and deferential reply was, "okay, we're going to do this!" Ollie and Wes indicated that they had discussions with their spouses, but that terminating the pregnancies was not the right option for their families.

Ollie said that he and his partner agreed that termination would be the right option under certain circumstances. He notes, "Let's be perfectly honest, there are some birth defects out there that it would be, it could be considered cruel." He cited an example where a girl was born "without a face." But he noted that in his family's case, he and his

partner decided that the baby was wanted “without question.” Brian recalled that the first question he asked his partner when she told him of the diagnosis was, “are you going to get an abortion?” During the interview, however, he said, “Looking back on it, it's a totally unfair question to ask.” His voice was heavy with regret and he added, “It was the wrong question.”

Two fathers in my study did not come to such undisputed and mutual decisions with their partners. Paul, who met his partner “later in life,” admitted, “We didn’t spend a lot of time sort of hashing out the whole pro-life/ pro-choice, or what happens if we were to have a child that was diagnosed in utero with a condition or something.” Paul, who described himself as an atheist with a science background, described his partner Meg as a practicing Catholic with anti-abortion values. He was somewhat resentful as Meg kept the diagnosis a secret from him. Paul, Meg, and their son Matthew were on vacation in California when Meg received a call from her doctor. Paul relays that “she got very emotional and she didn't really want to tell me what was going on. It was obviously hard to hide that something dramatic had happened.” It was then that she relayed the diagnosis to Paul. He felt betrayed and angry, and admitted that termination would have been his preference. However, he quickly accepted that terminating the pregnancy was not an option. In a couple of sentences, he summed up the diagnosis and flashed ahead to the present: “It was an emotional roller coaster for us, but, you know, today, while I’m still philosophically pro-choice, I can't imagine my life without [my daughter] Beverly in it.” Paul’s tone of voice during this part of the narrative seemed to reveal more forgiveness than bitterness, as though it were a resolved conflict.

Harrison's narrative revealed a deeper, unresolved gulf between him and his partner. He received the call in his classroom where he was a history teacher and his partner told him that the doctor suspected Down syndrome based on an ultrasound image. Harrison said he was devastated. When Harrison and Kayla reunited later in the day, he said, "My first reaction was, 'you need to get an abortion.'" He assumed that would be her natural decision as well. "Let's just say that that did not go over very well," he stated. Kayla was angry. Harrison noted, "She is very much an Evangelical Christian. She's almost fundamentalist, I would say. And I'm not." This incongruity in their values caused a rift in their marriage. Harrison explained, "It was weird, from two to six months in the pregnancy, we barely talked about the fact that she was pregnant. It was that bad. I mean I felt...there were times when I wondered 'are we gonna get a divorce?'" Harrison went on to discuss, somewhat charged, the politics of women's rights: "You know, they talk about choice, women having the right to choose...I had no choice in this. You know, I felt like, what I felt, what I wanted didn't matter. I had someone with veto power over me." The bitterness that Harrison reported feeling during the initial moment of diagnosis had not, at the time of our interview, been resolved.

Finding Five (a): 19 of 22 participants narrated that during the initial period of diagnosis they engaged in reflexive information seeking. Participants were trying to make sense of a disorienting event. Three participants did not narrate reflexive information seeking.

Another common theme that emerged from participants' diagnosis narratives was information seeking. The information seeking participants engaged in after the initial diagnosis tended not to be orchestrated with circumspection, planned with outcomes, or

guided by assistance from professionals. Rather, fathers described a kind of haphazard and reflexive approach to information, launched from quick checks against frames of reference, immediate grasps for connection to people and information: “Whom do I know that has experience with this?” and “What do I know about Down syndrome?” Orlando said, “We really didn’t know anyone, any friends or family or anything like that.” Matt relayed, “None of us really knew anything about [Down syndrome] or what it meant.” Mark had a cousin with Down syndrome and spent a few minutes relating his relationship and connection to his cousin. He told how his cousin’s parents sheltered his cousin as a kid, and later as a young adult, Mark’s cousin was not working or involved in any social, athletic, or educational programs. Mark lamented, “He just kind of hangs around the house all day, which is too bad, because he’s a smart kid.” I gathered that Mark wished he could help, and perhaps missed an opportunity. He lamented, “The first day I called [the parents of his cousin] with the news, but they really weren’t helpful. I’ve learned a lot from them in terms of what *not* to do parenting, whether it’s a typical or not a typical child!”

Branson also had a cousin with Down syndrome who died young of a heart condition. One of Branson’s first thoughts was, “Well, he had a chance. I want my daughter to have a better chance.” Branson noted that medicine, therapies, and education were much better in 2008 when his daughter was born than they were in the early 1980s. Samson, who had spent eleven years when he was younger volunteering at camps and residential facilities for people with developmental disabilities, reported that he was “familiar with many aspects of it. You know, good and bad. I’d seen a lot, so it helped me.”

Walter and Wes, both of whom had jobs working with people with disabilities, had frames of reference that helped them somewhat. Matt's sister-in-law Rayna was a speech therapist. Her initial reaction to the diagnosis was, "that's great!" Matt told that he and his partner were shocked. He said, "We were like, what?" Rayna's attitude and support were abundantly helpful. Matt continued, "Her response was, 'This is great!' where everybody else was, 'are you going to be okay?' That normal reaction helped us. Then she provided us with lots of help and information."

Many participants, desperate for information in the initial period of diagnosis, and having no personal frames of reference, disclosed resorting to the internet. It can be asserted safely that while the internet is a veritable repository of wealth and knowledge, it is also a hotbed of misinformation, ignorance, abuse, and pejorative humor. Fathers seemed to know this even as they reported their experiences. Among participants, all but one admitted to researching on the internet for information in the first few hours of the initial period of diagnosis. Trek admitted to diagnosing his own child before medical personnel did. Franco related, "All these super negative things pop up. Like all the possible medical problems, and like all these crazy things that happen, so, when I read that, I was like, this is really serious!" Branson said that everything he and his partner found on the internet told them that life was going to be difficult: "Unfortunately most of the information was negative. It was, 'these are the bad things that you're going to experience.' Medical issues, medical problems, social problems. It was all very negative."

Mark also turned to the internet for information and later regretted it: "I spent too much time online researching down syndrome. There are some things out there that will

just scare the crap out of you!” Brian shared a similar experience, saying, “It was pretty early on that I trusted the internet, and I seriously regret it now.” Wolfgang said that the initial sources he discovered on the internet tended to focus on the negative (i.e., medicalized) facets of Down syndrome and none of the positive ones. He added, “Our hopes and dreams of what we had built in our minds wasn’t going to happen. At the time we thought that we had lost the child that we had hoped for.” Wolfgang offered this: “If I were to have any advice for a parent going forward, it’s to read a little and become familiar, but don’t immerse yourself in the internet. It can be tremendously depressing.” Paul agreed. The advice he offered parents with new diagnoses was as follows: “Consider staying off the internet. It can be a scary place with lots of scary facts and figures, awful stories, and all that type of stuff. Before your child has come into the world it can be an overwhelming experience.”

Question Two

I presented question two to participants as such: “What have been your experiences as a father of a child with Down syndrome?” In most cases during interviews, an appropriate break presented itself for me to pose this question once fathers seemed to be done with their initial diagnosis narratives germane to question one. I proceeded in most cases with a permission-seeking phrase, such as, “It seems like an appropriate time to move on to our next question. May we proceed?” In some cases, participants continued their narratives into a period beyond the initial diagnoses without my prompting them to do so. I politely interrupted them by saying, “It seems as though you are ready to discuss what life is like raising a child with Down syndrome; may I read the second question, just to make it official?”

Finding Five (b). 21 of 22 participants narrated variations on the theme of information seeking, which continued past the initial period of diagnosis and into their time raising their children. Their approaches to information gathering during this period constituted a more measured and disciplined approach that included social support and critical information processing. Fathers demonstrated an increasingly sharper ability to evaluate information sources and use information. One participant did not narrate the theme of information seeking.

Just as it did from the narratives generated by the first question in my study, information gathering emerged as a theme from the narratives in the second question with a majority (n=21) of participants invoking the idea of having to (and wanting to) learn about Down syndrome. A noteworthy difference was evident in the tones of voice and details fathers chose when narrating their diagnosis stories versus their stories of raising children with Down syndrome. During the initial period of diagnosis, information seeking seemed to be a reaction to shock, an instinctual grasping for a frame of reference to make meaning of a sudden and unexpected event. In the narratives of experience raising children with Down syndrome, information seeking emerged as a launching point to new engagement with and orientation towards disability. Fathers generally described a more measured, careful approach characterized by a critical evaluation of information sources and guidance from helpful people.

Ollie told of a voracious consumption of information, noting, “We hit the library and we hit it hard.” He discussed how impressed he was by an essay called “Welcome to Holland.” In it, Emily Perl Kingsley, a onetime writer for *Sesame Street* and longtime advocate for people with disabilities, draws an analogy between a planned vacation to

Italy and a sudden and unexpected arrival in Holland to the birth of a child with Down syndrome. The shock and distress of an unexpected arrival causes pain and confusion that never go away. The poet Kingsley admits confusion, but offers the perspective that a vacation in Holland is no less rewarding than one in Italy. She depicts a hypothetical trip, one bound for Italy, but in her supposed trip, the speaker lands unexpectedly in Holland. The inference the reader makes is that while he or she expected to land in Italy, he or she has landed unexpectedly in Holland. It is an unexpected destination that is nonetheless comparable, beautiful, and rewarding. Ollie said, “It was the perfect analogy, and it really helped me.”

Brian said that he ordered a number of books, including one whose foreword was written by a young man with Down syndrome. Brian chuckled, “He could write better than I could, so I was pretty stoked about that!” He admitted regretting spending so much time reading about Down syndrome on the internet but found much wisdom in books. “There’s a lot of knuckleheads on the internet,” he explained.

Trek discovered that he had “serious, big misconceptions about Down syndrome.” He discussed how few interactions with people with Down syndrome he had had in his life. He said that he sifted through much misinformation in his first foray on the internet, admitting, “I thought [individuals’ with Down syndrome] mental acuity was far worse than it actually is.” Trek said he “went into learning mode really fast,” which included better approaches to information on the internet, as well as meeting helpful people.

Orlando said had he and his partner, just as many parents with an in utero diagnosis, “plowed” their way through several books and countless internet articles. He admitted that he had to learn “Responsible Googling,” a term he used to refer to a careful

process of evaluating sources, and sorting good information from bad. With a discerning system of researching information in place, information gathering was a coping measure for Orlando. He said, “Then it was kind of like, not to be drastic, but it wasn't a death sentence. It's like people with Down Syndrome can live full, you know, fulfilling lives and everything like that.”

Social Support

The theme of information seeking is truly part of a larger scheme of information-gathering employed by fathers of children with Down syndrome. Participants in my study sought information from people and found, beyond mere information, support and assurance. It was abundantly clear that most participants found meaning in the shared experiences and new directions meeting people offered them. Gibson (2016) prefers the term “Information Worlds” to describe the larger network from which individuals cull, compile, and synthesize information and make meaning. This framework of co-constructed realities attempts to locate people at the boundaries at which their information worlds collide with those of others.

Participants in my study tended to relay more positive outcomes and accounts of information gathering from smaller social circles and support groups (i.e., real people) than they did from their experiences with internet and media sources. Social support was important source for accurate and valuable information, but perhaps more importantly, participants described experiences of emotional support, belonging, bonding, and positive visibility or exposure to people with Down syndrome. In my study, 17 participants described benefitting from meeting others in support groups or other social settings.

Ryan, after he and his partner were given a prenatal diagnosis, connected with their local Down syndrome support group in California. They were invited to a pancake breakfast. Ryan did not know anyone with Down syndrome, and yet attending this one event helped him normalize his conception of children with Down syndrome. He said:

I saw that these kids were just like any other kids. There was a little kid with Down syndrome getting in trouble constantly and I know it sounds funny, but the beat in my heart felt good. It was just like...he's any other kid. He can get in trouble. He was a little pill to be honest with you. And it made me laugh. And at that moment, I realized I can do this.

In New Jersey, Orlando and his partner also joined a support group and attended a meeting before their child was born. He found that the people were “happy and supportive.” Questions people in the support group were asking were along the lines of, “Is she showing this or that?” The questions seemed normal and ordinary to Orlando, as if Down syndrome were not an extraordinary or medicalized phenomenon. People in the community directed Orlando and his partner to better resources in print and on the internet, as well as to better sources of care and support in the medicalized world of doctors and therapies.

Wayne described a member of [his local] Down syndrome Society visiting him and his partner. The representative said, “Congratulations; I’m here to give you a hug; and I want to tell you it’s going to be okay.” Wayne relayed, “So I said we’ll take the hug, and then we started talking.” Wayne continued, “She had a daughter with Down syndrome, and just talked about how it's not this terrible thing, not a stigma of being.” The representative told Wayne, “Our life is pretty normal and it's not as bad as people

think.” Wayne admitted, “That really turned us around and really that same day, she changed our outlook.”

Branson described a parent kit given to him by his local Down syndrome support organization. Although they were only able to attend one meeting before their daughter was born, he said, “We did have support from them even though we hadn't really been [actively involved] yet.” He and his partner would later become influential members of the group and they augmented the kit, changing the literature to offer more accurate information.

For several fathers, social support was a major factor in helping them transition through the shock and intense emotions of the initial period of diagnosis into the normative and more stable reality of raising children with Down syndrome. Paul provided a fulsome and beaming account of his first contact with his local Down syndrome support group. He said, “They call you, and listen to you, and provide you with information, and are very sweet. They spend an hour with you on the phone kind of calming you down.” Perhaps most importantly was that representative provided him with accurate information, which began to dispel false information from dominant cultural narratives. Paul noted, “They tell you what life is *really* like. That was a nice resource.” Paul said that he and his family attend meetings with that group somewhat regularly.

Some fathers indicated how support groups provided a sense of belonging and even purpose and advocacy. Chris and his partner Tiffany joined their local Down syndrome alliance group. Chris noted, “Once we had begun to communicate with other people who were raising children with Down syndrome, it became much less scary. Then later, with the fundraising and stuff, we had a sense of purpose.” Chris and Tiffany

became active in their group's Buddy Walks and other functions, and they are active on social media. Chris said, about this research, "I'm so glad you're doing what you're doing. On Facebook is the only thing I've ever seen exclusively for the dads." He referred to a group for fathers in which he found my recruitment message.

Chris's family also found support from another source. His partner Tiffany is a kindergarten teacher and actively involved in her school community, where she has taught students with Down syndrome in the past. It happens that Chris's mother and another close relative are teachers as well. Chris noted, with gratitude ample in his voice, "They're school teachers. We got a second or third grade teacher; we have a kindergarten teacher. They were pretty experienced with Down syndrome. That was very helpful for us."

Howard, a teacher himself before becoming an administrator and later a college professor, called the parents of a former student of his when his son was born unexpectedly with Down syndrome. Howard's friend explained that he "did not receive the child he was expecting and it was okay to feel bad about that," but Howard's friends oriented him to the question: "what are you going to do now?" Moreover, Howard's friend Jeremy and his partner Alexis provided Howard and his partner a "path forward, someone who has done this before."

Another finding reported by fathers was that social support derived often from unexpected sources. Several fathers told of friends, spiritual leaders, and strangers who provided serendipitous support. One example was Michaela, a friend of Bill's oldest daughter (not his daughter with Down syndrome), who with no formal training took up sign language just to support Maggie, her friend's sister, who is deaf. Michaela must be

particularly adept at signing, because Bill related, “She’s more efficient than any of us! She translates for Maggie and even finger signs words she does not know.” For Maggie’s benefit, she relentlessly and fluently narrates what she hears. Bill added, “You’ll be sitting there talking to her and she’s finger spelling words, just [sound effect] and not even think about it.” Maggie appreciates her being around. Bill appreciates her as well, considering that she is not a professional: “She’s not even...it’s just my daughter’s best friend.”

Trek discussed social support as a transactional relationship. Just as he himself experienced a life-changing moment when he had a daughter with Down syndrome, and just as he was ushered through those life changes with the help and support of others, he now regards his purpose and ministry to help create a changing perspective in society of people with Down syndrome. “It’s called changing the face of beauty,” he said, and he attributed it to better education and increased exposure of people with Down syndrome. Trek’s advice for fathers newly facing a diagnosis adheres to the two-way nature of support theme persistent in his narrative: “Join a support group, then advocate. Never give up.”

Social support as a bidirectional relationship was common in fathers’ narratives, almost arranging itself in the classic mythical structure in which a hero is given a task/crisis/journey, seeks a mentor, completes the journey, then becomes mentor to other. Several fathers described seeking or providing support according to his customs and talents. Samson, for example, the Manhattan lawyer, no stranger to powerful movers and shakers, joined the board of an international Down syndrome support organization and became actively involved in the planning and operations of his local Down syndrome

support group. He was careful to relate that he does not impart legal advice in any capacity, but serves as an especially informed advocate. As a rule, participants with older children (Ollie, Garth, Scott, Trek, Howard, and Wolfgang), were involved more with advocacy, viewed their role more as helper and advice giver, and weighed upon their experience to advise others. Howard, as an example, shifted his career towards educational law. He said, “I help people like my son and I help young teachers understand people like Jack. And Trek, focusing on families with people with intellectual disabilities, said, “this is my life now, families like mine.”

Finding Three (b): 12 of 22 participants narrated the theme of medical complexity after the initial period of diagnosis, and into their experiences raising their children with Down syndrome. The medical issues themselves shifted from emergencies to conditions requiring surgeries and long-term treatments. 10 participants did not narrate the theme of medical complexity in their children after the initial period of diagnosis.

As was seen in the narratives that emerged from question one, the presence of medical conditions in children was a common theme in fathers’ narratives in question two, coalescing as a prominent detail from 12 participants. Even as fathers reported settling more comfortably into their roles raising children with Down syndrome, they were simultaneously raising their children as they faced heart complications, cancer, or feeding issues.

Bill’s narrative was unique in that his daughter Maggie was born with two profound congenital disabilities. She spent her first two weeks in the NICU simply recovering strength and stamina until she was strong enough to go home. Eventually, she

ate and rested when she was supposed to. Bill said that they drew a breath of relief, happy that the stay in the NICU ended and they could “begin their lives.” Once home, just as they were processing the inevitable adjustments that come with having a child with Down syndrome, Bill and his partner Lucy began noticing alarming patterns. Maggie was not flinching when the dog barked or when people clapped loudly. Bill said he got right behind her and, as a test, banged on a pan with a spoon. He explained the outcome: “Nothing. We were like, umm, she’s deaf. She’s very deaf.”

Bill described Maggie’s Down syndrome and deafness as sources of stress, but asserted that those concerns became secondary when during her second year Maggie started having seizures. Bill relayed gravely that Maggie would be “jerking around on the floor; just her eyes would roll back into her head [sound effect] for 20 seconds and come right back and be fine.” She was enduring 40 to 50 seizures a day. A neurologist in St. Louis was treating her and could not determine the cause or correct treatment. A friend recommended a doctor in Memphis, who aggressively tried many courses of medications. Bill decried, “My lord, we went through 15 different meds trying to get this stopped, until we finally found something.” Trips to Memphis required more than just a day’s time. They were all day and occasionally overnight affairs. During this period, Bill said, “Her development kind of stopped. It was almost like we hit the pause button. Any language development stopped; any physical development stopped, anything. It was almost at a standstill.” Parents, doctors, and children confronting multiple diagnoses will classify and prioritize as needed, as do children in their own way. Bill noted, “Down syndrome didn’t matter any more; deafness didn’t matter any more; we had to find a way to get these stupid seizures stopped. It was just awful. Really terrible.” The eventual successful

treatment was a boon for Maggie. Bill narrated, “We finally got them stopped, a little over a year, and miraculously after that, boom! She was able to start walking!”

Samson’s son Evan was born with a condition he called TMD. Samson relayed, “So he was born with TMD, which either becomes AML or ALL. And it has to resolve on its own.” Doctors treated him with blood transfusions. Samson added, “There isn’t anything else they can do for it until it resolves or becomes full blown leukemia.” Evan underwent “seven or eight bone marrow biopsies, plus a few hospitalizations, and finally, a diagnosis.” Evan did in fact develop acute myeloid leukemia (AML), and underwent intensive chemotherapy treatments. Samson concluded by saying, “he’s in remission.” He closed off any further questions in a forceful interrogative/declarative utterance: “Next question?”

Similarly, Wayne, whose son Adrian was also born with leukemia, quickly described his son’s prodigious success under early and aggressive treatments. Wayne stated, referring to a child with Down syndrome, “You’re more likely to get it, but you’re also more likely to conquer it, and it’ll go away and never come back.” The accuracy and validity of that statement aside, it has rang true for Adrian. Adrian was four at the time of our interview and his cancer had been in remission for two years. I gathered that Wayne did not want to talk about leukemia. He glossed over this part of his narrative and began to talk about his son’s inclination for dancing.

Brian was more inclined to discuss his child’s medical issues at length. Brian invested a good deal of time narrating his son Wallace’s bout with leukemia, which came shortly after Wallace’s third birthday. Brian relayed, “He’s still got another two years left of chemo to go.” When I asked him why the treatment was so long, he replied, “There’s

two types of leukemia. There's one that's bone marrow and there's one that's blood. The bone marrow creates the blood, but his was coming from his spinal cord, so his treatment is longer than the other one. The other one is like a six-month-long treatment. This one is two-and-a-half to three years.” Brian had an aunt he never met who passed away from leukemia. “In those days,” Brian bemoaned, “You had a 50/50 shot.” Wallace’s prognosis is far better. Children with Down syndrome, according to Brian, now have a greater than 70 percent chance of successful treatment.

Wallace’s most recent treatment was particularly difficult. Brian related, “The last phase that he completed kicked his butt. For two weeks straight, because his immune system was at zero, all he wanted to do is sit there in your lap and snuggle. That was it. It was heartbreaking.” Wallace was in the hospital for five weeks. Brian says, “That was difficult for me and my wife, but luckily the hospital has beds for us too, so we can stay by his bedside the entire time.”

Howard told of how his son Jack was born with an A/V canal defect, which, as Howard related, “basically means he had a hole in the center of his heart. So when his heart would beat, all the blood would just kind of slosh around like a bucket.” Jack had an all-day surgery at four months-old that successfully repaired the defect. “It was a trying experience,” Howard said, handing over a four month-old son. An all-day surgery can be an eternity. Howard choked tears when he told of this experience, but the relief in his voice was clear even ten years later. Howard related, “So far he’s been fine!”

Wes narrated how his Daughter Anna had a similar condition to Howard’s son Jack. Anna’s heart was working unremittingly to pump blood despite a significant hole in her atrial ventric septum. Her cardiac surgeons wanted to see her reach eight pounds

before performing the operation. Wes related feeling stressed after day after day desperately wanting her to gain weight. He spent some detail discussing approaching “the scale” each day. It took Anna three months to reach eight pounds.

The doctors expected a seven or eight hour procedure. Wes’s voice changed when he narrated Anna’s surgery, turning grave as he recalled his fright: “That was the most terrified I’ve ever been in my life.” Wes choked up as he recounted his own story of a surgery to repair a plate in his vertebrae after an 18-foot fall. His family was worried about him. Like many parents who report waiting through surgeries, Wes discussed the themes of feeling utterly helpless and time dragging. Happily, Anna emerged from the surgery and within days was able to leave the hospital well ahead of schedule. Despair subsided and pride returned to Wes’s voice and face. “She is such a fighter,” he boasted; “She’s got such grit and determination. And I wish I had half her spirit!”

Ryan, who decried the lack of compassion during the diagnosis, praised the team of cardiologists who treated his son Julius: “This time they were more compassionate and for me, that’s what I needed right there.” Julius had his surgery at 14 months-old, just weeks before our interview. When Julius emerged from surgery, Ryan admitted, “I was scared. I was scared. I cried because I saw him there and he was helpless and not moving, tubes everywhere; that bothered me.” Ryan was in the room when Julius eventually opened his eyes. Ryan narrated this part of the story solemnly. He and his partner Ashley met another couple in the PICU family room whose baby died from a heart condition. He related, “I was sad for them. I cried for them. Their lives have changed forever. Their son’s never coming home again. To know that, to see the priest come...” After that, Ryan

put his son's successful surgery into perspective: "As bad as I felt for them, I was just like, oh my gosh, I'm so lucky, you know?"

Feeding and respiratory complications can be associated with Down syndrome as well. Barry estimated that his son Rory was hospitalized 13 times for aspirating pneumonia because of a persistent issue with gastrointestinal reflux. Shortly after his birth, he nearly died. Barry and June took Rory to the hospital when Rory was inconsolable, refusing to feed, and generally "not looking well." When the results of blood work returned, a doctor burst into the room and said Rory was suffering from septic shock. They rushed him by ambulance to a larger hospital. There, no sooner was he intubated and administered medication, a doctor said, "There isn't much we can do for him." Barry choked up, understandably, at recounting this trauma. Rory was air lifted from there to Children's Hospital in Vancouver. "Helpless," is how Barry and June felt. Doctors in Vancouver found that Rory was suffering from two different kinds of acute bacterial infections. He was, in their words, "slipping into failure." He was administered intensive antibiotics and put on a ventilator. Fortunately, Rory pulled through. Barry says, "Thankfully, we got to Children's Hospital in time!" The doctors impressed upon Barry that his son was close to death. They were there for three weeks before doctors released Rory. Barry declared that he was thankful to be Canadian. He added, as a rider to his experiences with Rory, "It's so heartbreaking to see a for-profit medical system [in the United States]".

Rory at the time of our interview, continued to subsist solely by nutritional supplement. Barry called this a catch-22: "He has an aversion to food because he has such bad reflux. And the only way to combat the reflux is just to give him a liquid. And

it's a formula, which makes him much more susceptible to reflux.” It is the most difficult part of their life, according to Barry, and he worries about its implications for Rory’s health. At the time of our interview it was an unresolved issue.

Ollie’s son Reid faced kidney problems in his first year of life, which Ollie says slowed his development. Once Reid’s kidney issues resolved, he began to thrive. Ollie, who had a tendency in his narrative to speak for the whole of the Down syndrome community, astutely pointed out: “So many people talk about delays, developmental delays, and they need to understand that it's not just the fact that there is a mental or developmental delay. It could be physical delays.” Children with Down syndrome who spend their initial years surviving medical complications tend to focus their energy on recovery, which impedes development. He added, “You know, kids learn so much in the first couple years and when they're recovering from surgery they're not learning.”

Finding Six: All 22 participants narrated some kind of challenge or change to their family relationships and roles. Participants demonstrated that raising children with Down syndrome could require reassessment of roles and relationships with their families and friends.

Changes to family was a prominent theme in the narratives of fathers, with 12 participants offering details about relationships with members of their immediate or extended families that were altered. Family, just as medical personnel, proved to be supportive and beneficial in some cases and harmful and deleterious in others. Matt told of his partner’s sister Rayna, a speech therapist, who not only helped them process the initial diagnosis, but also “was in [their] ear the whole time,” providing information and support about their son Andy’s development. She provided a positive outlook as well as

practical advice, especially as it pertained to Andy's speech development over his first few years. Matt spoke in earnest and appreciative tones as he detailed the emotional and technical support provided by Rayna.

By contrast, Matt described the bearing and demeanor of his partner Carmen's mother, Gertrude. Gertrude, Matt noted, "thinks that she can pray to heal the child from Down syndrome." Matt saw this as a delusion and a denial that has caused tension in their lives. Matt reported that he and Carmen would be talking with Gertrude about Andy's accomplishments and struggles and she would instead discuss how he could "get better" with the right amount of prayer. Some bitterness, but more a resolved sense of irony echoed in Matt's tone when he said:

On the one hand you have to acknowledge that Down syndrome is real. With that acknowledgement, you can view your child as they are no different; they're just a child, and that's sort of the healthy acceptance. Whereas unhealthy acceptance is sort of like, 'we can pray for him to get better, help get out of this'... Well past three years since Andy's birth, Carmen's mother has not changed. She still wants to pray away the Down syndrome.

Matt, whose usually even-keeled and genial nature developed an unusual tone of frustration when discussing his mother-in-law, reverted to the calm, even-natured tone of understanding when he declared that both he and his partner Carmen understood that Gertrude was both "toxic" and "narcissistic."

Matt told of his own experiences living with a learning disability. He stated, "I have kind of like a learning disability myself. So it's like, okay, now I have somebody, a child that's going to grow up with a learning disability that I can relate to, that's family.

So I thought that was kind of great!” He went on to describe how his partner Carmen has become a fierce advocate for people with disabilities, joining a statewide advisory board on which she interacts with politicians and agencies doing a program evaluation of Florida’s early intervention services. She has also initiated numerous petitions and letters to elected representatives. Matt spoke fondly and proudly of his partner’s efforts, but noted that he had settled into more into a role of family-level support. “Andy’s going to be with us forever,” noted Matt, and he vehemently said that he wanted to learn how to be “patient and accepting.”

On the subjects of patience and acceptance, Matt also noted that his elder son Victor, over the first three years of Andy’s life, began to show concerning signs. He was too rough with his infant brother and he began “hiding and throwing things.” He said, “After Andy was born, we spent a lot of time focusing on our older one, when we should have been focusing on our younger one!” They even had to separate Victor from Andy frequently for safety concerns. As it turns out, they were learning about two intellectual disabilities at once. Victor was eventually diagnosed with an autism spectrum disorder (ASD). At the time of our interview, Matt stated, “That was back then, and this is now.” Both of their sons have made strides towards therapeutic goals and their family is settling into processing both diagnoses. Matt stated, “Disability is a normal thing in my life, now.” He added, “It always has been, but I understand it a great deal more, thanks to my family.”

Harrison, too, came into conflict with his mother-in-law, whom he describes as an “Ultra fundamentalist Christian.” It made him “livid” when she suggested that this happened (meaning his son Watson’s Down syndrome diagnosis) to make him (Harrison)

change or grow, “like some kind of learning thing.” Harrison’s mother-in-law suggested that God gave him a child with Down syndrome to help or teach him. Harrison protested, “You know, like, come on! God’s going to purposely disable a kid for life in order to make me change or grow?” Harrison’s resentment and bitter feelings were palpable in his tone and facial expressions. Anger and perturbation came over his features on the video screen at this idea, which he found personally offensive and preposterous. Harrison snarled, “I love the self-righteousness that this reveals; I mean, this woman could use all sorts of things to make her better!” Harrison reflected on why his mother-in-law might have said what she did: “I think the idea is that she thinks I’m too cerebral. I’m too intellectual. I’m too in the clouds...that sort of a thing.” Harrison claimed that whatever those ideals may be--and he admitted agreement that they were true--that she was the opposite of all of them.

Bill told about his partner Lucy’s mother Gina, who is a speech and language therapist, recently retired. He said, “Maggie’s tongue and throat were so weak, we’d really work at it, and actually that’s one thing that really helped us, having the grandma that was an SLP, because every time she was around, she’d put on her SLP hat, she’d really work on exercises with her.” Bill was not as effusive about all family members. Of his sister, he sighed, “I have a weird relationship with her. She tried to be supportive, but not really; we actually reached out for help from her, but not really.” Bill’s mother has tried to be helpful, and loves her granddaughter, but has not met some of the specific challenges of taking care of Maggie. Maggie has difficulty regulating her body heat, for example. Bill says her sweat glands do not function well. Maggie would be playing outside and her grandmother would not notice her turning “beet red.” Or when feeding

Maggie, Bill's mom would forget that Maggie has low muscle tone and neglect to remove the bottle when milk was beginning to pool in her mouth. Bill said, "Mom, she's very tired. You have to hold it back so she can breathe." With an exasperated sigh, he added that his mother "loves, loves, loves Maggie, but she's just...the little extra things that Maggie needs, she just doesn't remember to do."

Among 22 total participants, 18 described or provided examples of roles and functions within their families changing, including their own or their partner's. Several fathers chose to discuss their own roles in the family and how that role changed or had been challenged. Some fathers discussed their role in the archetypal terms of patriarchy such as strength, stability, and provision. Barry said, "There's times in your life you're going to be faced with challenges. And I think depending on how you respond to those challenges is testament to your character." Franco described feeling as though he had to conceal emotions to be supportive, even after the initial period of diagnosis. He said, "I was a mess. I tried to remain poised for my family." He noted, "As the man, you have to kind of put up that persona that you're like unbreakable, or whatever, which is definitely not the case." Franco admitted feeling emotions of vulnerability and uncertainty, even as he tried to be a source of strength for his family, which he interpreted as being "certain and sure."

Howard's career, as he moved from teacher to administrator to university professor, took him from rural Missouri to Kansas City and finally to Arkansas. He expressed some guilt about his family needing to resettle several times: "Definitely for me as the husband and provider, you know, the main wage earner, it was really hard for me to know that that I was the source of the disruption to my family."

Samson, more than other participants, devoted a good deal of time musing about the nature of what it means to be a father. He discussed how he was comfortable with a patriarchal view: “The father of course is supposed to be the one who sets the rules.” He admitted, however, that he was “a little bit of a softie” and that his family has him “wrapped around their little fingers.” After providing several anecdotes to support this assertion, Samson said, “So it’s a little difficult for me, but I’m also trying to be the leader of the family.” Samson went on to affirm a dominant cultural narrative, saying, “There’s a unique role that fathers play, and mothers play a unique role that fathers don’t. Discombobulating those roles, it’s not healthy for kids.”

Samson then advanced to the essential question of the relationship between fathers and children. He said developing the patriarchal stereotypical relationship with his children was difficult because he did not have such a relationship with his father. He added, “Playing sports together. I’m not the most athletic guy. Going out to ball games, talking to girls, going for beers, that sort of stuff, going fishing.” Samson and his father did not do those things, but he has made an effort do those things with his children. His tone and attitude as he discussed these matters suggested that he was doing them because he thought he should do them, not that he necessarily wanted to. He said, “I dragged them fishing; I took them to football games and told them which teams to root for. Whether his heart was invested in the patriarchic model, he has tried to uphold and fulfill it. Now, with a young son with Down syndrome, he told me he was questioning his role even more.

Samson made it a point to credit his partner Miriam for her attentive and thorough care for their children, especially Evan. It is she who coordinates his therapy and medical

appointments, as Samson noted, “in the face of all the incompetency of the various administrative services.” As a practicing podiatrist, Miriam’s working hours allow her more flexibility than Samson’s, owing, he said, to his “particular career situation, which has been, well, a roller coaster. And not a fun one.” He is struggling with his career, his values, and his role in the family. Samson is a man, who by his own admission, is in existential and epistemological crisis, but he is wise enough to know that checking one’s values against dominant narratives can be difficult. Of his crisis, Samson said, “It’s going to be unresolved for a while.”

Four participants reported separating or divorcing from their spouses, although in none of the four cases did a father report the divorce resulting in lingering anger, spite, or conflict. In fact, in all four cases, the fathers have good working relations with their ex-partners. Walter was not married to the mother of his daughter Rhea or her two sisters, although they were a couple and have since separated when Rhea was young. Walter claimed that Rhea has two happy families and she gets along well with her siblings and step-siblings, although they engage in “normal sister stuff,” such as arguments. Walter and Paula have joint custody of Rhea and her biological sisters. They have a positive working relationship and make the best decisions in the interest of Rhea. Walter said, “We kind of sought people that had a vision. Where the way we do things, she’ll be successful. It has really paid off.”

Scott and Lilly divorced when his daughter Isabelle was two years-old. He said, “I don’t think divorce has been anything terribly traumatic for [Isabelle]. Her mom and I make it pretty easy for her.” Isabelle spends half of her time with Lilly and her second husband, who have twin one year-olds. Scott said the experience of younger siblings has

been good for Isabelle. In one of the twins, Isabelle has developed an “arch rival,” which made Scott chuckle. He said that Isabelle has had a “wake up call” and has had to realize the “world does not revolve around her.” Scott’s only minor complaint is that Lilly, as Scott sees her, allows herself to be Isabelle and her sister’s friend a bit more. Scott thinks the kids “get a pass with her, just a little too much.”

Branson and his partner Kathy divorced when their daughter Sarah was seven years-old, just several months before the interview. Branson did not dwell on the subject of the divorce except to call it “amicable.” Branson claimed he was instead focused on raising his two daughters, of whom he has custody during weekdays, as best as he could, and planning for their future with the understanding that, in his words, “Situations change and what might be a good plan for next year might not work in five years.”

Garth reported that he and his partner Ellie divorced in part due to disagreements about how to advocate best for their son Tucker. He said, “We got divorced. I guess when [Tucker] was in first grade, so we didn’t get along too well for about two years.” Garth expressed that he could not advocate for his son in his own way while his partner disagreed with him. He indicated, “One of the last things I wanted to do was go up there and fight for my son, and feel like I was fighting teachers and my ex-wife.” However, “Time is the ultimate teacher,” Garth mused, and it has resolved this conflict. While Garth once took, “the easier, softer way” with teachers, he now felt empowered, at the time of the interview, to advocate for Tucker in the best way he knew. Over the years, his ex- partner Ellie came to appreciate Garth’s sterner approach. Garth said, “There’s really no tension between us with the kids. There’s none period. I consider her a friend.”

Tucker stays with Garth about 90 percent of the time. Garth related, “I’m not going to say

for any particular reason, we've always let [Tucker and his brother] come and go where they've wanted." Garth provided a regimented summary of their weekly schedule, detailing how commodious it was for all involved. If divorced couples with joint custody have conflicts about childcare and schedules, such is not the case here.

Several fathers reported changing their occupations to accommodate changing needs of their families. Trek stated that he has steadily increased his understanding of providing financially for family members with disabilities, becoming familiar with investments, insurance, and protections. He and his partner Denise once ran businesses in website management, but they have since channeled their resources into a financial management company. They specialize in helping individuals with disabilities establish trusts and ABLE accounts and manage assets. Trek noted, "I started to realize, wow, this is what people need, education in this community. We have really dedicated our lives to helping families like ours, and that's helped our lives a lot."

Matt conveyed the theme of financially motivated changes to his work situation as well. He became a stay-at-home-dad. Both of Matt's children had newly diagnosed intellectual disabilities that required frequent attention and appointments. While Matt was once a driver and a shopper for a ride-share company, he gave that up so that he might facilitate his sons' frequent visits to neurologists, psychologists, psychiatrists, pulmonologists, ENT specialists, GI specialists, and allergists. While Matt was making good money driving, he was not able to provide healthcare, so his partner Carmen, a social worker and advocate, became the primary source of income and health insurance for his family. Matt spends his days on the phone with healthcare providers and

conducting his children to and from daycare and school. He said he is “happy with the current situation, despite the stress.”

After Maggie’s first year, Bill and Lucy realized they could better manage their schedule if Lucy were not working, so they made a decision for her to stay at home. Bill acknowledged Lucy’s sacrifice, saying he makes it a point “not to treat her like a housewife” and to honor her professional identity: “She has a master’s degree, and when she was working she made more money than I did.” Bill also acknowledged that whatever difficulties their life presented them, “she gets the brunt of it obviously more than I do.” Somewhat wistfully, Bill described his change of occupation as well. Once a music teacher, Bill now sells insurance. He acknowledged that his new job pays better and provides better insurance. In a perfect world, he might still be teaching.

Ollie, too, changed careers over concerns about providing for his son Reid’s future. A stay-at-home dad for his older children and for Reid’s first year and a half, Ollie took on employment at UPS, where he is comfortable and able to set aside money in an ABLE account to take care of Reid in the future. Ollie’s typically-developing older daughter is interested in engineering and Ollie and his partner Kim have done all they can to support her ambitions. Their hope is that she will be happy, prosperous, and well situated, and that she may be there to support and look after Reid one day. Ollie told me about adults with Down syndrome he knows who are married, happy, and self-sufficient. He has a vision of hope for Reid’s future. He wants Reid to have “a place, friends, and somewhere to be accepted.” It is the ideal scenario for any parent, but, Ollie claimed, parents of children with Down syndrome worry about it a bit more.

Brian reported perhaps the most radical change to a family's lifestyle. He was a logistics manager for a large company in California, but after his son Wallace was born with Down syndrome, he and his family made a drastic shift from suburban life to living in a place where their nearest neighbor "is more than a mile away." They purchased an enormous plot of land on the border of where the civilization of Southern California meets the vast desert. Brian swept the camera across the vista of their property to reveal the capacious landscape where "kids can grow up." Domesticated livestock and animals dotted the meadows in front of majestic golden mountains in the background. A Spanish-style hacienda sits on their property, which Brian has converted into an event venue. It has ten bedrooms surrounding a beautiful courtyard. They host weddings, quinceañeras, Bar Mitzvahs, corporate retreats, "all of those," Brian beamed proudly. This was a second career for Brian, and, while he works hard at it, it has allowed some flexibility in his schedule so he can spend more time with his kids. It also may be a business he can bequeath to his children. Wallace, who, Brian says, "knows no hate and absolutely loves everybody" might be enormously successful in the hospitality industry. At the time of our interview, Wallace was experiencing difficult gastrointestinal and feeding troubles, but Brian made clear his vision for the future, in which a healthy Wallace is a partner with his siblings in a successful business.

A finding is that fathers often, thinking ahead to when they and their spouses are no longer around, plan for, or at least wish their typically developing children to look after their children with Down syndrome. Wayne disclosed, "When we pray about Adrian's care, it's that Kelly (his sister) will grow up and one day take care of him when

we're gone, and look out for him. And I see that already she just cares for him and she understands.”

If providing for children and their needs is hierarchal, it seems that given financial security, fathers might focus more on continuing care and relationships for their children. When Barry discussed his experiences upon the diagnosis, his initial concerns were providing for his son Rory financially: “I was worried about how he was going to make his way in the world and what's going to happen after I'm gone.” Barry admitted that as his son got older, his concerns shifted to supporting Rory emotionally and advocating for him: “There's going to be a time when we won't be there for him. And that's very, very worrisome, but that's just life in general.” Branson, similarly, admitted that once he felt more secure about his daughter’s financial well-being in perpetuity, he was more able to worry about “who’s going to be there for her.” And Trek, as mentioned above, sees it as his life’s ambition to “make a better world” for his children.

Finding Seven: 21 of 22 participants included prominent narrative details of their children’s expected outcomes and their children’s accomplishments. Fathers were nearly unanimously proud of their children with Down syndrome, especially when their children exceeded expectations. Fathers of older children may be more proud and content with their children’s accomplishments. One participant did not include prominent details of his child’s accomplishments.

Almost all of the participants in my study, 21 fathers, expressed progress and pride of their children’s accomplishments. Accounts abounded about varying facets of life and growth. Narratives of such achievements are great indicators of developmental and lifespan psychology. Fathers with infants and toddlers boasted of their children’s

developmental milestones, first steps, growth indicators, and first words. Fathers with elementary-aged children spoke of achievements in school. Fathers of older children told of jobs and friends, athletic successes and dating adventures. Although reproducing all of these accounts in this section would be prohibitively voluminous, I will present a few illustrative examples that address specific aspects of the theme of accomplishments. One specific and illuminative subfinding within this theme is that fathers of children with Down syndrome were especially proud of their children's accomplishments when those accomplishments defied expert opinions, exceeded expectations, or flouted dire warnings.

Wes beamed with pride when he revealed that doctors told him and his partner that their daughter Anna would be in the NICU for several weeks and she went home after just 24 hours. Franco boasted that his daughter was learning English, Spanish, and American Sign Language simultaneously. "Three languages! And they said she was going to struggle with language!" he sneered. Branson laughed as he revealed, "I always liked seeing Sarah beat professionals' expectations!" He added, "When she beats those expectations, or if she's done before they believe that she should be able to, it's far more rewarding." His own pride aside, Branson said achieving ahead of expectations was great for his daughter Sarah as well: "And it's not just for me; that's for her as well, because she's a kid. She can see."

Chris, whose son Jake was born with a hole in his heart, was clearly grateful and proud when he told of a pediatric cardiologist who, astounded, said, "I'm not one to talk about miracles, but what happened was as close to one as I've seen." Jake's heart had repaired itself and he would not need surgery. Howard told of his son's first victory in a cruel world, breastfeeding against doctor's recommendations. He added animatedly that it

was just one example of what would become a character trait: “When professionals tell Jack he can’t do something, Jack finds a way to do it!”

Orlando said that his daughter Lilah skipped crawling. She started to scoot, and then, “I mean she just got up and started walking one day!” Shaking his head ironically, Orlando added, “She’s very stubborn. She does what she wants, when she wants to do it.” Walter agreed with this sentiment, adding that goals are somewhat more celebrated when it comes to kids with Down syndrome. Walter said of his daughter, “She stubbornly goes about her own way through development. Oh my god it was an awesome moment when she walked about five steps!”

Of all participants, Wolfgang was the narrator most gifted in storytelling. He blended experience, emotions, humor, irony, and wisdom throughout all elements of both questions. A self-described “raconteur,” Wolfgang introduced his son Wade as a “local minor celebrity.” Using elements of flashback and foreshadowing, Wolfgang first provided a glimpse of his 18 year-old son Wade’s success, a video he insisted I watch. Wolfgang then returned to the moments after Wade’s birth and lamented the low expectations given to him by medical personnel. And then, anecdote after anecdote, Wolfgang painted a picture of an 18 year-old life, one of a young man who is the living embodiment of the theme of defying expectations.

The beginning and end of Wolfgang’s story was Wade’s latest accomplishment, which had occurred just weeks before our interview. Wade had spent his childhood dedicated to becoming a talented and accomplished swimmer. He performed well enough at the state level to become part of the Louisiana delegation for the national Special Olympics. The video Wolfgang directed me to at the beginning of our conversation was a

clip of Wade on local television discussing his success at the national level. Wade won two gold medals in the four by 50 free-relay and 50 meter butterfly, as well as a silver and a bronze in other competitions. ESPN aired the events and Rowdy Gaines, a one time Olympian swimmer, honored the competitors.

It was just one story of many Wolfgang revealed—“Wade stories are a dime a dozen,” he joked—which included Wade’s mastery of several musical instruments, his talent at persuading people, his hatred of cigarette smoke, his various dating stories, and a public education career that resulted in a high school diploma. Each of these accomplishments Wolfgang juxtaposed against some lower expectation set by a medical professional, a coach, a teacher, and even Wolfgang himself. Wolfgang seemed confident that Wade will one day defy the ultimate expectation. The last story he told was about Wade’s brother Nate, who was reading a *Guinness Book of World Records* account of an individual with Down syndrome living into their late 70’s. Nate turned to Wade and said, “Oh, you can beat that!”

Of 22 participants in my study, four had children of double-digit age. Those children were 10, 10, 12, and 18. It may be coincidence or it may be attributed to experience and time, but the most proud and contented of fathers I interviewed were those with older children. Wolfgang, in particular, whose son was 18, had the oldest child. He seemed, more than other participants, confident and sure of his son’s ability to exceed expectations and be more than what was expected. Wolfgang’s son Wade was a high school graduate, an accomplished swimmer, a musician with published tracks, and a “local minor celebrity.” Will had defied many expectations in his years and Wolfgang expressed with loud and effusive positivity that children with Down syndrome can

accomplish so much. His advice to fathers was to “give them what they need and stay out of their way.” Even his advice included the “stay out of their way” clause, which suggests an understanding that even parents can inadvertently repress their children because of over-protection, prejudice, or low expectations, or even hide their children from visibility, as was seen in Neely-Barnes et al. (2010).

While Wolfgang’s and Wade’s narrative suggests that it is more than possible for children of fathers raising their children with Down syndrome to expect great things and exceed expectations, given their fathers’ support and willingness to “stay out of the way” to a degree. Wolfgang and Wade underwent many of the same struggles with stereotype and ableism that other fathers in this study currently (at the time of the interview) were experiencing, and found great outcomes.

Finding Eight: 19 of 22 participants narrated the themes of daycare and education.

Finding the right daycare and education settings for their children was important and sometimes difficult for fathers. After the challenges they faced, fathers did eventually find the right placement for their children. Three participants did not narrate the theme of daycare or education.

Daycare and education are inevitable themes that emerge from fathers’ narratives raising children with Down syndrome, considering that these themes pervade the landscape of all parents with young children across the modern American landscape. Among participants in my study, 19 fathers elicited these themes. The three fathers who did not specifically address their children’s placement in learning environments were fathers of children who were very young and not yet placed in such an environment and under the full-time care of a parent. Among those fathers who did have children in such

environments, their narratives offered a moving blend of successes and challenges, compromises and resignations. Most often, parents of children with Down syndrome want to have their children included in the general curriculum, as part of campaigns that avow children with Down syndrome are “more alike than different,” and several participants in my study exemplified this struggle. Other participants in my study revealed that the right path to success for their children was either a hybrid model of general and special education classes or settings dedicated 100 percent to special education. A repeated and unifying theme, though the wishes of the participants were different, was contention with school officials or IEP teams.

Howard, for one, was a father who sought full inclusion for his son Jack. Howard began his career as an elementary school teacher, and eventually took a job as an administrator at a preschool, where he saw that “children with Down syndrome were sent to one class; children with autism were sent to another; and then the other kids got to be in regular classes.” He observed that his son with Down syndrome was not going to be around other kids in the general curriculum, and he said, “I was not okay with that!” Howard left that job and his family moved to a part of rural Missouri. Howard returned to the classroom as a first grade teacher. Jack was also in first grade, but placed in a special education classroom. Teachers in the special education classroom were “pushing” a functional skills curriculum on Jack when he was quite capable of academic skills. Jack was not happy in this circumstance and he struggled behaviorally. Howard met with the principal and asked him to place Jack in his (Howard’s) classroom. Howard beseeched the principal, “Do something radical that’s going to change the life of this child.” The principal appeared to consider the move, but ultimately resorted to the school district’s

policy against children being placed in their parent's classroom. Howard, despite his more colorful thoughts, told the principal that he was allowing Jack to "flounder and struggle" and he told the principal that he "would have to live with that on his conscience." Shortly after, Howard resigned.

Adhering to the theme of radical decisions in the best interest of children, Howard decided to home school Jack for second grade. Howard called this a "hard reset" for Jack: "He learned to read, he learned to write, and he learned to understand numbers." Howard relayed many rich stories of Jack's emergence as a reader and thinker. The decision was a success. When Jack returned to school for the third grade, the IEP team wanted to place him in the special education classroom again. Howard reminded the team of a basic tenet of educational services: "I would talk about how we needed to consider least restrictive environment, and that's presumed to be the regular education classroom." In the end, Howard advocated to have Jack placed in the general classroom for 97% of his day, and he won. The school's administrators were not happy because they had to rearrange their schedules, but it was a decision that proved successful for Jack. Jack's teacher also admitted that teaching him helped her become a better teacher. She began using techniques and materials she had prepared for Jack to help other students, to great success. Howard beamed, "Universal design for learning, right there!"

By contrast, Garth's son Tucker was placed in a general curriculum where he was mostly successful in grades one through three. However, Garth said, "In fourth grade, finally Tucker had a meltdown and they were going to try to punish him like a 'normal' kid." Garth and Ellie went to the school for a special, parent-generated IEP meeting, and Garth noted, "[My ex] let me be a little more firm with them." Garth admitted that he can

be forceful and unyielding when he needs to be. During the interview with me, this seemingly gentle, quiet, and calm man developed a lower register in his voice when he delivered an anecdote about a disagreement between he and his ex partner:

She says if you're too much of a butt to [the IEP team], then [Tucker's] going to suffer for it. I said, 'I see where you're coming from but that's not the case. I'd rather that they're worried about us being up there because they're not doing what we're asking, than thinking if they're not doing what we're asking and we come out there and they say, 'well we didn't know.'

In other words, Garth would rather forcefully and steadfastly advocate for Tucker, and have a reputation as a demanding parent than representatives at the school fail their son and exclaim that they did not understand the parents' wishes. Garth's narrative was a glimpse into the struggles with education that parents and advocates of children with Down syndrome endure, but also evidence that the struggle is not a monolithic narrative. Some parents contend for inclusion for their kids while others resist it, as situations dictate. Garth and his ex- partner advocated, successfully, for a 50 percent inclusion model. Tucker, at the time of our interview, was spending half the day with his peers in the general tract and half the day in a special education tract. Garth intoned, "He has some time with the kids. He wants to think he's doing the work they do, but most of the time he isn't." Garth opined that Tucker "is in the best place he can be."

Branson reported a similar journey of advocacy. When it came time to place Sarah in school, they interviewed with her zoned school. Branson said "the disposition of the officials was, 'here was a problem and this problem was called Sarah, and that's before they even met her!'" Branson and Kathy found a more accommodating school. He

said, “The school that she's in now, it was, ‘here's a student; let's see what we can do to educate her and help her.’” Branson said they were fortunate to have found that school as Sarah was entering kindergarten. He added an interesting afterthought. The people at the school district who were supposed to be advocates for students with disabilities tended to bow to the schools’ intentions. At Sarah’s zoned school, the district representatives also acceded to the notion that she was a problem or a burden. When they met with representatives from Sarah’s current school, the same district representatives changed their tune to be more accepting and accommodating, per the school representatives’ viewpoints. “And they’re supposed to be the leaders!” Branson stated with irony, adding, “If the attitude of the school is positive, then everyone seems to be.” It is a noteworthy bit of wisdom for school officials in power.

Wolfgang related a similar story in which he was attempting to move his son to a new school during third grade. While he was interviewing with the principal, his son Wade was sitting in the office with a secretary. The secretary saw that Wade was bored and asked him if he wanted to go to class. Even before enrolling in that school, Wade felt like he was in the right place. “This is my school; I want to stay,” Wolfgang, quoting Wade revealed. The culture of that school was “just different,” Wolfgang said. Both he and his son knew they were in the right place.

Orlando, with gratitude, discussed how other advocates in the Down syndrome community who have come before have helped him in his advocacy for his daughter. He said, “We've been lucky that we haven't had to be the trailblazers. Others have come before.” The support group to which Orlando and his family belong has been very helpful. One mother in particular has a daughter in 10th grade. Orlando said, “We thank

her because she's been going through a lot to kind of make everything inclusive.” She has fought the fight to have her daughter included in the classroom and beyond. Orlando relayed, “This mom argued with the theater director to allow her daughter to have a part in their production of *The Little Mermaid*. The director commended her at the end and said she did great!” Orlando said that that mother’s example gave him and Melinda a voice when a director at their daughter Lilah’s daycare wanted to remove her, at two years-old, from the program because she was not crawling or walking and therefore could not go out to the playground. Orlando and Melinda advocated for Lilah to return to the infant room only when other kids were outdoors. That arrangement succeeded long enough for it to become a moot point, for a month later, Lilah began walking. Sometimes things take just a bit longer for kids with Down syndrome, and parents often know better than schools what is best for their children.

Walter somewhat disagreed with the parents-know-best message. He manages a residential and day facility for individuals with intellectual disabilities, and he described several adults with Down syndrome whom he has met, in which cases their parents have “sucked out of them” things they have been capable of doing or learning. He said he does not want to see that same fate in his daughter Rhea, so he provides her with as many opportunities to be as independent as she can. And he trusts educators to make the right choices. He and his partner Paula enrolled Rhea in a preschool that specializes in Emilia Reggio methods, which center on self-directed and experiential learning. Still, as a professional conversant in the vocation, Walter said, “I don’t think there’s anything more nerve-racking than not knowing what’s going on with your kid’s education.” One concern that Walter had is that children with disabilities placed in included settings tend

to be “mascotted.” He said defiantly, “I don’t want her to be a mascot.” This is a double-edged sword for many parents of children with a disability. While they strive for inclusion, universal design, and visibility for their children in society, they do not want their children to be exploited for purposes of institutions ostensibly trying to promote an image of inclusion. Rhea is cute and tends to be used for “headline grabbing.” Walter said, “She has to learn that she won’t be cute forever and the world is not going to be a friendly place to her.” Perhaps Walter is somewhat of a cynic, but he is also pushing for her independence. He is not sure she will have the “safety nets” she has in place now in twenty years.

Ollie, discussing his son Reid, who is eight and mostly nonverbal, expressed that children with Down syndrome who are nonverbal are at a disadvantage because, “people instantly assume he’s not as intelligent as he is.” Ollie, who spoke adamantly about this issue, said, “If you’re nonverbal, people don’t think you’re smart.” He added that Reid, “also loves to play with the smaller kids’ toys, like blocks and Legos and stuff like that.” Reid is somewhat caught between. Ollie said, “He’s too big to be in there with [typically-developing] kids. It was going to be too much work for [teachers]. If he was in the smaller classroom it would have made them too nervous (because he was too big) and if he was in the classroom with kids his age, if he didn’t want to participate. He basically would need to have someone there guiding him.” That struggle was unresolved, according to Ollie, at the time of our interview.

Barry said that his son Rory was doing well in school in a mainstream classroom but he was placed with a one-on-one aide who was not a good fit. Barry was clearly holding back choice words and decidedly not discussing details. “Let’s just say she didn’t

have the right personality to work with him,” he said, through clenched teeth. Barry and his partner advocated for a new aide, but it took three reconventions of the IEP team. Ryan, similarly, summoned one quickly-resolved instance of institutional ableism. When inquiring about placing his son Julius in the daycare center where their four year-old attended, a director told them flatly, “We don’t take children with Julius’s condition.” He immediately withdrew his other son and enrolled them in a setting where they both were “happy and successful.”

Even when things were going well, fathers tended to relay narrative details with cautious optimism. A curious datum is that the phrase “knock on wood” emerged six times in fathers’ narratives. It is as if successes are hard fought for and hard won for children with Down syndrome, and the transition to the next challenge is perhaps a bit more tenuous than it would be for typically-developing children. Scott, for example, acclaimed his daughter Isabelle’s success in elementary school and seemed downright surprised at how well everything transpired. Still at the time of our interview, which was during summer, he admitted he was “very worried” about Isabelle as she was progressing from elementary to middle school. She would be sure to experience a different setting, different faces, new challenges. Scott said, “She has a lot of determination in her. When she really wants something, she can make it happen.” He added, “This is after difficult transitions. She is big on routines. Once they are in place, she will be fine.”

Several fathers echoed the theme of routine. Bill said his daughter Maggie “loves, loves, loves school!” She is in a mainstream classroom with a general education teacher, a special education teacher, and aides for some of the kids who need them. Another girl with Down syndrome is in the same class, as are other kids with speech delays. Many of

the kids have learned some sign language to communicate with her. Maggie feels welcome. Maggie also loves routine. Bill emphasizes, “routine, schedule, routine, schedule!”

Garth was somewhat critical of himself for not establishing a better routine for his son. He said, “If you can get a routine going when they’re two or three years old...” Garth welled up a bit at this point, interrupting himself: “It’s my fault. I don’t know what else to say...” He explained how Tucker performed well with routine, but that he (Garth) had been busy over the years with work and his other children, and was not able to maintain Tucker’s routines as well as he would have wished.

Not every school narrative involved a struggle. Paul told his narrative with the following caveat: “I understand my privilege.” He said this not to be boastful, but as part of a wish that all children with Down syndrome could have the opportunity that his daughter Beverly has. Beverly attends a private daycare with a specialized model of instruction and inclusion. The student-teacher ratio is four to one and the population averages 50 % typically developing kids to 50 % kids with special needs. Teachers are all certified and most if not all of them have master’s degrees. The school has on-site therapists in every specialization including music and arts. Every student has a quarterly team-based care meeting where teachers, parents, therapists, and para-support personnel contribute towards academic and behavioral goals. Paul, despite his busy schedule, said that he keeps acquainted with all of Beverly’s goals and progress, as the school avails this information for him in a tidy weekly report. Paul positively gushed about the school. He directed me to its website and pointed out certain areas, including pictures of Beverly

happily learning and growing in all facets. She appeared exceedingly happy. The circumstances seem ideal, but, of course, it comes with a hefty tuition fee.

Finding Nine: All 22 participants demonstrated that the experience of raising children with Down syndrome includes some collision with dominant cultural narratives.

One of the stated purposes of my study was to understand fathers' experiences within the sociocultural context of the dominant cultural narrative of Down syndrome. Though they did not often employ the jargon of academia or critical disability studies, fathers did seem implicitly aware of their positioning in a discourse in which their experiences differed from the conceptions of and common understandings of life raising children with Down syndrome. While encounters with the dominant cultural narrative with medical systems and personnel were common in the narratives participants relayed in the context of the first question, in the second question fathers tended to convey details about interactions with strangers and coworkers. In one way or another, evidence of an encounter with the dominant cultural narrative was included by all 22 participants.

Some fathers reported instances of cruel and unadulterated ableism. Franco, a sailor in the Navy, relayed an account of when he asked his commanding officer for an extended lunch so he could take his daughter to a therapy session. Franco disclosed about the officer, "He likes to joke around a lot." The officer said, "Just be glad she wasn't born during the time of *Game of Thrones*, because you know what they did to those kind of people." Franco reported that he was stung by the remark, but he was relatively new to that particular command, so he bit hard on his tongue. Respect for his superior officer caused him to stay any response. A short while later, however, in a meeting in front of many people, the chief called another sailor the R word, then turned to

Franco and said, “No offense.” Franco relayed, “So at that point I just blew up on him. Like, I completely lost it.” Fellow sailors had to restrain him bodily. Franco said that he has experienced insensitive remarks and ignorance, but this was the only time Franco could remember anyone treating him or his daughter with *intentional* disrespect or malice. The satisfying result of that anecdote was that the Navy penalized and transferred the commanding officer.

Brian described an incident on an airplane when his family was returning from a vacation. A teenage girl a few seats up was making “[R-word] gestures and using the R-word.” Brian said that he got really mad, and felt “hostility,” but he was patient and tolerant because he used to use that word before he knew it was hurtful to others. He even wondered if he was using any words now that might be considered bad in the future. Brian shrugged on the video screen, “So what I say now to my friends when I hear that word is, ‘you’re being offensive.’ Most people will apologize,” he said.

Barry related an example of a time his partner June and son Rory were in a grocery store when an “older woman” approached June and said, “Down syndrome is the one time I would advocate abortion.” Barry said that June was “beside herself” with anger, and he added, “Good thing I wasn’t there. I don’t know what I would have said or done.” Barry indicated that his own mother was a social worker who worked with individuals with disabilities in West Germany after World War II, so he understood some of the context. He said, “She didn’t exactly come from the most tolerant time and place.” The woman in the grocery store also happened to be German, Barry’s partner believed, “So I understand where she might have been coming from,” he added.

Samson has worked for three different law firms since his son was born and has experienced institutional ableism on multiple occasions. When his son was younger and fighting leukemia, Samson said he was “frozen out of the firm,” because he needed to take extra time off. He went to work at another employer, about which he disclosed, “I’m trying to explain to him the extra sort of medical needs my son has and the extra responsibilities that that puts on my family. He was just totally oblivious. So I had to leave that place.” Samson found employment at yet another firm but elected not to tell his supervisors about his son’s diagnosis. He found himself sitting next to a supervisor in a meeting in which that supervisor was promulgating the myth of the super parent. Samson said, “He was just in awe of parents of children with special needs and he couldn’t believe that they had the will to get through.” Samson found himself thinking about the complexities of that myth: “I’m sitting right next to him, and I’m like, well, yes and no. Resignation? Maybe.”

Other fathers reported acquaintances and strangers conferring on them the myth of the super parent (sometimes called the uber parent in the literature). That is, people ascribed to them “the rhetoric of specialness” (Lalvani, 2011) applauding their parenting abilities as they interpret fathers’ lives and their children as other than normal. Scott told of an episode when strangers said to him something akin to, ‘I can’t believe how you do this.’ Scott, with a mirthfully wicked laugh, said, “Sometimes I want to look at them and say, I’m really sorry. Mine has an excuse to be a little bit more challenging, what’s yours?” Just as Scott rejected the idea that he is a super or an uber parent, somehow different from any dad who loves his kids, so too does he reject the idea that Isabelle is fundamentally different. He said, “I have this mindset that Isabelle’s just Isabelle. To

other people she's this kid with Down syndrome, but to me she's just this sometimes cool, sometimes a pain 10 year-old kid. She's just Isabelle, just like Myra's just Myra." He concluded, "I don't think I necessarily parent any differently or treat her any differently."

Ryan relayed several anecdotes in which he experienced the myth of the super-parent, particularly from his coworkers, who marveled that he has five children, one with Down syndrome. They would say things such as, "I don't know how you make it to work every morning" or "I don't know how you manage it all." One person said, "I wouldn't be able to do it." Ryan admitted their hearts were in the right place and acknowledged the sentiment was not meant as offensive, but he reduced it to an absurdity, chuckling all the while, by examining a hypothetical alternative: "What am I supposed to do, roll up into a ball in the corner?" Ryan concluded reflectively, "If I don't take care of my family what kind of life do I have? What kind of life do we all have?"

As discussed in a previous subsection, Harrison's mother-in-law argued that God gave him a child with a disability to help him (Harrison) "change or grow." Her argument that God gave him a child with a disability to "teach him" is embedded in predestination theology, from whence comes much of the impetus for the "super parent" myth, or at least "the rhetoric of specialness." A contrasting, but not opposite idea, because it also evokes specialness as otherness, is that Down syndrome is a tragedy, an affliction of accident or bad luck. Parents in the literature report hearing "Sorry" or "that's too bad," and many other apologetic synonyms. Fathers in my study have been put off about such platitudes. Harrison, however, might have welcomed such a position. "Not a damn bit. Not once!" Harrison said, when I exclaimed surprise and told him that many fathers and

parents in general, have rejected such apologetic advances. Harrison rejoined, “They probably do, yeah. I didn’t get a bit of that. It might have to do with the circles I run in. That’s the last thing any Christian’s going to say. They’re going to be like, oh no, part of God’s plan, you know?”

Other than Harrison, fathers in my study who heard “I’m sorry” or any of its synonyms, preferred not to hear such statements. Scott said that the thing he hated to hear the most was, “I’m sorry.” He added that when he revealed the diagnosis to friends, family, and strangers, they would express sorrow. He developed a script as a response, which was, “Well, we’re not sorry at all. She’s just Isabelle and she’s going to be awesome.” Scott said of his acquaintances, “I think people learn pretty quickly, at least our extended family and friends learned it wasn’t the right thing to say.” It was as if making them uncomfortable about expressing grief might be the thing that they need to hear to spur their own critical thinking about disability. Scott reflected on this idea, saying, “You know, initial reaction, they probably didn’t know what to say. So by default, it just comes out as ‘sorry to hear that.’”

Wayne said that some people said, “I’m sorry,” or “If there’s anyone who could handle it, you can,” but for the most part, people were accepting. Wayne and Jessica simply replied, “Don’t be sorry.” Wayne discussed that understanding a diagnosis is a process. He pointed to his mother’s reaction: “There’s a point in that process where you have some grief, and you kind of move on to accept it at some point, so that happened initially. It just took her some time to adjust, to accept the diagnosis.”

Mark said that he heard apologies frequently after his daughter Natalie was born, both from family and coworkers. He was an EMT at the time and many of his fellow

first-responders and even nurses he knew from the emergency room came in and said “sorry.” “And I didn't know how to take that,” he intoned. Mark was bothered by the fact that people were making assumptions that there was something wrong with his child or wrong with his life now. He would say, “Well there's nothing to be sorry about. Come meet her!”

Branson reported that some people have said, “I’m sorry” to him. He related that he responds with a one word answer: “why?” This, of course, put the onus back on the sorrowing person. Branson intoned, “Sometimes they respond, sometimes they don't. Usually when they do respond it's, ‘well it must be difficult.’” Branson laughed and said to me, “My response is, ‘well being a parent is difficult.’” In saying so, this is Branson’s way of countering the myth that raising a child with Down syndrome is somehow a burden or a detriment, or fundamentally different from raising other children.

Bill said, of expressions of sorrow, “It’s meant in a sympathetic way. But not sorry that you’re pregnant. I’m sorry that you’re having to go through this. Type of sorry that, you know, some people think it’s a burden. They’re saying sorry for the burden.” Trek similarly dismissed the idea, discussing his grandmother who said sorry to him. He said to her, “I’m not [sorry]; it’s not a burden.” Trek’s grandmother understood quickly, and moved to a position of support instead of sympathy. Trek explained, of families (or perhaps his family), “We adapt quickly.”

In public, fathers experience rudeness and awkward stares. Bill noted that, “Maggie makes a lot of noise and when she is happy, she does a shaking gesture”. Bill observed, “The more happy she is, the more she shakes or whatever. And that’s cute, but

she also makes like a [excited noise sound effect] with it, and so, when we're out, that gets a lot of stares, and eating with her is hard."

Matt said that he and his family have not found much discrimination or ignorance in public. He reported that most people treat Andy with positivity. He noted that they get some stares, but "not much you can do about it." Andy has a habit of wandering in restaurants. "Most people smile at him," according to Matt: "He pretty much makes everybody's day!" Matt declared that he has seen evidence that kids with disabilities are more accepted in society than they were when he was a child. Matt's son Victor has a friend in the neighborhood who is autistic and whose parents were worried about him playing with other kids. Matt and Carmen were similarly worried about their kids, but, Matt reported, "It turns out the kids in the neighborhood treat him just the same as any other kid. They all just get together and want to run around and play."

One father in particular seemed aware that socioeconomic or cultural privilege confers benefits to parents of children with Down syndrome. Paul and Meg have clearly worked hard and positioned themselves well, but still, Paul is mindful that not every family enjoys what they have: "You know I'm sensitive to this because I feel like if we weren't at the financial situation we were, maybe we would feel differently." He told me that Texas is known for being a "crappy" state in terms of supporting persons with disabilities. Beverly is on a list to receive state services, but probably will not receive them until she is 14 or 15. Paul sees other families that are not as financially secure as they, and he sad, reflectively, "Sometimes I wonder if we had to make sacrifices and not go on vacation one year or something in order to afford this or that for her, if there would be any animosity or something like that."

Trek pointed to inclusion in schools and shifting cultural modes of normality, such as Gerber using a model child with Down syndrome for its iconic face. For the sake of Faith and for the sake of combating dominant cultural narratives, Trek and Denise are doing their part. “We make it a point to not hide her,” he boasted, “We encourage her proclivity to go to people. We want her to be herself, and we don’t want her to shut down.” It is a keen observation. Some parents can synthesize hegemonic thinking about disability, something Trek has picked up on: “I think that is what happens. I see a lot of adults who are very quiet. I think adults have tried to silence and control their children with Down syndrome.”

Finding 10: 15 of 22 participants discussed the theme of stress as a component of their lives. These fathers described their jobs, daily schedules, and meeting the medical needs of their children as stressful. Only one participant unequivocally connected stress to his child having Down syndrome. Five fathers vehemently rejected the notion that their lives were stressful because of raising children with Down syndrome. Two participants did not narrate the theme of stress.

Stress is a ubiquitous in the literature, and though I discussed it with all participants, an element of my research design was to observe how many participants generated the theme without being prompted to do so. Some 15 participants in my study invoked the theme unsolicited. Fathers seemed intuitively to have some awareness of a cultural narrative concerning stress. They had heard that life raising children with Down syndrome is stressful and they have encountered people who supposed that they (fathers) had a stressful life. Wayne, for example, said, “So I know that kids with Down Syndrome and families with Down syndrome are supposed to be all stress and sadness

and hardship, but I don't see that at all.” He added, “Andrew is a truly a special, special little boy. And my life is blessed so much by him, and anybody who's around him feels the same way.”

Garth also seemed to be aware of the assumption that his life was stressful: “Just because I have a son with Down syndrome my life is more stressful? No. False. No, as a matter of fact it's actually kind of it's neat having...I always refer to [children with] Down syndrome as Perpetual huggers. They're just happy-go-lucky, fun-loving, you know? They just make life a little bit better as far as I'm concerned.”

Franco, who was actively deployed in the Navy at the time of our interview, graciously arranged an hour of his free time to video conference from his base in Djibouti. Stress in his life has little to do with Down syndrome and was attributable, he said, to being away from his family. “Being deployed is challenging,” he admitted, with a hint of sadness creeping over his face. Franco did admit to feeling stress. He disclosed that he has missed birthdays, anniversaries, Thanksgivings, and Christmases. He described how he has observed much of his daughter Lorna's progress by video conferences. Franco noted with glee, “She goes crazy when she sees me on Facetime!” The Navy, according to Franco, has a policy by which the more profound the disability experienced by the child of a service member, the more likely it is to place the child with the parent on deployment. Lorna is doing well, having escaped many of the medical conditions to which people with Down syndrome are susceptible. Franco noted he was exuberantly glad for her health, but noted with some irony, that it was part of the reason he was not able to see her as much as he would wish.

Mark said that he did not find meeting his daughter Natalie's needs to be stressful. "I would call it more frustration," he noted. Natalie, at 14 months, was crawling and pulling herself to stand. Mark said he was resolved to keep up the support: "She's not walking yet, and it's a little frustrating. But, you know, we just got to keep working with her." In the narrative Mark delivered, perspective led to wisdom. As he noted, "It takes a little bit longer for [children with Down syndrome] to do stuff, but things happen in their time." Every day, Mark said, "She gets stronger and she gets better."

Scott attributed the stress in his life not to having a child with Down syndrome, but having a child at all. A first child can change parents' lives, and in Scott's case his second child was born with Down syndrome. He explained, "We had a child and I think that was a huge adjustment for us, because we were pretty active and independent, a social couple before we had children. So our whole lives were turned upside down just having that first child." Scott and then partner Lilly were "shocked" by the changes in their lives after their first child. Scott concluded with this thought: "By the time Isabelle came around, our whole lives had changed anyway."

Ollie said that his family's life was stressful but admitted that the onus of caretaking was mostly on his partner. He divulged, "I work mostly nights. I try to be there either in the morning or the evenings, if I can't do both. That's the biggest stress really. The partner has taken on the primary caregiver and so she's the one that has to coordinate getting home and getting dinner on the table, try to go to the gym as many nights as you can, or getting the kids want to go to the pool." Ollie went on to describe his job as the primary source of his stress.

Samson admitted that the source of stress for him had to do with his family, which included moving in with his parents. He said, “Our life was a roller coaster, between chemotherapy, and my wife lived in the hospital for like six months with my son, and I was at home with my daughters. You know, I’d take them up every week, I’d be up there if possible. We were living with my mom at the time, and that helped, but that just meant that my mom, my sister, and my brother, three more mouths that I had to feed and cook for.” He added, “Then dealing with finances and school, and the added stress of dealing with therapies...” Samson became the caretaker of his extended family while his partner Miriam, then a resident physician in podiatry, attended to their son’s chemotherapy and other appointments. Stress was a permanent and unresolved factor in their lives. At one point Samson admitted, “I wouldn’t say we’re very happy.”

Among all participants, Bill exhibited most signs of stress. Frustration was visible in his features and palpable in his body language and diction. He sighed frequently and resorted to filler phrases and sound effects to convey unutterable ideas: his transcript is peppered with phrases like “I dunno” and interjections like “ugh.” Bill, with zero malice, and completely devoid of derision or resentment, located the source of his stress on his daughter’s behavior and caring for her needs. No doubt exists whether Bill is a loving, caring, and patient father, but he is frustrated. He ended our interview by thanking me and admitting that talking about his life was cathartic. “It was like a free therapy session!” he joked.

Bill’s daughter Maggie, aforementioned, was born with Down syndrome and deafness. She also developed a seizure disorder during her first year. Bill admitted, “I don’t remember what we did our first year other than having a million therapy sessions

and appointments every week.” Some appointments were local, but many of them required trips to St. Louis Children’s Hospital, an hour away. Maggie frequently required trips to ENT’s, audiologists, ophthalmologists, neurologists, and surgeons. Considering the hour drive in both directions, in addition to parking, walking, and waiting room time, these visits to specialists often ended up being whole-day affairs. Bill laughed and added, “all that for a ten minute follow up appointment!” Bill and his partner were both working when Maggie was younger, but frequent trips to the doctors and therapists became too much. Bill’s partner Lucy stopped working and Bill changed careers, a move that has mitigated the stress somewhat.

Bill said that his family takes solace in familiarity and routine. In church, everyone knows Maggie, for example, and they are used to her. The family attends fundraisers and outings for the local Down syndrome guild, but those can be difficult to predict. Bill said he and Lucy have a hard time knowing, “Is Maggie going to like it? Will she tolerate this event? Or is it going to be something that will turn into a nightmare and we can’t be bothered to go?” They have to consider contingencies, “How is that going to work if we take her and try to make her do these things that she doesn’t want to do and doesn’t know how to do, or doesn’t understand why we’re doing them?” One example he cited is bowling events that the Down syndrome support group organizes: “And she can enjoy it for a little while. But a little while can be 15 minutes; it can be an hour sometimes. After that, she’s done. That’s it. Party’s over.” Maggie becomes defiant and distracting. The planning, travel, and emotional difficulty that come with Maggie’s behavioral challenges can make such outings feel prohibitive: “If it’s something that we

have to drive like an hour to get there, it's just like, eh forget it. It's kind of got to be worth the while."

Bill said that Maggie requires constant supervision, which can be tiring. He noted, "I get frustrated because...there'll be parents sitting around the bench and their kids are playing and they're just sitting there staring at their phones and we can't do that. We need to be with Maggie, which is nice because we're playing with our kids, but you have to be with her. And playing on the equipment with her. The kids will be staring at her." Going out to eat occasionally frustrates Bill: "if she gets in a little bit of a mood, or gets a little upset, eating with her is challenging. She'll want to throw her drink. So she'll sling her stuff on the floor [sound effect]. It's hard to go eat in public anywhere at all." Going out "can be overwhelmingly hard sometimes," Bill concluded, "So often we just don't."

Our interview occurred at the end of a very difficult summer during which Maggie presented a number of behavioral challenges. Bill was at a loss for words to describe his exasperation: "Just phew! Crazy!" he said. Without school and her routine, Maggie was bored. Bill said, "just cannot handle when things are off or different, or whatever." A few months later when I presented him with a re-storied narrative, I asked about Maggie. "Now that school's started, she's a whole lot better!" Bill said.

Brian, too, admitted that his life was stressful. The medical challenges that his son Wallace faces are difficult, and make life demanding, but Brian was careful to disassociate them from Down syndrome. He declared, "Having Down syndrome isn't as quite bad as it could possibly be in life." Cancer is stressful because, Brian said, "It breaks my heart to see him sick." Will is a "complete daddy's boy," and Brian described the tender image of Will with his head on Brian's lap while doctors and nurses

administered chemotherapy at the hospital. Life is difficult but Wallace has made it better for everyone in his family, Brian emphasized. Brian, reflecting on his life said that he obviously wished Wallace did not have to undergo cancer treatments, but otherwise he “wouldn’t have it any other way!”

Finding 11: 10 of 22 participants narrated positive substantive positive personal changes that came as a result of raising children with Down syndrome. These participants demonstrated changes to the self that resulted in substantive positive changes to world views, spirituality, views about disability, and personal characteristics. 12 participants either did not narrate themes of positive personal change or narrated changes that did not qualify as substantive.

For the purpose of coding, I included only narrative accounts of fathers who reported substantive changes to their world views or spirituality, their conceptions about life or disability, their emotions, their temperaments, or their outlooks. I excluded from this section narratives about changes to family relationships, careers, or financial factors, which appear elsewhere in the findings. Concerning the effect of raising children with Down syndrome, 10 participants discussed a kind of substantive personal change in their narratives.

For Garth, no doubt can be cast about whether or not his life is better because of Tucker. Garth said he has battled addiction on and off for over 15 years. He asserted that he was “either going to end up in jail or get my life together” after his son Tucker was born. Clearly, he has chosen the latter, and he credited Tucker for teaching him “a lot of lessons.” His sobriety aside, Garth also credited Tucker for helping him change the way he approached life: “I thought I appreciated the small things in life, but until you are dealt

something and you see the world through somebody else's eyes who actually does do that, you realize, you were just fooling yourself.”

Mark admitted that having a daughter with Down syndrome has made him better at doing his job as an EMT, but more importantly, “a better person.” He noted, “I've learned very quickly how to deal with children and adults with disabilities.” An added benefit surprised Mark. “I'm better at my job, but I'm a better and a happier person when I help people,” he said, a beaming smile radiating across his face.

Chris said effusively that his life has “never been better!” He continued, “Having my son, he's just a ray of sunshine. He's always happy. He's always positive.” Chris said that Jake has taught him to be more patient and more understanding, more tolerant of differences. As all parents, he admitted that he was worried about the future, but his trust in the goodness of people has been fortified by his experiences. He said, “Now that I'm part of the Down syndrome community, I'm around people that have Down syndrome, other parents, and so on, I realize that they do have a really bright future. I'm a more hopeful person.” Hope is a wonderful salve against a society that propagates discourses suggesting lives raising children with Down syndrome are beset by misery. Chris added, “And right now is one of the best times to be born with Down syndrome. There's more understanding about it, more acceptance, brighter future, you know?”

Trek noted, of what his daughter Faith taught him about success and worth, “With her I've really learned that we all have different gifts. How smart or how strong you are, how ‘whatever’ is not necessarily a measure of who you are.” Faith has taught Trek the greatest gift of wisdom: “If you really look at somebody, in everybody you're going to

find something that's amazing about them. So, if you have one criteria, you're judging people, you're going to miss out on some amazing relationships!"

Branson said that he has a "better outlook on life" because of raising Sarah. He noted, "She helped me look beyond myself and beyond my own social circles." He also credited his experiences raising Sarah as helping him become "more adaptable." While he once was a goal-oriented person who "planned out five-years ahead," he now views himself as better able to "cope with change and impermanence."

For his part, Paul said he is more "patient, understanding, and empathetic," but he is not sure if parenting a child with Down syndrome is the causal factor: "I'm not sure that there's been some earth-shattering thing that I've learned about myself in the world by having her. I think having kids in general was probably most of that."

Wolfgang said that, while he once thought having a child with Down syndrome meant he was "thrown for a huge loop," he added that, "the loop has taught me so much, including compassion, patience, acceptance." Wolfgang admitted that many of those positive qualities came with age anyhow, but the presence of Wade in his life has only accentuated them.

Ryan, who works in a prison, also indicated with a deep sigh that there are people who use and hurt others, people who, he says, "you can just tell don't get it," meaning they do not understand what it means to be good. Ryan contrasted them to Julius: "He's not like this. He knows the meaning of life. He understands goodness." When things are stressful at work, Ryan said, "Julius is going to be my smiles. For me, he's the biggest blessing in the world." Ryan concluded with a final thought about Julius's spiritual

addition to their family: “He’s here for a reason. He ties things together. The stress that we have, he eliminates all of it, so he’s just a blessing.”

Wayne said that having a child with Down syndrome “taught me about life.” Pressed for details, he then put forth a remarkable and poetic idea. He discussed some current events from the time of our interview, a story of a father who murdered his family, as well as a tragedy about a girl who was murdered while on a jog. Then he raised the issue of division in American politics. “It is so easy to get discouraged, dismayed, and jaded by politics and gruesome stories in the news,” Wayne said, “But I think Adrian is luckier than we are. We as typically functioning people sometimes have a hard time seeing [goodness in humanity] but I think Adrian is more blessed than we are because I think he will have a different view of the way things are.” Wayne added, “Adrian brings about purity and an innocence that I don’t know he’ll even ever outgrow, which I’m thankful for.” His next thought was a spiritual one: “When Jesus said you need to be meek like these children to inherit the Kingdom, I think that’s what he’s talking about.” In closing, Wayne described people the Down syndrome, and the parents that raise them, as “an elite group.”

Chapter Five -Interpretations

Overview

The purpose of this study was to conduct a narrative inquiry to understand the experiences of fathers upon an initial diagnosis of Down syndrome in their children as well as to understand the experiences of those fathers later raising children with Down syndrome. The methodology of the study called for three interview phases, including question one, which concerned fathers' experiences upon the initial moment of diagnosis; question two, which concerned fathers' experiences raising children with Down syndrome; and a third conversational phase. The process of narrative inquiry required transcribing the interviews, and then re-storying the narratives. Long transcripts became shorter narratives from which key details and other salient features of the narratives were reconstructed. In a subsequent round of data analysis, the narratives were analyzed for thematic data. Recurring ideas and reactions, descriptions and terms were grouped together in the interest of finding common elements and sometimes poignant but not common details of diagnosis stories and lives raising children.

Fathers recalled extraordinary clear details in their narratives, as ideally the narrative selections in the findings chapter revealed. These details may be attributed to "flashbulb memory" (Skotko, 2005), the notion that traumatic memories may be immune to forgetfulness. Alternatively, vivid details are expected in narrative inquiry on the basis that the fluidity of time and tenuousness of memory are merely one aspect of narrative and narratives can be reconstructed. That is, the passage of time between the event and the later narration is an expected tension (Clandinin & Connelly, 2000) and that certainty belongs to the teller or the recipient of a narrative as they see fit. Thus, the first act of

interpretation I offer is to suggest that fathers chose their narrative details carefully and narrated them explicitly. Obvious enough is the conclusion that fathers wanted to participate in this research, but furthermore, their decisive selection of narrative data, clear recreations of events, and vivid retellings of those events may serve as evidence of the authenticity and what Clandinin and Connelly (2000) term the “wakefulness” of their narratives for the purposes of this study. Wakefulness is a term those authors use to describe the “ongoing reflection...at the boundaries of reductionistic and formalistic modes of inquiry,” in place of such terms as validity, transferability, and causality (p. 184). The data gleaned from the narratives of the fathers in my study are wakeful in that they teem with meaning and reveal much about the phenomenon of raising children with Down syndrome. The findings, I aver, are transferable, perhaps not in any statistical way, but transferable in terms of evidence that dominant cultural narratives about Down syndrome do exist and that they erroneously cloud the authentic lived experiences of people with Down syndrome and the fathers that take part in raising them. While I can not claim the findings are generalizable, given such a small participant sample, I suggest that they are valuable and transferable. The findings add to a small but mounting body of evidence that suggests that fathers’ lives raising children with Down syndrome, similar to mothers’, are far better than they expected during the moment of diagnosis and generally are good lives with loving and productive relationships and families.

Anyone, parents and professionals alike, who has an interest in understanding the diagnosis and later lived experiences of fathers raising children with Down syndrome, can understand something of the experience and perhaps apply it to their own

interpretation of what it means to process a diagnosis and raise children with Down syndrome, and thus question their perspectives.

The findings of this study are repeated verbatim from the previous chapter in subsections below, followed in each case by interpretations. Implications for practice and further research, as well as a general discussion about limitations and conclusions are presented in the final chapter.

Interpretations of the Findings

I offer interpretations of the findings in order in this section, with the exceptions of finding three and finding five, which emerged as similar themes from the narratives generated by question one (concerning fathers' initial diagnosis experiences) and question two (concerning fathers' experiences raising their children). Fathers narrated details about the experiences of medical complexity and information seeking in both the initial moment of diagnosis and during their later experiences raising their children. Although the themes were alike, the manners in which fathers narrated and detailed those themes differed from question one to question two, which was in itself a revealing finding because it suggested change in fathers' perceptions over time. Therefore, findings three and five are parsed out in sub-findings labeled with letters a and b.

Finding One: Of 22 total participants, 18 participants narrated interactions with medical personnel while four participants did not mention interactions with medical personnel. 13 participants reported negative interactions with medical personnel, while five participants reported exclusively positive interactions. Three participants narrated a combination of positive and negative interactions.

Finding one revealed, unsurprisingly, that participants chose to narrate their interactions with medical personnel. The diagnosis of Down syndrome must be delivered by a medical professional, and since it is a moment of shock, confusion, and other intense emotions for fathers, it follows that fathers would take stock of details about the setting, the timing, and the manner of the professional(s) delivering the diagnosis. The conviction and intensity demonstrated by fathers in my study relaying negative experiences revealed that medical professionals are not universally adhering to best practices. Participants who had negative experiences with medical personnel were especially moved by them, as evidenced by the manner in which they shook their heads and heaved exasperated sighs as they told of their experiences.

Among the 13 participants who reported negative experiences, the themes of their complaints demonstrated that medical personnel were not following best practices outlined by the Down syndrome Diagnosis Network (DSDN, 2020) and Skotko et al. (2009a, 2009b), as nine participants described the diagnosing professional (whether it was a physician or a counselor) as delivering “bad news.”

The themes generated by participants in my research also aligned exactly with those found in Van Riper and Choi (2011). Those investigators found that medical personnel persuaded parents to terminate pregnancies, promoted stereotypes about Down syndrome, were evasive with information, were void of compassion, lacked forthrightness or honesty, provided lack of support or information, and communicated low expectations about children with Down syndrome. My interpretation of the narrative evidence participants in my study provided is similar to what Van Riper and Choi offered: that some medical personnel are aiding to perpetuate the dominant cultural

narrative that people with Down syndrome are unwanted and that the lives of their fathers are beset by grief and tragedy.

Not all medical personnel serve to perpetuate the dominant cultural narrative. In fact, five participants in my study revealed that they had exclusively positive experiences with medical personnel. Those participants tended to be fathers of younger children ($\mu = 2.75$ years), and therefore a possible explanation is that the fathers whose children were born in somewhat recent years have had better experiences with medical personnel as medical personnel have become better trained and positioned to adhere to best practices in diagnosing Down syndrome.

The children of fathers in my research were born with Down syndrome between 1999 and 2017, but the average age of children of the fathers who reported negative interactions with medical personnel was just over six years-old, suggesting the children were born after the publication of Skotko et al's research and the subsequent dissemination of materials by the DSDN. This may indicate that medical personnel are better trained in recent years and that they are receiving and delivering the message that Down syndrome is not "bad news," and that life raising children with Down syndrome is not necessarily beset by tragedy.

In my research, the experiences of fathers with prenatal diagnoses and their interactions with medical personnel differed from fathers with postnatal diagnoses. I attribute the differences in their experiences to the presence of medical complexity in their children. The participants in my study receiving prenatal diagnoses were fortunate in that none of their children experienced life-threatening medical complexities during their gestation. Of the 14 fathers in my study who received postnatal diagnoses, 12

reported emergency medical circumstances. Fathers in those cases were not concerned with the bedside manners of medical personnel or the messages about Down syndrome medical personnel delivered; understandably, the fathers' foremost concern was the health of their children. This was reflected in their narrative details.

Fathers with postnatal diagnoses in my study did not mention the idea of a prenatal diagnosis once in terms of "what if" thinking. They told of their diagnoses, narrated details of medical complexities, and advanced the narrative to some later date, as if they understood that their experiences were rushed and happened suddenly. Participants revealed in my study that the pace of their experiences around the time of diagnosis (which unfurled more rapidly for fathers whose children had medical complexities at birth) influenced the pace at which they relayed their narratives.

My findings disagreed somewhat with Nelson Goff et al. (2013). In their survey of 161 parents of children with Down syndrome, they found no difference in the experiences between prenatal and postnatal groups in terms of their negative experiences with medical personnel. One difference is that Nelson Goff et al. surveyed parents generally, but had a participant pool of mostly women (93% in the prenatal group and 90% in the postnatal group). An interpretation is that gender difference *might* account for how individuals interact with medical personnel and narrate their experiences with diagnoses.

A more confident interpretation I make is that learning of a diagnosis of Down syndrome in their children can for fathers be made the more difficult, painful, and confusing, or the more accepting and copacetic depending on the attitudes and behaviors of medical personnel. Instead of providing comfort, empathy, and authentic outlooks for

fathers raising children with Down syndrome, some medical professionals propagated dominant discourses of children with Down syndrome as “bad news,” as unwanted, and as a medicalized problem. They projected unhappy lives for fathers. The fathers who reported positive interactions with medical personnel moved more quickly from the initial period of diagnosis to a more stable and happy period of raising their children.

Finding Two: 20 of 22 participants reported experiencing intense negative emotions at the initial moment of a diagnosis of Down syndrome in their children. Participants reported shock and devastation, being scared or nervous, or expressing sorrow or loss of an expected child. Two participants did not report experiencing intense negative emotions, both of whom were personally familiar with people with Down syndrome.

Most participants in my research reported negative emotions such as shock, devastation, fear, concern about the future, sorrow, mourning, and loss of an expected child when they learned that their children would be, or were, born with Down syndrome. The fathers in my study narrated their experiences also with intense emotions during the interview as they recalled painful and vivid memories. In some cases shame, upon retrospect, that they felt ashamed that they experienced those emotions during the diagnosis. Dominant cultural narratives about disabilities have conditioned fathers to react insentiently as if a disability is an unwanted and tragic turn. I interpret, from the findings in my study, that upon diagnosis fathers initially view an individual with Down syndrome into their family as “bad news” for that family. I posit that the negative emotions derive from uncontested ableism that resides in the subconscious layers and conscious layers of most individuals, but they neither know nor understand the source of those feelings.

In none of the 20 narratives of fathers in my study who experienced negative emotions did fathers implicate dominant culture as the source or fundament of their negative emotions upon diagnosis. Only upon reflecting on their lives later during question two did participants explore the disparity between their expectations during the initial diagnosis and their later experiences upon raising their children. Fathers seemed aware in their narratives upon question two that their lives were different from what other people thought they were or should be, so participants did arrive at the conclusion that a false narrative about raising children with Down syndrome exists. Why did they not retrofit that awareness and apply it critically to the medical professionals who mistreated them? My analysis suggests that they were disadvantaged unfairly, and this was an unfamiliar experience for many of them. They were unwilling subjects to dominant discourses of people with Down syndrome and the parents that bring them into this world. One explanation of why participants in my study did not fully understand their diagnosis experiences at the time of their diagnoses is that they were once willing participants in dominant culture who did not question dominant cultural narratives and had little experience thinking about power structures involved in the way that people treat other people.

Able-bodied people do not spend much time investigating the actual experiences or narratives of people with disabilities until disability affects them personally. At the time of their children's diagnoses, participants in my study perceived their children as other than what they expected. Their children were medical "problems" that arose. Their children's birth circumstances marred their expected joy of a typical child. Participants' lack of experience encountering people with Down syndrome and their knowledge of the

lives of families with children with Down syndrome was limited and flawed prior to receiving the diagnosis of Down syndrome.

Fathers in my study admitted that their understanding of what their lives might entail was based not on experience, but on an unwritten, inferred dominant cultural narrative, mostly false, and mostly based on ill-formed images from dominant culture on television and the internet, as well as medical models of disabilities. In short, they lacked experience understanding what Down syndrome was. During question two when they began to question dominant cultural narratives, they mainly blamed themselves for their erroneous visions of people with Down syndrome instead of dominant discourses or medical professionals who mistreated them.

Secondly, participants in my research might not have seen themselves as disadvantaged by the medical personnel who mistreated them or implicated those medical professionals as perpetrators of dominant culture and medical models of disability because the fathers in my study lacked experience with disadvantage. Participants in my study were overwhelmingly white, financially secure, cisgender, able-bodied, heterosexual men. Only three participants mentioned that they had some status of privilege. The remaining 19 did not name sociocultural power specifically as a source of their negative emotions, though every participant in my study would describe dominant discourses in one way or another in their narratives. Systems of power and advantage and the discourses that drive them are subtle and insidious. Hegemonic thinking has a tendency to pervade consciousness and sub-consciousness and influence the way that individuals interpret experience. Fathers in my study who were angry about medical professionals' attitudes or reflecting on their own orientations to disability during the

diagnosis did not think to investigate the source of their intense emotions, but rather accepted them as “the way things are.”

Two participants in my research were exceptions that served as evidence for my assertion. Wes and Walter explained that their jobs working with people with Down syndrome positioned them with understandings that the diagnoses they received were not causes for shock or grief. Their narratives were marked by one thing other participants lacked: experience. Having known many individuals with Down syndrome, and indeed being friends with people with Down syndrome, helped those participants to dispel the effect of the dominant cultural narrative and see people with Down syndrome as entirely human, not as unwanted, other, as living tragic lives or causing ambiguous grief for their parents, a finding that runs counter to Kaposy’s (2013) autoethnographic account. Those participants knew that their experiences raising children with Down syndrome would probably be happy because they had realistic examples of people with Down syndrome as fully human beings and their families as happy.

All other participants in my study did not have more than passing relationships with individuals with Down syndrome. If the closest an individual comes to knowing someone with Down syndrome is “that guy who bags groceries at the supermarket” or “that woman in church,” then their superficial understanding of what life is like for individuals with Down syndrome will be based on whatever impressions they garner from medical professionals and dominant discourses. They suddenly feel like tragedy has struck them. When faced with a sudden and unexpected diagnosis, a new father’s frame of reference about disability is to be shocked and feel sadness, shame, fear, or sorrow

(although guilt was not seen as it was in the literature on mothers' experiences, as will be discussed later).

My findings suggest that the process of questioning a hegemonic dominant discourse begins for most fathers very shortly after the initial period of diagnosis. Most fathers began with researching Down syndrome on the internet. While fathers in my study reported some success in information gathering on the internet, most found only negative, erroneous, or misleading information during the initial period of diagnosis. The factor that helped fathers most was social support, and it appears that they found it shortly after diagnosis. Meeting other families with children with Down syndrome, fathers began to understand that their lives would be, in the words of a participant from my study, "pretty normal [and] not as bad as people think."

Fathers in my study did not corroborate the notion of chronic sorrow as a repeating and continuous experience caused by disparity between their expectations and their realities, as suggested by Eakes et al. (1998). Participants in my study did seem to narrate experiences that align with Bentley et al.'s (2015) findings that fathers of children with Down syndrome experience ambiguous loss in stages described as mastering, connecting, and thriving. According to Bentley et al., "The thriving cluster personifies what Boss (1999) calls 'making sense out of ambiguity'" (in Bentley et al., 2015, p. 12). Fathers in my study seemed to make sense out of ambiguity very shortly after the initial moment of diagnosis and thus their accounts seemed to repudiate the notion of chronic sorrow. They reported what human beings do in any situation that presents them with difficult emotions and change; they immediately tried to begin to make sense of ambiguous loss. While fathers in my study described loss as a reaction to the initial

diagnosis, I saw no evidence that loss was long-term driving force behind meaning-making of their children's diagnosis of Down syndrome or their lives generally.

In fact, the orientation and general attitudes of the majority of fathers in my study at the end of question one, as they pivoted from describing their initial moments of diagnosis to their experiences raising their children with Down syndrome were future-focused. The driving force behind their actions and their narratives was love for their children and an openness to change and new learning. I agree with Poehlmann et al., (2005) and other researchers (e.g., Fleming, 2013; Nelson Goff et al., 2013; and Ridge, 2013) who view the initial moment of diagnosis as a process that some individuals experience in a way similar to Kubler-Ross's stages of grief. Participants in my study did experience anger over loss, some denial, and brief depression, though bargaining and guilt were not present. The last stage of Kubler-Ross's process is acceptance, and fathers in my study demonstrated in their narratives that acceptance is not only possible, but a probable outcome of processing a diagnosis of Down syndrome.

Findings Three (a) and Three (b)

Finding Three (a): 17 of 22 participants narrated issues of medical complexity in their children during the initial period of diagnosis. As the severity of the medical condition increased, participants were more likely to focus on the details of their children's health than any other narrative detail, including their own feelings. Five participants did not narrate issues of medical complexity at the time of diagnosis.

Finding Three (b from question two): 12 of 22 participants narrated the theme of medical complexity after the initial period of diagnosis, and into their experiences raising their children with Down syndrome. The medical issues themselves shifted

from emergencies to conditions requiring surgeries and long-term treatments. 10 participants did not narrate the theme of medical complexity in their children after the initial period of diagnosis.

The medical concerns in both findings three a and three b varied by their scope and severity, by the effects they had on biological systems and family psychology, by the degree to which fathers afforded them narrative importance, among other factors. The thematic label I have chosen to ascribe to such medical conditions is “medical complexity.” In the literature, no common term exists. One may find labels such as “medical fragility” (Counselman Carpenter, 2015), “fragile health” (Bingham et al., 2012), “medical problems” (Nelson Goff et al., 2013), and “medical crises” (Constantino, 2010). I employ the term “complexity” to imply any status, however permanent or severe, other than typical, anticipated health.

In the literature, in which studies do not often separate parents’ initial diagnosis experiences from their later experiences raising their children, medical complexities in children with Down syndrome are not always explored across a narrative landscape of time, but instead as a static phenomenon or a once-measured statistic. It is common, however, for children with Down syndrome to be born with conditions that resolve within hours or days (Leshin, 2008). Of course there are also conditions that extend over years or are otherwise chronic. Finding three (a) resulted from question one, from participants’ narratives of initial diagnoses, while finding three (b) emerged from question two, which accounted for fathers’ experiences raising their children. The findings, while related thematically, demonstrated that in my study, fathers’ understandings, expectations, and narrative approach to medical complexity in their children changed over time.

Finding three (a) was based on 17 participants in my study who narrated details about their children's health at birth. Some of the conditions described by some fathers were, to be sure, frightening medical emergencies that were traumatic and stressful. None of the fathers in my study had a background in birth medicine, so to their untrained experience, the speed, alacrity, and movements of the physicians and nurses during birth, while presumably routine to medical personnel, provided frightening experiences for fathers that later turned into narrative details. Fathers described emergency C-sections, respiratory distress, breastfeeding difficulty, kidney problems, and cardiac concerns.

All of the emotions of a childbirth (any childbirth), as well as sudden and unexpected medical complexities in their children, had fathers describing their reactions to medical complexities as rapid, astonishing, frenzied, confusing, and traumatic. Neonates with Down syndrome can and often do present with medical complexity at birth, but many of the complexities with which they are born resolve in short time (Leshin, 2008). This was evident in the manners of fathers and the narrative details they divulged between question one and question two. The emergent circumstances during birth, which became the finding three (a), gave way to the more rationally narrated findings of three (b), which emerged from the second question.

Fathers narrating their children's health during the second question focused on surgeries for heart conditions, long-term treatments for leukemia, and severe long-term feeding issues. Despite the medical conditions themselves being more acute and serious than the birth complications, fathers narrated the descriptions of treatments and procedures with calm, measured, systematic terms that implied that their children, while facing critical medical procedures, most likely would have favorable outcomes and

prognoses. Ironically, while fathers describing emergency medical complexities during their children's birth as stressful and traumatic, fathers describing medical complexities with far more serious implications were calmer and narrated those experiences with more equanimity and measured tones.

This may serve as further evidence of the influence of medical personnel. The demeanor, attitude, and ability to educate or relate what is happening to fathers matters. One possible explanation is that the medical personnel in birth circumstances have fewer experiences with developmental disabilities than medical personnel who treat long-term medical conditions, and thus fathers encounter medical professionals later on who are more accustomed to working with families with individuals with developmental disabilities. Or it may be that fathers, absent of the strong and sudden emotions of the initial diagnoses, are better able to work with medical personnel. It is likely that fathers gain more confidence as they gain more experience raising their children and supporting them through their medical complexities.

In this study, medical complexity of the participants' children continued as infants with Down syndrome became toddlers and were somewhat resolved by the time the children reached adolescence. The four participants with children bearing double digit ages reported no medical complexity. This may be because adolescents with Down syndrome experience fewer medical complexities in their adolescent years or because fathers simply have learned to incorporate medical complexity into their lives and chose to focus on other narrative details about their adolescent children.

The fact that medical complexities do come part and parcel with Down syndrome cannot be ignored or understated. While fathers in this research did choose to include

those narrative details in their stories, most fathers insisted that their lives were not beset by misery or suffering, as implied in dominant cultural narratives and medicalized models of Down syndrome. Bill, among all participants in my study, was the sole participant who admitted that medical complexity made his life more difficult. His daughter's medical complexities extended beyond Down syndrome (in that they included deafness, seizure disorders, and psychological complexity). Even Bill was adamant about his love for and commitment to his daughter and emphasized that he was not unhappy.

The most important observation from these two findings is that fathers did not characterize Down syndrome as a medical phenomenon, but discussed medical complexity as one facet of their own experiences raising their children and one aspect of their children's identity. Fathers' characterizations of their children did not define them by the medicalized presentation of Down syndrome, any more than a father might define a child by obesity, ADHD, cancer, or juvenile arthritis. Nor did fathers define themselves by the actions they undertook to support their children's health. Fathers did not sculpt themselves as heroic super-parents rising to conquer their children's medical "problems" or as pathetic sufferers struggling to meet their children's needs. In short, the narratives of fathers in this study rejected medical models of Down syndrome in favor of social models (Ferguson, 2002; Poehlmann et al., 2005).

Finding Four: Of eight participants with prenatal diagnoses, all discussed the theme of women's reproductive rights and abortion in their narratives. Six participants agreed uniformly with their spouses to keep the pregnancy, while two participants reported conflicts with their partners. 14 participants reported postnatal diagnoses, and thus did not narrate the theme as a part of their experiences.

Finding four concerned participants whose children were diagnosed prenatally. All eight participants with prenatal diagnoses in their pregnancies narrated the subject of women's reproductive rights and abortion. Perhaps this finding is not surprising considering that most prenatal diagnoses result in termination globally and in the United States. If termination is something of a standard practice, expected by diagnosing physicians, and borne by a dominant cultural narrative which positions children with Down syndrome as unwanted, it would arise as a prominent theme

Of eight fathers with prenatal diagnoses in my study who chose to include in their narratives the theme of women's reproductive rights or abortion, two cited the reason for not terminating their pregnancy as their or their partners' religious views. Conversely, two fathers cited their desire to terminate the pregnancy whereas their partners had strong anti-abortion sentiments.

The finding in my study is interesting in that most fathers did indeed invoke the issue of abortion and admitted it was an important factor in their lives but chose not to discuss their own roles in detail or at length. Between the two fathers who reported conflict with their partners, one assented to his partner's desire to maintain the pregnancy, describing how he and his partner had not discussed the issue ever, and he found her desire to maintain the pregnancy a surprise. That participant, upon realizing his partner's fervent belief, acknowledged that he was amenable to maintain the pregnancy because their marriage depended on her insistence on the matter, that her belief was so adamant that he found himself willing to support her, and that it was the right decision for their family eventually. That father seemed to be offering parabolic wisdom for younger

fathers: have discussions about important potential outcomes with your spouses was his strongly implied message.

The interpretation of this sub-finding, or this father's anecdotal evidence anyhow, is a lesson for young married couples. Disability might happen. What are your separate and combined beliefs about and orientations to disability and how will you react to a diagnosis of Down syndrome or any other developmental disability? This level of advice and analysis in some ways transcends the scope of this research, but it does reveal something in the heart of the theoretical grounding of my study. If the subject of disability and potential response to it is not always involved in discussions between couples hoping for children, what does that say about disability itself? Disability is seen as other, as unwanted, as taboo, and as something that happens to *somebody* else and not discussed as a matter of *what if?*

The second participant who reported conflict with his spouse did not come to a prenatal resolution. The unresolved conflict caused that participant to have bitter feelings against his partner, against fundamental Christianity (which he blamed), and in some ways affected the relationship he had with his son. This participant, as discussed in the findings chapter, also had feelings of bitterness and resentment towards his mother, as he endured years of neglect and later years of taking care of his mother due to her substance abuse. The notion of being responsible for another adult, whom he saw as helpless and dependent on him, distressed this father and caused him to associate disability in his son with his previous and unresolved emotions about substance abuse in his mother. From this sub-finding, I interpret that the notion of disability, informed as it is from a dominant cultural narrative, is conflated with other negative emotions and situations from

individuals' pasts that have had deep effects on the psyche. This participant's narrative reminds and informs that the complicated emotions of encountering a diagnosis of Down syndrome is not a phenomenon that happens as an isolated event in a vacuum, but is conflated and intermixed with all of the good and bad experiences that make people who they are.

It also seems, based on the responses from fathers in my study, that fathers were aware of the suggestion (however strongly expressed) from medical personnel that they should terminate the pregnancy. Two fathers with prenatal diagnoses told of medical personnel who strongly suggested or assumed they would want to terminate. Ultimately, what should be an issue to be discussed between two would-be parents, deciding about whether to bring a child into this world, has become so political, so rife with the issues of modern ethics, that fathers thought they should make it a part of their narrative. Even when aborting a pregnancy was a non-issue between them and their partners, as was the case in six of eight fathers in my study with prenatal diagnoses, those fathers elected to discuss the matter because they knew it happens to other fathers. All of them acknowledged the issue, some with phrases such as, "I know some fathers have a more serious discussion about abortion than I did..."

The subject of elective termination of pregnancies on the basis of a diagnosis of Down syndrome exists at a contentious cross-section of ethics, politics, public opinion, and critical academic traditions. While many adherents to feminist disability studies are careful to proclaim their position that women must have the right to choose termination of pregnancies under any circumstances, they simultaneously argue that decisions to terminate otherwise expected and desired pregnancies is tantamount to medical eugenics.

The inevitable and quintessential question that follows is whether people with Down syndrome deserve to exist (see Ashe, 2015; Berube, 2009; Forte, 2018; Gabel & Kotel, 2015; Hubbard, 2007; and Ridge, 2015). Some feminist disability scholars have maintained a delicate separation between the ethics of the right to exist for people with disabilities and “sanctity of life” anti-abortion arguments, which they define differently (Ashe, 2015). While eight fathers narrating prenatal diagnoses did raise the issue of elective termination in my study, only two of those eight participants discussed in length the ethics or decision-making between them and their partners. Fathers were aware of the issue, enough to bring it up, but not apt to discuss their own positions on the matter.

The presence of dominant cultural narratives and medicalized models of disability certainly influence how potential mothers and their partners discuss termination or continuation of their pregnancies. Lalvani (2008, 2011), Gabel & Kotel (2015), and Piepmeier (2015) have demonstrated that mothers may be keenly aware that feelings of guilt and shame they experience during the diagnosis derive from dominant culture and feelings that they are transgressing cultural norms. Little is known about how fathers view the issue of terminating or continuing a pregnancy with Down syndrome and the narratives of fathers in my study added only a slight shade of insight.

Three fathers in my study who had prenatal diagnoses did discuss some “turning point,” as a moment at which they moved from their initial misgivings surrounding the diagnosis to a realization that raising their child with Down syndrome would be amenable and acceptable to them. Ridge (2013) found that fathers who, along with their partners, elected to maintain the pregnancy, found some “turning point” after which they were more confident and happy about their decision to raise a child with Down syndrome (p.

90). This serves as evidence that fathers may become aware at some point of the false nature of the erroneous information purveyed by the dominant cultural narrative of Down syndrome and begin to come to terms with their orientations to Down syndrome. This is the exact moment when the initial period of diagnosis subsides and fathers begin to prepare for their lives raising children with Down syndrome.

Findings Five (a) and Five (b)

Finding Five (a): 19 of 22 participants narrated that during the initial period of diagnosis they engaged in reflexive information seeking. Participants were trying to make sense of a disorienting event. Three participants did not narrate reflexive information seeking.

Finding Five (b): 21 of 22 participants narrated variations on the theme of information seeking, which continued past the initial period of diagnosis and into their time raising their children. Their approaches to information gathering during this period constituted a more measured and disciplined approach that included social support and critical information processing. Fathers demonstrated an increasingly sharper ability to evaluate information sources and use information. One participant did not narrate the theme of information seeking.

In the combined findings, most fathers admitted to reflexive, almost kneejerk reactions to information gathering during the initial period of diagnosis and later during the period of life raising their children described their information gathering as a more purposeful and measured approach. This change in their ways of gleaning information serves as further evidence that fathers in my study moved on from their sense of consternation of the initial diagnosis and settled into “normal” lives happily raising their

children. This change is attributable to fathers' changes to their social support structures and their increasingly sharper ability to evaluate sources of information and use information.

When fathers in my study first encountered a diagnosis in their children, even a suspected diagnosis, the result of a markers test, for example, they immediately turned to the internet. Not one father in my study narrated a question they asked of a diagnosing medical professional. An imagined question might be something like "What does this mean?" or "What will my child be like?" Or even, "What will my life be like?" Perhaps participants did not ask any questions, or their questions were suppressed by the lack of comfort afforded by the medical professionals, or they chose not to narrate such a detail in the interviews. Perhaps it is an issue of vulnerability or pride that fathers have or perhaps their reaction was fueled by panic or shock from the diagnosis. My research reveals that a combination of feeling shock and tragedy; a feeling of being positioned in a dominant discourse that predisposes fathers to believe they suddenly have an unwanted pregnancy or child; the diagnosing personnel's lack of preparedness, training, or empathy; exigent medical circumstances in their children; and lack of exposure to families that have children with Down syndrome: all of these factors prohibit fathers from asking timely and important questions in the immediate moments after diagnosis. Whatever the case, almost all of the participants in my study conducted extemporaneous and ill-informed internet searches about Down syndrome directly after the diagnosis.

When participants in my study narrated their experiences upon the initial diagnosis, their quick impulse to seek information on the internet was an abrupt and impromptu reaction. In a reaction to what Mezirow (1991) termed a "disorienting

dilemma,” in the form of a sudden, unexpected diagnosis of Down syndrome in their children, fathers immediately sought for frames of reference. What and whom questions were their first reactions. They immediately turned to the internet to find answers to the “what” question. What is Down syndrome?

What does one find in a first foray on the internet concerning Down syndrome? Often, misinformation, fatuous and cruel humor, acts of malice against people with developmental disabilities, articles (perhaps from older, less reliable, or indeterminate sources) that “medicalize” the effects of Down syndrome on the body, and propagate the message that people with Down syndrome are unwanted, to name a few examples of things fathers described encountering. Facing the disorienting dilemma of a diagnosis, fervently charged with intense negative emotions, adrift in confusion, fathers’ efforts at information-gathering in the moments right after diagnosis were disorganized and unfruitful.

As for the “whom” question. Fathers in my study reported searching, at the moment of their children’s diagnosis, their own memories for people with Down syndrome they had met. The answers from fathers came in the form of distant acquaintances: children that they had seen in church, parents’ neighbors from years ago, an employee at the grocery store who sometimes bagged their groceries, to list a few examples. Down syndrome is uncommon enough that individuals with Down syndrome simply do not enter most people’s lives in meaningful ways. It is possible also that the residual effects of keeping people with Down syndrome intentionally “hidden” so common decades ago, may yet linger, an unfortunate aftereffect of the days of institutionalization. My interpretation of fathers’ experiences of learning about Down

syndrome suggests that they found themselves disoriented and confused. Not knowing anyone with Down syndrome compounded their confusion.

In my study, the few fathers who were fortunate enough to encounter medical personnel who set them in the right direction moved more expeditiously from the period of initial diagnosis to a period of settling in to raising their children and beginning new lives. Participants who experienced kindness, empathy, and simple, short explanations about what causes Down syndrome and what their lives might be like were the same participants who reported that their initial experience with the diagnosis was short and their time raising their children began sooner.

This in accordance with Skotko et al. (2009a), who recommended that physicians limit discussions of medical expectations to the child's first year. When medical personnel present fathers with a barrage of possible negative problems their children may face over a lifetime, they help to position those fathers to believe the worst of their possible futures, which may or may not be relevant. At the heart of finding five (b) was the theme of social support, which was above all, the most helpful resource for pivoting fathers from the initial moment of diagnosis to a more stable version of their lives raising their children. In the experiences of fathers in my study, movement from a status of utter ignorance, a complete lack of knowledge of Down syndrome and what the experience of raising children with Down syndrome might be like was the beginning of their journeys.

For fathers who encountered negative interactions with medical personnel during the initial period of diagnosis, their orientations to their new information worlds came later, and often relied on meeting other families with people with Down syndrome. The vision of an older child with Down syndrome thriving in some way helped fathers

understand that their children, their families could thrive in the same way. This finding underscores the importance of community, belonging, and shared experience in the lives of fathers raising children with Down syndrome.

The general findings in the literature describe models of stress, coping, and resilience (Esbensen & Seltzer, 2011; Hauser-Cram et al., 2001; and Poehlmann et al., 2005) and fathers in my study generally adhered to that pattern, with information seeking and social support playing large roles in their experiences with coping and resilience.

Finding Six: All 22 participants narrated some kind of challenge or change to their family relationships and roles. Participants demonstrated that raising children with Down syndrome could require reassessment of roles and relationships with their families and friends.

As discussed in the findings, fathers generally were happily married and proud of their nuclear families, and they discussed changes within their families with acquiescence or acceptance more than annoyance. Only two participants spoke of any hostility or resentment toward their spouses. Having a child with Down syndrome need not bring about negative changes to a family, as a dominant cultural narrative about Down syndrome may suggest. While all 22 participants described changes in roles or relationships in their families, in no cases did fathers seek to “blame” or impugn their children as a source or cause of frustration for changes, as might be suggested by dominant cultural narratives. The changes were simply adjustments to family function. In most cases, fathers narrated details of their families’ changes as positive vicissitudes.

The four fathers in my study who reported that they divorced from their spouses all had amicable relationships with their spouses, and only one of the divorced fathers

claimed that Down syndrome factored in the divorce, also admitting that many other factors were involved. Most participants in my study overwhelmingly reported happy and harmonious relationships between them and their spouses and among their children with Down syndrome and their siblings. My participants' narratives were peppered with the usual family complaints about behaviors and frustrations of modern domestic life, but none of those complaints identified their child with Down syndrome as the root or cause. My interpretation of this sub-finding is that life raising a child with Down syndrome has its unique challenges, very few of which affect the nuclear family's relationships in a meaningful way.

Participants in my study did evoke many narrative details about relationships with extended family members, such as grandparents, brothers and sisters, and close family friends. Generally, having a child with Down syndrome can make fathers busy and reliant upon supports. Fathers in my study reported that the need to reach out and depend on extended family and friends was a test to some of the relationships in their lives.

The themes of anecdotes about extended family and friends tended to fall into one or two categories: fathers were either appreciative of the support and love from extended family members and friends, or they were frustrated by the behaviors and actions of extended family members and friends. My interpretation of this sub-finding is that their appreciation or frustrations had little to do with Down syndrome itself, and exceedingly more to do with the personalities and the willingness to learn and understand change, of the family members and friends themselves. Fathers in my study were willing to reassess their orientations to disability and their understanding of Down syndrome, while some of the people closest to them were not. This required a reassessment of relationships in

participants' lives. Raising a child with Down syndrome did not end or significantly mar any of the participants' relationships, but rather yielded a better understanding of those relationships. It is almost as if raising a child with Down syndrome can position a father to be more acutely aware of interpersonal relationships and make adjustments to those relationships. My analysis suggests that while nuclear families make adjustments readily and happily to families with an individual with Down syndrome, extended families and friends may or may not make such adjustments.

Participants in my study also discussed career and vocational changes. Some fathers had to make adjustments to their careers out of financial necessity and the logistical concerns of healthcare, government benefits for individuals with disabilities, and the financial security of their families. Other fathers, perhaps better positioned financially, made radical personal and career changes that changed the direction of their lives. In sum, two fathers made significant changes to their careers as a financially motivated adjustment. Three fathers made dramatic alterations to their careers based on new understandings and orientations to disabilities. My analysis suggests that all of the fathers were happy and willing to make changes. They narrated them as fortuitous and welcomed changes. The fathers who took the biggest risks, who while admittedly were better positioned financially to do so, were more happy and excited as they relayed their narratives. The fathers who made bold changes described their adjustments in near mystical terms. It was as if having a child with Down syndrome provided them with new purpose and calling, and the guts to make big changes. The participants' relative happiness with their careers serves as further evidence that the inclusion of a child with

Down syndrome in their lives is not something that makes fathers unhappy, but rather serves to increase their wellbeing.

Fathers in my study generally were active and involved in the lives of their children and happy with their involvement. My findings are in accordance with Ridge (2013) and Norton et al. (2016) who found that fathers' involvement in their children's upbringing resulted in their increased happiness for themselves and for the family at large, in spite of the many changes to roles and relationships they experienced. Urbano and Hodapp (2007) found that married parents of children with Down syndrome were slightly less likely to divorce and were happier than parents in the general population. Nothing in my research contradicts that.

The conclusions my findings suggest are that fathers may experience changes in family roles and relationships, some positive and some negative, some financial and some perfunctory changes to roles and routines. But the preponderance of narrative evidence suggests that changes to fathers' lives are to be expected and predicted but yield positive results. The changes to family roles and relationships are mostly changes that lead to personal growth, understanding, and positive fluctuations.

Finding Seven: 21 of 22 participants included prominent narrative details of their children's expected outcomes and their children's accomplishments. Fathers were nearly unanimously proud of their children with Down syndrome, especially when their children exceeded expectations. Fathers of older children may be more proud and content with their children's accomplishments. One participant did not include prominent details of his child's accomplishments.

Fathers in my study were overwhelmingly and abundantly proud of their children. Participants, regardless of the age of their children, beamingly spoke of their children's accomplishments. An immediate and obvious analytical framework began to form in my interpretive efforts, which arose in stark contrast to the dominant cultural narrative and even in contrast to academic studies which suggested that parents raising children with Down syndrome may experience chronic sorrow or ambiguous loss.

The participants in my study, except for one, were surprised, impressed, and encouraged by their children's accomplishments. That 21 of 22 fathers in my study narrated happiness, gain, and accomplishment in their children suggests to me that fathers were either choosing to narrate the happy and fortuitous elements of raising their children and not choosing to narrate moments of loss, sadness, doubt, or disappointment, or their experiences simply did not account for those negative elements.

The presence of those negative emotions may come from the dominant cultural narrative and may have been corroborated by studies using only survey instruments which assumed the presence of those emotions, as suggested by Lalvani (2013). Fathers in my research did admit to those occasional feelings, but what they chose to highlight in their narratives were positive developments, accomplishments, and pride. Their stories, informed by the richness of their experience and the overall balance of negative versus positive themes they revealed, suggest that the fathers in my study wanted to tell about their positive and happy experiences as they contributed to and observed their children's development.

A second sub-finding revealed that fathers in my study were especially pleased when their children exceeded expectations, predictions, or prognoses. It was as if fathers

knew their children faced low expectations and predicted outcomes in their medical prognoses, developmental milestones, and expected educational outcomes. Implicit in this sense of “defiant” pride is a struggle against a dominant cultural narrative. Over-medicalized characterizations and negative depictions of people with Down syndrome inherent in dominant discourses have weighed heavily on the fathers’ minds, even if they did not use academic vocabulary to define such discourses. When their children did anything to defy expectations, amalgamated in the fathers’ narratives in my study was pride, but also a sense of retribution against subtle oppression. A tone and attitude of “who says my kid can’t do this?” reprisal was loud and confident among fathers.

There is wisdom in the adage that the harder one works for something, and the more oppressive the forces against accomplishment, the greater the feeling of accomplishment. Fathers in my study understood that their children’s accomplishments were hard-earned victories, proof that their children’s accomplishments were not mere self-measures against their own potentials but relative measures against a system that militates against them. In my study, the fathers’ combined anecdotes suggest that their children with Down syndrome must work harder to achieve developmental milestones and educational achievements, partly because their bodies are different from typically-developing children and their cognitive abilities lag behind those of their typically-developing peers, but also because of low expectations and suppression of their right to be fully human.

My findings align with those of Skotko (2011), who found that nearly all parents of children with Down syndrome love their children and are proud of them. The fathers in

my research emphatically agreed, in the narratives themselves, and in the telling of them that they love their children and were proud of them.

Finding Eight: 19 of 22 participants narrated the themes of daycare and education.

Finding the right daycare and education settings for their children was important and sometimes difficult for fathers. After the challenges they faced, fathers did eventually find the right placement for their children. Three participants did not narrate the theme of daycare or education.

Fathers in my study narrated difficulty in finding the best arrangements for their children and, and while most narrated some conflict resulting from placement choices, they all resolved their conflicts through acts of persistent advocacy. The theme of childcare itself was in no way unexpected given that most parents in The United States have to make decisions about daycare and education, as it is a pervasive issue in modern American life. For fathers of children with Down syndrome, decisions about where to place their children are the more difficult because of the unique needs of the children themselves and because of childcare providers' and education professionals' lack of experience with, care for, or willingness to work with children with Down syndrome. Children with Down syndrome in many cases do have unique needs and sometimes are nonverbal, making their placement in the right school or daycare complex, or their placement under the right educator thorny, or the right services outlined in an IEP difficult to get an IEP team to agree to or to implement.

Fathers with pre-school aged children did report some difficulty finding the right daycare providers and caretakers. Their narratives included details of minor and slightly irksome difficulties with people and places that were summarily resolved. Fathers with

school-aged children found more difficulty. Their narratives revealed that schools do not experience many children with Down syndrome and may view them as a burden or a problem. As a result, instead of finding the best individual solution for children, schools tended either to want to place the child in a segregated ESE classroom or fully mainstream them, when the reality was that children needed individual programs with a mixture of autonomous and professionally aided learning situations. Fathers in my study were frustrated by stubborn and procrustean administrators and teachers who seemed to seek easy solutions to the complicated nature of their children's learning. This was seen in Krueger et al. (2019), who found that parents sought inclusion, equality, and acceptance.

In every case, however, participant narratives revealed that with some effort, fathers came to a sense of resolution for their children's placement. Some fathers repeated this search for the right setting or the right professional several times, and with persistent advocacy, until they found what Sauer (2013) terms "an inclusive Oz," a placement or institution where they were welcomed and where the culture and philosophic mindset was inclined towards wanting their children to be a part of the community. All the participants in my study with school-aged children found what they believed to be the right setting eventually, evidence, perhaps that institutional practices and philosophies differ from one to another, depending on culture and resources, even within the same district.

Finding Nine: All 22 participants demonstrated that the experience of raising children with Down syndrome includes some collision with dominant cultural narratives.

All 22 participants in one way or another described coming into contact with some feature of a dominant cultural narrative of Down syndrome, whether it was hearing slurs such as the R-word, or medical personnel treating their children as a problem, or family members saying “sorry” at the announcement of a birth of a child with Down syndrome, or schools denying their children their best access to free and appropriate public education. From small faux pas committed unintentionally by well-meaning individuals, to overt institutional ableism, to blatant animosity inherent in odious humor in internet memes, fathers in my study, to an individual, were aware of some aspect of their lives that felt wrong or negative, as imputed on them by others. They recognized that this dominant discourse was mostly false and that they were living “proof” that a life raising a child with Down syndrome need not be beset by tragedy and that the source of negativity. Their lives simply did not match the expectations that they had during the initial moment of diagnosis, nor did their experiences raising their children match how others viewed them.

Some participants did explicitly address or narrate their changed perspectives, noting the differences between their previous frames of reference (informed by the dominant cultural narrative) and their more recent experiences, while others did not specifically address such a change (see finding 11). Most of the fathers, whether they specifically addressed their changed perspective or not, revealed something of a perspective transformation in their general attitudes and shifts in tone as they relayed their narratives.

Participants who experienced intense negative emotions at the moment of diagnosis (20 of 22), and later came to view their lives as “normal,” manageable, and

happy raising their children, conveyed a tone of bemused irony or resigned wisdom as they relayed their later experiences encountering dominant cultural narratives. This serves as evidence that fathers may come to understand the social model of disability is the more viable, more accurate model than the medical model. While no participants betrayed any semblance of anger, some did demonstrate irritation as they spoke of their encounters with ignorance and ableism. For the most part, however, participants narrated details of their encounter with the dominant cultural narrative with patient acceptance. The participants' bearing and their diction suggested that they understood ableism and lack of awareness of Down syndrome, having once been complicit in such a discourse.

Because all 22 fathers were aware of this disparity between their experiences and the way others perceived their experiences, I conclude, as Lalvani (2011) did after examining the narratives of 19 mothers, that participants in my study became aware of their "otherness." Their narratives, similar to those of mothers in Lalvani, demonstrated a resistance to that otherness. Generally speaking, participants in my study characterized their lives as normal, their experiences as manageable, themselves as happy, and without using academic language, contrary to dominant discourses.

Fathers in my study did experience intense negative emotions during the moment of diagnosis. This is consistent with research on mothers' experiences as reported in the literature (Gabel & Kotel, 2015; Isgro, 2016; Lalvani, 2008, 2011; Poehlmann et al., 2005) as well as fathers' experiences (Fleming, 2013; Nelson Goff et al., 2013; Marshak et al., 2019; Ridge, 2013). As Lalvani noted, "Interpretations of the birth of a child with a disability are socio-politically and historically situated" (p. 277). As I have mentioned, however, beyond the initial period of diagnosis, perhaps after personal experiences

increasingly set in and rewrote those socio-politically situated narratives, fathers understood that their experiences were not beset by tragedy and chronic sorrow, as they initially expected. Participants in my study also were aware of the fact that other people, as evidenced by the way they treated and spoke to the fathers, were informed and governed by the dominant cultural narrative, which miscasts them and their children.

Finding 10: 15 of 22 participants discussed the theme of stress as a component of their lives. These fathers described their jobs, daily schedules, and meeting the medical needs of their children as stressful. Only one participant unequivocally connected stress to his child having Down syndrome. Five fathers vehemently rejected the notion that their lives were stressful because of raising children with Down syndrome. Two participants did not narrate the theme of stress.

Finding 10 concerned fathers' descriptions of stress. In my study, 15 participants invoked the idea of stress in their lives. Only one father attributed a source of his stress to his child with Down syndrome, so I declare confidently that most fathers in my study did not want to "blame" their stress on their children with Down syndrome, even while two thirds of them did describe stress in their lives. That stress exists in anyone's life in modern America is something of a straw man argument. Stress is a ubiquitous aspect of many Americans' lives and it seems that stress is a characteristic of the lives of parents raising children with Down syndrome, as was reported in the literature review.

Among fathers in my study who did find their lives stressful, the sources of stress derived from vocational burdens, childcare concerns, frustrations with extended family, institutional ableism, and the pace of life in general, factors at best secondarily related to Down syndrome. In the literature, some investigators who have focused on stress among

parents raising children with Down syndrome classified their findings by child-based, parent-based, and psychological-based stressors (e.g., see Cuskelly et al., 2008; Esbensen & Seltzer, 2011; Hauser-Cram et al., 2001). The sources of stress fathers in my study invoked were very seldom child-based, a finding that contradicts earlier studies on fathers (e.g., Krauss, 1993).

Five fathers in my study did directly link the idea of stress to meeting the needs of their medically-complex children. Children with Down syndrome can and do exhibit medical complexity, and finding the right therapies and treatments for them can be stressful. Of five participants who linked stress to medical care for their children, four of them had children under five-years old. This generally aligns with the findings of Hauser-Cram et al. (2001), who suggested that fathers found their lives to be more stressful when their children were younger.

I found little evidence for chronic stress or clinical-level stress among my participants. Only one participant, Bill, admitted that the sense of stress in his life approached unhealthy or beyond-manageable levels. It was something of an unresolved conflict in his narrative. Most fathers describing stress or medical care for their children did not link stress or medical care to Down syndrome. This is not to suggest that life is absent of stress for most fathers raising children with Down syndrome, or that even among participants in my study life was not stressful. Rather, reiterating findings from above and in the literature, raising a child with Down syndrome can be stressful, but most fathers fall into a pattern of stress, coping, and resilience. The literature from 2000 to the present has provided ample evidence for this (Bingham et al., 2012; Cuskelly et al., 2008; Esbensen & Seltzer, 2011; Hauser-Cram et al., 2001; Farkas et al., 2019; Poehlmann et

al., 2005). The narratives of fathers in my study did little to contradict this pattern and offered much support for it.

Still, one of the impetuses for my research was the work of critical disability studies researchers, such as Lalvani (2008, 2011); Lalvani and Polvere (2013); Gabel and Kotel (2015), Piepmeier (2015), and Isgro (2016). Lalvani and Polvere in particular argued for critical approaches that uncover the source of stress among mothers raising children with Down syndrome. Collectively, these investigators found evidence that mothers did find themselves situated in a discourse in which their children were unwanted and in which they themselves were positioned to feel guilty for their reproductive decisions. Fathers in my study, as reported in finding four, participated in reproductive decisions, but did not overwhelmingly report awareness of women's reproductive rights as a central issue in understanding dominant cultural narratives about Down syndrome and whether people with Down syndrome deserve to exist.

Fathers in my study did, however, seem to understand that stress was a frequently-examined phenomenon in their demographic and phenomenological category of fathers raising children with Down syndrome, part of a dominant cultural narrative that they rejected. They understood that stress was something expected in their narratives, and were keen to discuss it, but were also careful not to blame their children or Down syndrome for the stress. Recall that fathers were not predisposed to any ideas in the questions I posed to them. They introduced the idea of stress in order to discuss it or otherwise rebut it. Five participants in my study even invoked the theme of stress only to repudiate it. Those five participants indicated awareness that their lives were "supposed"

to be stressful, simply because they had a child with Down syndrome, as I reported in the findings chapter, but those fathers did not characterize their lives as stressful.

In summary, while five fathers refuted the idea that their lives were stressful, and two others did not discuss stress at all, the fact that 15 fathers in my study did invoke the idea of stress suggests that most fathers in my study did find their lives stressful. The fact that they were careful not to blame their children or Down syndrome suggests that while navigating the realities of raising children with their medical complexities can be stressful, this does not mean that fathers' lives raising children with Down syndrome are unhappy, or that fathers regret or lament that they are raising children with Down syndrome. The fathers in my study, even with the acknowledgement that their lives were stressful, mostly reported coping and resilience, and even a degree of awareness that they were living lives that contradicted dominant cultural narratives that suggested they should be unhappy, beset by tragedy, or that their children did not deserve to exist.

Despite whatever stress the medical complexities of caring for their children caused, or whatever stress the changes to their families created, or whatever stress to their lives happened after the birth of their children with Down syndrome were born, fathers were mostly copasetic and resilient suggests that fathers raising children with Down syndrome in my study viewed their lives as happy Stress was present but manageable in most of the lives of fathers in my study.

Finding 11: 10 of 22 participants narrated positive substantive positive personal changes that came as a result of raising children with Down syndrome. These participants demonstrated changes to the self that resulted in substantive positive changes to world views, spirituality, views about disability, and personal

characteristics. 12 participants either did not narrate themes of positive personal change or narrated changes that did not qualify as substantive.

As I stated in the findings chapter, I restricted coding to account for data that revealed “changes to [participants’] world views or spirituality, their conceptions about life or disability, their emotions, their temperaments, or their outlooks. I excluded from this section narratives about changes to family relationships, careers, or financial factors.”

Fundamental aspects of character, epistemological foundations, and worldviews are difficult for adults to change, according to Mezirow (2000). Yet ten fathers in my study reported that the experience of raising children with Down syndrome led them to some positive change to their selves. The way these fathers emphasized the dramatic and unexpected nature of the changes to themselves presented as evidence for the possibility of transformative learning, which Mezirow described as being spurred by a disorienting dilemma. Delivered a sudden and emotionally intense diagnosis of Down syndrome, confronting the dominant cultural narrative that suggests their children are not valued and their lives would be beset by tragedy, and ultimately coming to change one’s world view (or at least conception of disability) to such an extent that participants admitted that they themselves were better people is redolent of the process of transformative learning.

Fathers in my study overcame substance abuse, became better at their jobs, made bold and decisive changes in their careers. They were more tolerant and patient. They gained new spiritual understandings. They revised their views of what it means to be a human being. Two participants described themselves as radically different and better people with entirely new orientations to life. Truly, if fathers in my study are an indication of what life raising a child with Down syndrome can be like, then a new or

newly expecting father can take encouragement. It may be a positive transformative experience which leads to a better and happier self.

Chapter Six - Conclusions

Overview

This study purported to examine the narrative experiences of fathers of children with Down syndrome. It set out to do so on the basis that few studies dedicated exclusively to understanding fathers' experiences exist in the literature, and that those which have examined fathers' experiences have largely been survey-based and thus have not yielded data which examine the narrative experiences of fathers. An extensive body of research does exist that examines stress and depression of both mothers and fathers of children with Down syndrome, among other aspects of parents' lives, but the scope, methodology, and focus of those individual studies may be limited. Lalvani and Polvere (2013) note, "In this extensive body of research that seeks to explore depression and stress among these families, issues pertaining to sociocultural attitudes, values and beliefs about disability are not explored" (p. 5). Lalvani and Polvere (2013) therefore recommend studies grounded in critical interpretation and methodized by narrative inquiry. While Gabel and Kotel (2015), Isgro (2016), Lalvani (2008, 2011), and Piepmeier (2015) have in varying ways answered that call, they have featured exclusively mothers as participants. Some studies have focused on fathers and have used narrative methods, including dissertations from Fleming (2013) and Ridge (2013), but those studies have focused on prenatal or postnatal diagnosis experiences only. My study purported to address the need for research on fathers of children with Down syndrome, while employing a critical disability studies perspective employing narrative inquiry.

My research began with a premise which was based on the corpus of literature on parents of individuals with Down syndrome: that the period of diagnosis is distinct from a later period in which parents are settled into a life raising children with Down syndrome.

Generally speaking, the literature suggests that while the experience of a diagnosis of Down syndrome in a child is a devastating singular event, its effects for most parents are not long lasting. Undeniably, the diagnosis is for most parents an experience of intense negative emotions including shock, grief, depression, fear, tragedy, and a sense of loss. It is a disorienting dilemma that forces a moment of reckoning and change. After parents recover from their initial shock, confusion, grief, or sense of loss, their lives raising their children are mostly good, and characterized by, as the preponderance of research suggests, stress, coping, and resiliency.

With that understanding in mind, I thus made a research design decision to interview fathers about their moment of diagnosis and then to create a second question which necessarily caused participants to think about their lives raising their children after the initial moment of diagnosis. The two questions are by no means arbitrary, but they were defined somewhat nebulously. I offered participants no time frames, no parameters, no criteria by which they might have known when they transcended the initial period of diagnosis into the next. Despite the lack of boundaries or definitions, participants intuitively knew what I was asking them and readily answered the second question. The results clearly demonstrated that the periods are distinct; the diagnosis is a moment of tragedy that most participants cope with and settle (most often resiliently) into a happier, more comfortable life.

A hypothetical question follows this conclusion and sets up a second premise with which this investigation began, a premise already posited by Lalvani and Polvere (2013). What sociocultural factors contribute towards that feeling of tragedy, loss, grief, and depression? Why should parents *feel* that the diagnosis of Down syndrome is so tragically

undesired? Dominant discourses equate disability generally with unwanted and abnormal statuses. Just as Lalvani and Polvere (2013) and others have demonstrated in their studies with mothers, my study wondered if fathers would come to feel the sting of bringing into this world a child which dominant cultural narratives suggest is unwanted, other than normal, beset by tragedy, and a burden on their family and society. Mothers in Gabel and Kotel (2015), Isgro (2016), Lalvani (2008, 2011), and Piepmeier (2015) came to identify and even challenge those dominant cultural narratives. My research investigated whether fathers would as well.

My findings suggest that fathers did, in fact identify dominant cultural narratives, and while their diagnosis experiences were tragic, sad, beset by grief, one emotion that fathers in my study did not narrate is guilt. Feminists such as Lalvani (2011) suggest that women bear the consequences of dominant cultural narratives more than men do. Women face increasing pressure to meet cultural demands of responsibility of their reproductive choices. The implication is that women must pass on “*valued*” children (emphasis Lalvani’s) as opposed to children with “diminished personhood” (p. 278). Gabel and Kotel (2015) found that women interpreted such discourses about their responsibility as hostile and that they (mothers) were caught in a “discourse of deviance” (p. 7). Therefore, choosing to allow a child with Down syndrome into the world is simply the wrong thing to do. Fathers in my study did not discuss such implications whatsoever.

This may be a key understanding of how fathers’ experiences differ from mothers’. While most participants in my study described intense negative emotions at the moment of diagnosis, not one father described any semblance of guilt or shame. One possible explanation is that fathers do not understand power structures and discourses

about reproduction responsibility in the same way that mothers do. Another factor is that fathers in my study, while not necessarily aggressively and overtly promoting dominant, white male power (although one father did use language suggestive of white, male power), all fathers in my study cohered to dominant culture in some way or another. Participants all identified as white men, cis gendered, heterosexual, mostly Christian, mostly average or above average socioeconomic status, and all able-bodied. In many ways, the participants in my study came from places of privilege and power. While they were aware of their own subjection by a dominant culture that views their children and their lives as burdensome, unwanted, and tragic, the fathers in my study felt no charge of personal responsibility for their children's status.

As men with relative privilege and power, it was perhaps easy for participants in my study to reverse or reframe their narratives and reposition themselves away from a discourse that says they live tragic lives with unwanted children to a reframed discourse which says they tolerate and manage stress, live "normal" lives, love their children, and reject the fact that they are to be pitied or elevated as super-fathers. It was easy enough for fathers, perhaps, that they did not even know what they did was an act of power, a counter narrative against dominant culture. Participants seemed to be aware perhaps for the first time in their lives that they were in a minority group. In a new and unexpected way, many of the fathers in my study found it relatively easy to repudiate the dominant cultural narrative and establish a counter narrative through their lived experiences or through more active advocacy, as many fathers have. Still, while they did seem to be aware of such a false dominant cultural narrative, most fathers in my study did not recognize it as an element of sociocultural power or seek to examine its source or

purpose. Such is the effect of hegemonic discourses. We do not recognize them even as we live in them.

In terms of what my study learned about fathers' experiences in a broader and more general sense, a striking pattern emerged from my research, one which participants in my study nearly unanimously confirmed and one which closely matched the experiences of mothers as reported in the literature and the experiences of mixed parents. The pattern participants in my research demonstrated is thus: a father learns of a diagnosis of Down syndrome and experiences one or more intense negative emotions, often loss, sadness, shock, concern for the future, anger, or depression. Their intense negative emotions were either fomented by negative interactions with medical personnel or otherwise ameliorated by supportive interactions with medical personnel. Although the intensity and duration of those intense emotions vary, the emotions typically culminate in acceptance. If medical complexities are present in the child, addressing those immediately superseded any concern about Down syndrome. Fathers along with their partners at some point evaluate their orientations to disability together with their worldviews, their religious beliefs, their future plans, and their abilities to tolerate change and the unexpected. In narratives of postnatal diagnoses, fathers presented their reactions as rushed, confused, frenzied, and spurring an inclination to seek information quickly and uncalculatedly.

Eventually, as the father begins to learn about Down syndrome through a complex and more carefully designed information world (which includes social support and more circumspect consumption of information) the father understands that his life and the lives of his family and children are not nearly as bad as expected. Half of the fathers in my

research find that their lives are actually better and enriched by their children with Down syndrome. Most fathers tend to develop problem-solving (as opposed to palliative) coping strategies and eventually demonstrate resilience and happiness. Most fathers become advocates for their children in some way or another. Most fathers recognize that many of the sources of stress in their lives are attributable to erroneous and harmful conceptions that others hold about Down syndrome. Most fathers recognize that a dominant cultural narrative militates against them. Some fathers go on to become advocates for others and contribute to the Down syndrome community.

Divergences from this pattern certainly did exist among participants and were reported in the findings. In these, the experiences of some participants seemed to run counter to common experiences in ways that were decidedly orchestrated, notably exceptional, or emphatically narrated by participants. These provided unique insights into fathers' experiences and underscored the value of narrative inquiry. While generalizations can be helpful to understand how lives *might* be lived, variations of typical experience remind those who would find edification in findings that the experiences of fathers raising children with Down syndrome are not universally shared and can provide interesting divergences. Narrative methods proved valuable in this study for not only establishing common experiences, but also understanding why and how some participants do not share common experiences with others. Above all else, these divergences offered up a reminder that every father is different and every child with Down syndrome is different, and that many other factors in life affect relationships, parenting, and families in general.

The main conclusion resulting from my research, worthy of reiteration because of its fundamental importance, is that despite what is suggested by dominant cultural narrative, raising a child with Down syndrome is not an experience fathers in my study considered grief-stricken, beset by tragedy, or debased in any way. To the contrary, most fathers in my study were happy and resilient. In sum, my research makes a strong case that a dominant cultural narrative exists, that its effects on sociocultural power and hegemonic thinking are extensive, and that it is as false as it is far-reaching.

Implications

The findings in my research have important implications for academic practitioners or adherents of critical disability studies who concentrate the focus of their research on families with Down syndrome. My research demonstrates that fathers do tend to adhere to the established pattern of stress, coping, and resilience. This study reaffirms the pattern and can assert that fathers' experiences are more alike than different from those of mothers. The differences were somewhat discussed above. Per the suggestion of Lalvani and Polvere (2013), this research can confirm that the narrative voices of fathers, combined with a critical approach to understanding them, yields results that confirm the presence of a dominant cultural narrative and sets about the business of deconstructing it. Research suggests that the work of academicians to distinguish between medical and social models of disability does have an impact on social policy (Dirth & Branscombe, 2017). Narrative inquiries such as my research demonstrate that fathers of children with Down syndrome define Down syndrome mostly by the social implications of their children's and their own experiences. Academicians would do well to take heed and

direct their research adopting the social model of disability to lawmakers, educational and social policymakers, workplace designers, and healthcare professionals.

Secondarily, perhaps, this research has implications for academicians in the field of adult learning and development, particularly subscribers to Mezirow's (2000) theory of transformative learning. Fathers of children with Down syndrome, by virtue of confronting the diagnosis of Down syndrome in their children, in most of the cases among participants in my research, encountered what could only be described as a disorienting dilemma. In at least half of the cases of participants in this research, the fathers advanced along further stages of transformative learning as it was set down by Mezirow (2000). Indeed, fathers in my research questioned their orientations to learning and knowledge about such important topics as developmental disability and what it means to be a human being. Many participants found themselves (or narrated their experiences) such that they had undergone substantive transformation. And while participants did not identify or reflect on the hegemonic power structures inherent in dominant discourses, they did come to understand that they were living a narrative seen by many as "otherness," and that they themselves saw that narrative as other, once. Whereas, at the time of the interviews, raising children with a disability felt normal to them. Some fathers were truly moved by this change in themselves. Truly, fathers of children with Down syndrome are a demographic worth considering as a test of transformative learning theory. If half of the participants in my study in some way found themselves transformed by the shaking up of their worldviews, what insights might the greater population of fathers (or mothers) of children with Down syndrome reveal?

This study also has implications for fathers of individuals with Down syndrome and for prospective fathers. Reduced to its simplest message, this study demonstrates that raising children with Down syndrome is not a bad life for a father and in fact has the potential to make a prospective father happier, wiser, and transformed. My research has implications for people with Down syndrome as well, for fathers have some degree of agency, along with their partners, to determine whether individuals with Down syndrome may enter the world. At the heart of the insidious dominant cultural narrative is the essential malicious idea that people without Down syndrome should not exist. Even at a time in which through therapeutic and educational interventions people with Down syndrome have increasing quality and length of life, fewer and fewer people with Down syndrome exist globally because of genetic prenatal screening. It is not the screening itself that is to blame, but the messages that come along with it in the ethos of dominant discourses and in the persons of doctors and genetic counselors. People with Down syndrome are complete human beings, replete with all of the ups and downs, the ins and outs of life. They learn, grow, and develop differently than some, but their experiences in life are worth living, and they have much to offer “the rest of us,” just as any human being does. and Parents who raise them are the better, the richer for the experience. My research on parents of children with Down syndrome reveals that most parents (fathers and mothers alike) are better people, having explored humanity and epistemology to deeper extents than many.

Research such as this study, which can serve to illuminate the actual experiences of fathers of children with Down syndrome, ideally has implications for dispelling the dominant cultural narrative that says a life raising children with Down syndrome is a

tragic or grievous one. Prospective fathers (with prenatal diagnoses), who along with their spouses have to choose whether to bring a person with Down syndrome into the world, should be provided accurate and non-coercive information about what their lives might be like. Their choice should be informed not by a hegemonic discourse or a coercive doctor, but between them and their partners. Similarly, new fathers with post-natal diagnoses ought to begin their lives with their new children buttressed with accurate and empathetic support. This research contributes to provide examples, accurate depictions of fathers raising children with Down syndrome. It would be well if its message in some form found its way to fathers facing those new diagnoses.

My research does not support a position against prenatal genetic screening, and does not imply that prenatal genetic screening is at fault for eradicating Down syndrome. Prenatal genetic screening is a tool, one meant to provide information to people making important decisions about their reproductive health and their families' future. Rather, my research supports the idea that while women deserve the reproductive choices that they want, and technologies including genetic screenings exist that help them make such decisions, women and the fathers involved in reproductive decisions for their families should absolutely be made aware, as accurately and specifically as possible, what their futures might entail. For children with Down syndrome, this position is of great consequence. Therefore, on the basis of promoting knowledge of what raising children with Down syndrome may entail, the results of my study should serve as evidence that fathers who raise their children with Down syndrome, along with their partners who make decisions to accept and continue pregnancies with Down syndrome, live happy and productive lives alongside their children and their families.

This research has implications for medical personnel. The findings of my study add little to the existing best practices literature for diagnosing professionals, except to clarify and augment the message: fathers want accurate information about Down syndrome, both medical and pragmatic. They want the dignity of honest, straight-forward prospects, as well as a supportive reassurance that they are up to the task of raising children with Down syndrome, that their families will be okay, their futures secure, their lives more “normal” than they might envision upon diagnosis. With the benefit of narrative hindsight availed to participants in my study, most of them looked back on the diagnosis experience and, comparing it to their current experiences raising their children, believed that their lives were “normal.” The term is regrettable, given that one of the properties of hegemony is creating false premises of normality (Haskollar & Koprulu, 2014). What fathers wanted was to know their lives would be manageable and happy. Medical personnel have tremendous influence and can make those basic reassurances. They really can set the tone for the beginning part of a journey for fathers. This research reveals that many medical personnel set the wrong tone.

Medical personnel should adhere to the best practices already outlined in the research. To review, medical personnel should deliver diagnoses according to the joint statement created consensually by multiple professional organizations, which urged them to discuss Down syndrome in “complete, consistent, non-judgmental, and non-coercive” terms (American College of Obstetricians and Gynecologists, 2009, p. 6). Skotko et al. (2009a; 2009b) provided more specific best practices. Their recommendations included delivering the news to both parents simultaneously, holding conversations in private settings, providing accurate and timely information, availing parents of opportunities to

meet families and connect with support organizations, limiting discussions of possible medical conditions in the child to within one year of age, and avoiding using phrases such as “I’m sorry,” “Unfortunately,” and “I have bad news” (p. 2364).

My research has implications for supportive personnel, organizers and members of social support groups, who extend hands of welcome and support to fathers facing new diagnoses. They likely already know the importance of their work and the need for their existence. My research offers them reassurances and a rallying cry to continue what they do. What support organizations may or may not know is that their purpose is two-fold. Not only do they offer the vital beneficence of belonging, community, and kindred spirit, but they also offer the wisdom of an informed information world. Their book recommendations, political advocacy, experiences with good doctors and therapists, suggestions for dealing with institutional ableism inherent in schools and insurance behemoths, in government and in society is positively immeasurable.

On the subject of institutional ableism, the findings of my research have implications for schools, principals, IEP team members, and paraprofessionals. Fathers in my study demonstrated that they can tend to view schools and IEP teams as enemies, rather than allies. Fathers in several cases found that they needed to move on from schools which did not welcome them, or which thwarted their beliefs about least restrictive environments for their children. Ultimately, what fathers sought from their children’s schools is that the schools themselves wanted their children to be there and genuinely had the best interests of their children at heart. If the fundamental purpose of public education in America is to serve all children and leave no child behind, then each institution should seek the same lofty ideal. Fathers of children in my study (and parents

in the wider research) demonstrate that they will keep seeking ideal placements for their children to escape ableism and places where their children are misunderstood or treated hostilely. The implication is this: if a father of a child with Down syndrome withdraws a student from your school, it may be a kind of indictment on your school. At the very least, schools should follow the law, including recent landmark court cases such as *Andrew F.v. Douglas County School District (2017)*, which continually reshape and redefine what appropriately challenging education means for students with disability.

Daycare and education personnel in general should be aware that children with Down syndrome present with a variety of challenges and needs, but they are not a “problem;” rather they are human beings with unique abilities and many unanticipated strengths. Communities that embrace and support people with Down syndrome are not weakened but rather strengthened by people with Down syndrome and the families that support them. Educational personnel encountering people with Down syndrome for the first time should review pertinent laws that protect people with developmental disabilities and assume that inclusion in all educational programming is the norm, the least restrictive environment, and then adjust according to individuals’ needs. Fathers of children with Down syndrome may present as overprotective and overbearing or may not have experience with developmental needs and require support and guidance.

Finally, this research has implications for a group it will least likely reach: the extended families and friends of fathers raising children with Down syndrome. Fathers in my study revealed that extended family and friends were either supportive of or detractive from their efforts. Fathers revealed that they needed the support of extended family, and as they relied on them, extended family and close friends either understood

their new and changing worlds, or else hindered their difficult new vicissitudes by their overbearing ideologies or their lack of willingness to adapt. Extended families and friends of fathers with Down syndrome should take heed: the fathers of children with Down syndrome in your life need you and they need you to listen and observe the changes to their routines and their beliefs.

A summary of the implications section of my study is such that anyone reading it can take away from its observations. Fathers of people with Down syndrome have discovered and continue to discover that their children are capable of so much more than how they are portrayed in media, medicine, arts, and journalism. Reduced to its simplest message, fathers of children with Down syndrome do not view their children as less than human, as abnormal or other. People who can or should support fathers of children with Down syndrome should acknowledge that their lives are more difficult, but that difficulty is due in larger part to the attitudes and predispositions of others than anything having to do with Down syndrome itself. New fathers with diagnoses of Down syndrome in their children need not view their lives as beset by grief or tragedy. Their lives will most likely be happy and fulfilling, despite any medical complexities in their children. In short and in sum, fathers who raise children with Down syndrome are happy and fulfilled.

Limitations

In the interest of full disclosure of bias, I divulge here that I am a father of a daughter with Down syndrome. Her sudden and unexpected presence in my life changed the course of my doctoral studies. Her birth was a matter that in no small way spurred this research. As such, I identify and sympathize with all of the participants in this study. I cheer on their efforts and I share in their struggles and victories. My information world is

as theirs. It is somewhat impossible for me to declare any degree of neutrality in editing, re-storying narratives, and interpreting data. I can only reassure any assessor of this research that I acted in good faith, attempted as best as possible to check my own bias, and to follow the methodology of narrative inquiry as I understood it from descriptive literature. I attempted to counter the possibility of bias by virtue of intensive member checking. I frequently contacted participants to clarify narrative details as I rewrote their narratives, and I insisted that every father read and certify the final re-storied versions of their narratives before I culled any data from them. In some cases, I contacted a few fathers even after they certified their re-storied narratives as I moved to interpret them. In all cases fathers reassured me that I captured their intentions and the details of their narratives correctly.

The homogeneity of demographic factors of participants in my research is something of a limitation. While my study *can* boast of heterogeneity in terms of participant age (range = 31-55 years-old), the age of their children (range = < 1-18 years-old) and geographical location (16 American states and one Canadian province), the participant pool was not socioeconomically or racially diverse. Participants used self-descriptors to refer to their socioeconomic class. Most participants used some variation of average or middle class. They also used self-descriptors for racial identity. Most identified as white or Caucasian (17), with two identifying as Hispanic, one identifying as biracial, one identifying as ethnic Jewish, and one response left blank. To my knowledge, no study has examined the experiences of fathers of color raising Down syndrome specifically as a critical intersection of race and disability, or any other critical intersections. Further research is clearly indicated.

Furthermore, participants in this research study responded enthusiastically to the call for research. Each individual wanted to tell his story and 20 of 22 participants wanted to promote the message that their lives were happy and raising a child with Down syndrome. All but one father had amicable relationships with their partners, though one was not married and four were divorced. They were to an individual committed to their children and involved in their children's lives. As such, the pool of participants in my research does not account for the experiences of fathers who are only marginally involved in their children's lives, fathers who have abandoned their families, fathers whose children are deceased, or single fathers with sole custody of their children. Research on all of these subsets of fathers, and many others, is required if a holistic picture of fathers' raising children with Down syndrome is to be assembled. Many of these biographical conditions would call into question the definition of the term "raising" children, one of the claims to understanding my study makes. While my study can provide information about the experiences of fathers raising children with Down syndrome, further understanding of men who have children with Down syndrome generally is required. As one father astutely asked of me in an interview, "What about those of us who don't stick around?"

A reminder of what narrative inquiry does not endeavor to accomplish is in order, as it concerns considering the further limitations of this study. Indeed Clandinin and Connelly (2000) dedicate an entire chapter to the "persistent concerns" (p. xii) of the method. In the chapter, they admit that the "distinction between fact and fiction is muddled" (p. 179). Narrative is a phenomenon that relies heavily upon memory, individual interpretation, and a deference to relativism. I do not mean to suggest that

participants in my study deliberately prevaricated details or that their stories were invented wholesale, but one must consider that narratives are recreations of events and reconstructions of experiences, subject to change, the effects of time, bias, and editing, which preside along vectors of choices participants make about which details to include and which to omit. Granted any considerations of “flashbulb memory,” the inevitable and inexorable force of time must necessarily admit the possibility of revision and reconstruction of memory. Furthermore, in narrative inquiry, an agreement between participants and researcher occurs: participants tell long stories, then researcher/investigator/inquirer refines and re-stories such stories for the purposes of space, brevity, focus, and organization. It is an imperfect system, and all such considerations should be taken into account when considering the verisimilitude of findings of this study. Readers of this study might consider the fact that the factors of time and interpretation are accounted for in narrative inquiry and are expected tensions to be taken into consideration in interpretation and use of findings.

I remind here that narrative inquiry does not yield generalizable findings. No inferential statistics or predictions of probability may be gleaned from this study. No causal or even correlative relationships may be assumed to be meant to describe a larger population of fathers raising children with Down syndrome. Any statistical data in the findings of this research reveal something about the group of participants who answered the call to research in my study but not beyond. What my research does offer is an organized and cohesive discourse which reveals that lives of most of the 22 fathers in this study are happy, agreeable, and flourishing. The testimony of fathers in my research offers a counter narrative to the dominant cultural narrative. Should this research fall into

the hands of fathers themselves with new diagnoses in their children, or professionals who may support them during the initial moment of diagnosis, the stories of participants in my study may help to reveal a possible (and maybe probable) outcome in their lives raising their children is happiness, or even increased happiness and personal betterment.

Discussions and Recommendations for Future Research

Each one of the eleven findings in my research warrants further exploration. Because of the paucity of research on fathers of children with Down syndrome, little is known about fathers' experiences, even after this study. As I peer over the findings, dozens of follow-up questions emerge from each, which suggests that fathers of children with Down syndrome are still a little understood group. In this section I present my findings again along with possible directions for new research.

Finding One: Of 22 total participants, 18 participants narrated interactions with medical personnel while four participants did not mention interactions with medical personnel. 13 participants reported negative interactions with medical personnel, while five participants reported exclusively positive interactions. Three participants narrated a combination of positive and negative interactions.

Finding One suggests that many fathers characterize their interactions with medical personnel upon diagnosis as a negative experience, while fewer of them characterize their interactions as positive. Future research on fathers of children with Down syndrome should distinguish between moments of diagnosis and later experiences of fathers raising their children. Research on fathers' diagnosis experiences should distinguish between prenatal and postnatal diagnoses.

Finding Two: 20 of 22 participants reported experiencing intense negative emotions at the initial moment of a diagnosis of Down syndrome in their children. Participants reported shock and devastation, being scared or nervous, or expressing sorrow or loss of an expected child. Two participants did not report experiencing intense negative emotions, both of whom were personally familiar with people with Down syndrome.

Finding two supported the understandings from studies in the literature. Fathers in my research unquestionably experienced negative emotions upon diagnosis, save for two fathers who had professional experience with individuals with Down syndrome. Further narrative inquiries might examine connections between fathers' levels of familiarity with people with Down syndrome and their emotions upon unexpected diagnoses. Research examining the moment of diagnosis for fathers should not consider theories of chronic sorrow or grief, or newer theories of ambiguous sorrow, which rely on understanding long-term or chronic effects. The effects of the initial period of diagnosis is for most fathers an impermanent phenomenon. Future research on fathers during the initial period of diagnosis might examine the factors such as medical complexity that supersede powerful negative emotions about Down syndrome, as well as factors that otherwise exacerbate or mitigate intense negative emotions.

Findings Three (a) and Three (b)

Finding Three (a, from question one): 17 of 22 participants narrated issues of medical complexity in their children during the initial period of diagnosis. As the severity of the medical condition increased, participants were more likely to focus on the details of their children's health than any other narrative detail, including their own feelings.

Five participants did not narrate issues of medical complexity at the time of diagnosis.

Finding Three (b, from question 2): 12 of 22 participants narrated the theme of medical complexity after the initial period of diagnosis, and into their experiences raising their children with Down syndrome. The medical issues themselves shifted from emergencies to conditions requiring surgeries and long-term treatments. 10 participants did not narrate the theme of medical complexity in their children after the initial period of diagnosis.

Finding three revealed that medical complexity may be a factor involved in processing a diagnosis of Down syndrome as well as raising children with Down syndrome. The narrative data participants in my study generated suggest that medical complexity in children affects fathers differently during the initial moment of diagnosis than it does during later periods raising children. Fathers in my study revealed increasing competence to support their children through medical complexity during the period raising their children than they did during the moment of diagnosis. Future research might examine fathers' reactions to the effects of medical complexity in their children upon diagnosis or otherwise might examine coping strategies fathers use to process medical complexity in their children during later periods. It would be interesting to see if future studies would demonstrate increased competence in fathers and what that might look like in fathers of young children, adolescents, and teenagers with Down syndrome.

Finding Four: Of eight participants with prenatal diagnoses, all discussed the theme of women's reproductive rights and abortion in their narratives. Six participants agreed uniformly with their spouses to keep the pregnancy, while two participants reported conflicts with their partners. 14 participants reported postnatal diagnoses, and thus did not narrate the theme as a part of their experiences.

Save for Ridge (2013), I am not aware of any narrative inquiries which have examined fathers' roles in discussions or decisions about abortion of pregnancies with Down syndrome. My study revealed, as did Ridge (2013) that fathers tend to be deferential to their partners in the matter of determining whether to continue or terminate their pregnancies which would result in a child with Down syndrome. Research into men's roles in the reproductive choices of their partners is necessarily entangled in ethics, women's reproductive rights, and philosophical questions, but it is required if we are to better understand fathers' experiences with processing a prenatal diagnosis of Down syndrome. Any further understanding (narrative or otherwise) of fathers' role in making reproductive decisions for their family is warranted.

Findings Five (a) and Five (b)

Finding Five (a, from question one): 19 of 22 participants narrated that during the initial period of diagnosis they engaged in reflexive information seeking. Participants were trying to make sense of a disorienting event. Three participants did not narrate reflexive information seeking.

Finding Five (b, from question two). 21 of 22 participants narrated variations on the theme of information seeking, which continued past the initial period of diagnosis and into their time raising their children. Their approaches to information gathering during this period constituted a more measured and disciplined approach that included social support and critical information processing. Fathers demonstrated an increasingly sharper ability to evaluate information sources and use information. One participant did not narrate the theme of information seeking.

The combined findings of five (a) and five (b) reveal the importance of the information world that fathers navigate as they process an initial diagnosis and settle into a pattern of coping and resilience. As with competence in managing medical complexity in their children, it seems as though fathers gain competence with managing their social worlds. Future research might look more closely at factors that are conducive to fathers' becoming wiser, better informed, and better connected socially. Future research might begin with a premise outlined by Gibson (2016), who suggested that since we understand how information-seeking patterns are likely to occur, we can construct a progressive-situational model in which parents receiving diagnoses of Down syndrome are guided in their information-seeking and supported with specific, responsive resources and strategies. Research using Gibson's model with fathers of children with Down syndrome would be a worthy next step in understanding how fathers and medical professionals may collaborate in the construction of fathers' information worlds. An investigator taking up this premise might also review Douglas's (2014) suggestions about helping new parents seek meaning-making.

Finding Six: All 22 participants narrated some kind of challenge or change to their family relationships and roles. Participants demonstrated that raising children with Down syndrome could require reassessment of roles and relationships with their families and friends.

Finding Six was defined somewhat ambiguously, and was done so because of the ambiguous grouping of family members described by fathers in my research. Fathers in my study revealed that changes in and to their families was a constant and prevalent factor, both positive and negative. Future researchers should continue to examine fathers'

changing roles and relationships in those fathers' immediate families and extended families. My research resulted in enough narrative data to suggest that changes to both roles and relationships are rich phenomena that demand further understanding together or separately, especially as those roles and relationships fall within a larger context of the changing nature of fathers' roles (see Chelsea, 2011 & Ginsburg & Rapp, 2015).

Finding Seven: 21 of 22 participants included prominent narrative details of their children's expected outcomes and their children's accomplishments. Fathers were nearly unanimously proud of their children with Down syndrome, especially when their children exceeded expectations. Fathers of older children may be more proud and content with their children's accomplishments. One participant did not include prominent details of his child's accomplishments.

Finding seven indicated that overwhelmingly fathers in my research were proud of their children. While pride has been consistent in the literature on parents raising children with Down syndrome (King et al., 2000; Lalvani, 2008; Marshak, Lasinsky, and Williams, 2019; Skotko et al., 2011), a unique finding in my research is that fathers associated such pride with defiance. In the words of one participant in my study children with Down syndrome's accomplishments are "that much sweeter" because of various sources of opposition and low expectations of them. Future narrative inquiries should examine fathers' perspectives on their children's accomplishments; such investigations might uncover the sources of fathers' sense of defiance and thus help continue to reveal fathers' positioning in a dominant cultural narrative.

Finding Eight: 19 of 22 participants narrated the themes of daycare and education.

Finding the right daycare and education settings for their children was important and

sometimes difficult for fathers. After the challenges they faced, fathers did eventually find the right placement for their children. Three participants did not narrate the theme of daycare or education.

Of course many American families with working parents and children face issues of placement of their children in daycare and in educational settings. The finding in my research suggested that fathers found decisions about placement of their children with Down syndrome the more difficult. My research also revealed that fathers were successful, in some cases after several trials, at placing their children in optimal settings. Future research should examine fathers' experiences of finding appropriate daycare and educational settings for their children with Down syndrome. Narratives of their struggles, their oppositions, their strategies, and their ultimate successes may yield greater understandings of their experiences as well as greater understandings of institutions into which they seek admittance.

Finding Nine: All 22 participants demonstrated that the experience of raising children with Down syndrome includes some collision with dominant cultural narratives.

Given that fathers in my study demonstrated awareness of being positioned in a dominant discourse, despite those fathers arriving at my call to research in states of relative privilege and comfort, much remains to be known about fathers of children with Down syndrome who belong to disadvantaged and minority demographic groups. Fathers in my study, given their statuses of (mostly) white, Christian, economically comfortable, cis gendered, heterosexual, able-bodied men, who were active in their children's lives found themselves, by virtue of their children with Down syndrome, disadvantaged, misunderstood, mischaracterized, and subject to the forces of ableism.

Future research should seek to include all fathers of children with Down syndrome, but especially whereby those fathers belong to diverse racial, religious, gendered, socioeconomic, ethnic, and body ability groups. Such research should examine important intersections of Down syndrome and other social and demographic types. Fathers of color and fathers of varying disadvantaged groups may reveal unique understandings about their experiences with dominant cultural narratives that define what “normal” is and how ideas of standard patterns of living are driven by dominant discourses.

Finding 10: 15 of 22 participants discussed the theme of stress as a component of their lives. These fathers described their jobs, daily schedules, and meeting the medical needs of their children as stressful. Only one participant unequivocally connected stress to his child having Down syndrome. Five fathers vehemently rejected the notion that their lives were stressful because of raising children with Down syndrome. Two participants did not narrate the theme of stress.

Ample research has shown that fathers raising children with Down syndrome usually fall into a pattern of stress, coping, and resilience (Cuskelly et al., 2008; Myers-Walls, 2017; Van Riper, 2007; Walsh, 2003). Fathers in my study demonstrated in their narratives that they fell into such a pattern. Further research is warranted, as prescribed by Lalvani and Polvere (2013), which examines the source of such stress in fathers. Future studies should continue to adopt narrative inquiry as a method and employ critical theoretical backgrounds to examine sources of stress in fathers' lives.

Finding 11: 10 of 22 participants narrated positive substantive positive personal changes that came as a result of raising children with Down syndrome. These

participants demonstrated changes to the self that resulted in substantive positive changes to world views, spirituality, views about disability, and personal characteristics. 12 participants either did not narrate themes of positive personal change or narrated changes that did not qualify as substantive.

My research has shown that the process of engaging with a difficult diagnosis of Down syndrome as a disorienting dilemma and later raising children with Down syndrome may result in a transformative process for fathers, insofar as they may come to find their worldviews substantively transformed. Further narrative evidence is required to understand how raising children with Down syndrome leads some fathers to substantive positive personal changes. It would be interesting to investigate which fathers report such changes and which do not, and what conditions and factors are in place that might facilitate such changes. Mezirow's (2000) Transformative Learning theory could be a useful framework for future research on fathers raising children with Down syndrome as it entails a theoretical framework for adults experiencing substantial change.

Final Conclusions

The narratives of fathers in my study serve as evidence that fathers raising children with Down syndrome and their families live mostly happy and productive lives. Fathers in my study also provided evidence that they find their lives to be "normal," and that despite the intense negative emotions they experienced at the moment of diagnosis found their later experiences raising their children with Down syndrome to be rewarding. Most participants in my study experienced those negative emotions at the moment of diagnosis and most fathers in my study seemed surprised at how much better their lives were than what they foresaw during the diagnosis.

From whence do those intense negative emotions derive? A dominant cultural narrative pervades popular culture and modern medicine, one which equates Down syndrome with an unwanted pregnancy or child, with a less than human medical “problem” that soon may be eradicated through increasing genetic screening. An obvious follow-up question is why does such a narrative exist? Goodley (2017, 2018) borrows the terms biopolitics and biopower from Foucault (2017, 2018, as cited in Goodley) to explain how dominant culture uses narratives and labels to maintain power. Dominant culture controls ideas of normal/abnormal, able/disabled, impaired/non-impaired to maintain a status quo, what Foucault saw as a global capitalist machine in which producers work for those in power. People with disabilities are seen as atypical and nonproductive, therefore not serving the machine, and are maligned as taking resources from others.

As with all dominant discourses, the narrative of Down syndrome is hegemonic in the sense that few people are aware it exists or that injustice resides in the way they think about disability until they inescapably must engage with the narrative when it enters their lives. It is easy to understand how fathers in my study and others in the literature defined their state of being at the moment of their children’s diagnosis as shocked, devastated, and sad when popular thinking and conventional wisdom about Down syndrome is based on a mostly erroneous discourse.

Most fathers in my study were aware of a disparity between what they once “knew” about Down syndrome and what their lives were really like raising children with Down syndrome. Fathers even had a sense that the very institutions that are supposed to help others (medicine and education) were disadvantaging them. Participants were keenly

aware their lives were seen inaccurately by most people. And yet, participants in my study revealed above all else that they were living happy and fruitful lives in spite of medical models of disability and dominant cultural narratives suggest.

References

- Ashe, A. (2015). Reproduction. In A. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for disability studies* (pp. 155-157). University Press.
- Bamberg, M & Andrews, M. (2004). *Considering counter-narratives: Editing, resisting, making Sense*. Benjamins.
- Bentley, G.E., Zvonkovic, A., Mccarty, M., & Springer, N. (2015). Down syndrome and fathering: An exploration of ambiguous loss. *Fathering, 13*(1), 1-17.
- Berube, M. (2009). Equality and/or justice for all: A response to Martha Nussbaum. *Metaphilosophy, 40*(3/4), 352-365.
- Bingham, A., Correa, V.I., & Huber, J.J. (2012). Mothers' voices: Coping with their initial children's disability diagnosis. *Infant Mental Health Journal, 33*(4), 372-385. <https://doi.org/10.1002/imhj.21341>
- Brookfield, S.D. (2011). *The power of critical theory for adult learning and teaching*. Open University Press.
- Chelsea, N. (2011). Stay-at-home fathers and breadwinning mothers: Gender, couple dynamics, and social change. *Gender and Society, 25*(5), 642-664.
- Cimini, N. (2010). Struggles online over the meaning of 'Down's syndrome': A 'dialogic' interpretation. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 14*(4), 398-414. <https://doi.org/10.1177%2F1363459309358598>
- Clandinin, J. & Connelly, M. (2000). *Narrative inquiry: Experience and story in qualitative research*. Jossey-Bass.

- Clandinin, J. & Rosiek, J. (2007). Mapping a landscape of narrative inquiry. In J. Clandinin (Ed.) *Handbook of narrative inquiry: Mapping a methodology* (pp. 35-76). Sage.
- Cole, K. L. (2012, July 1). Disability studies: an evolving discipline and its literature. *CHOICE: Current Reviews for Academic Libraries*, 49(11), 1999.
- Connor, D.J. & Gabel, S.L. (2014). *Disability and teaching*. Routledge.
- Corrice, A.M. & Glidden, L.M. (2009). The Down syndrome advantage: Fact or fiction? *American Journal on Intellectual and Developmental Disabilities*, 114(4), 254-268. <https://doi.org/10.1352/1944-7558-114.4.254-268>
- Costantino, M. (2010). Parenting children with disabilities: Navigating through the storms. *Journal of Creativity in Mental Health*, 5(1), 87-92. <https://doi.org/10.1080/15401381003627335>
- Counselman Carpenter, E. A. (2015). *The lived experience of mothers whose children were born unexpectedly with Down syndrome* (Publication No. 3662175) [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global.
- Creswell, J.W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Pearson.
- Cuskelly, M., Hauser-Cram, P. & Van Riper, M. (2008). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome Research and Practice*, 12(3).

- Davis, L. J. (2006). Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century. In Davis, L.J. (Ed.) *The disability studies reader* (2nd ed., pp. 3-16).
- Dirth, T.P. & Branscombe, N.P. (2017). Disability models affect disability policy through awareness of social discrimination. *Journal of Social Issues*, 73(2), 413-442.
<https://doi.org/10.1111/josi.12224>
- Douglas, H.A. (2014). Promoting meaning-making to help our patients grieve: An exemplar for genetic counselors and other health care professionals. *Journal of Genetic Counseling*, 23(5), 695-700. <https://doi.org/10.1007/s10897-014-9731-6>
- Driscoll Nugent, J.C. (2011). *Different challenges and different blessings: Life experiences of young mothers of children with Down syndrome* (Publication No. 3460086) [Doctoral Dissertation, University of Montana, Missoula]. ProQuest Dissertations & Theses Global.
- Eakes, G.G., Burke, M.L., Hainsworth, M.A. (1998). Middle range theory of chronic sorrow. *Journal of Nursing Scholarship*, 30(2), 179-184.
<https://doi.org/10.1111/j.1547-5069.1998.tb01276.x>
- Edwards, J. & Ferrante, R. (2013). *Toward concurrence: Understanding prenatal screening and diagnosis of Down syndrome from the health professional and advocacy community perspectives* [Summary of Consensus Conversation]. The Genetic Counseling Program at the University of South Carolina Conference, Columbia, S.C. (2008, November 16-17). American College of Obstetricians and Gynecologists, American College of Medical Genetics, National Society of Genetic Counselors, National Down Syndrome Society, National Down

- Syndrome Congress.
https://www.geneticcounselingtoolkit.com/pdf_files/ConsensusConversationStatement.pdf
- Esbensen, A.J. & Seltzer, M.M. (2011). Accounting for the “Down syndrome advantage.” *American Journal on Intellectual and Developmental Disabilities*, 116(1), 3-15. <https://doi.org/10.1352/1944-7558-116.1.3>
- Elliott, J. (2005). *Using narrative in social research: Qualitative and quantitative approaches*. Sage.
- Andrew F., a Minor, by and through his Parents and Next Friends, Joseph F. et al. v. Douglas County School District Re-1. 15 U.S. 827 (2017).
<https://www.supremecourt.gov/docket/docketfiles/html/qp/15-00827qp.pdf>
- Farber, B. (1962). Effect of severely mentally retarded children on family relationships [Monograph]. In P.M. Ferguson (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with disability. *The Journal of Special Education*, 36(3), 124-130.
<https://doi.org/10.1177%2F00224669020360030201>
- Farkas, L., Cless, J.D., Cless, A.W., Nelson Goff, B.S., Bodine, E., & Edelman, A. (2019). The ups and downs of Down syndrome: A qualitative study of positive and negative parenting experiences. *Journal of Family Issues*, 40(4), 518-539.
<https://doi.org/10.1177%2F0192513X18812192>
- Ferguson, P. M., Gartner, A. & Lipsky, D. G. (2000). The experience of disability in families: A synthesis of research and parent narratives. In E. Parens & A. Asch

- (Eds.), *Prenatal testing and disability rights* (pp. 72-94). Georgetown University Press.
- Ferguson, P.M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with disability. *The Journal of Special Education, 36*(3), 124-130. <https://doi.org/10.1177%2F00224669020360030201>
- Fleming, S.A. (2013). *Fathers' experiences after their child has been diagnosed with Down syndrome: A phenomenological study* (Publication No. 3587086) [Doctoral Dissertation, Capella University]. ProQuest Dissertations & Theses Global.
- Forte, D.F. (2018). From termination to extermination: The international Down syndrome genocide. *The Journal of the Witherspoon Institute*.
- Gabel, S.L. & Kotel, K. (2015). Motherhood in the context of normative discourse: Birth stories of mothers of children with Down syndrome. *Journal of Medical Humanities, 39*(2) <https://doi.org/10.1007/s10912-015-9367-z>
- Gibson, A.N. (2016). Building a progressive-situational model of post-diagnosis information seeking for parents of individuals with Down syndrome. *Global Qualitative Nursing Research, 3*(1), 1-11. <https://doi.org/10.1177%2F2333393616680967>
- Gilmore, L., Cuskelly, M. (2007, March). *Parenting satisfaction and self-efficacy in mothers of children with Down syndrome: Early childhood to adolescence* [Conference session] *Parenting an Adolescent with Developmental Disabilities: Do Developmental Principles Apply? Society for Research in Child Development Conference, Boston* (March, 2007).

- Ginsburg, F. & Rapp, R. (2015). Family. In A. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for disability studies* (pp. 81-83). University Press.
- Glidden, L.M, Grein, K.A., & Ludwig, J.A. (2014). The Down syndrome advantage: It depends on what and when you measure. *American Journal on Intellectual and Developmental Disabilities, 119*(5), 389-404. <https://doi.org/10.1352/1944-7558-119.5.389>
- Goodley, D. (2017). *Disability studies: An interdisciplinary introduction*. Sage.
- Goodley, D. (2018) Understanding Disability: Biopsychology, biopolitics, and an in-between-all politics. *Adapted Physical Activity Quarterly, 35*(3), 308-319. <https://doi.org/10.1123/apaq.2017-0092>
- Hartley, S.L., Seltzer, M.M., Barker, E.T., & Greenberg, J.S. (2011). Marital quality and families of children with developmental disabilities. *International Review of Research in Developmental Disabilities, 41*, 1-29.
- Haskollar, E., & Koprulu, O. M. (2014). Hegemony. In S. Thompson (Ed.), *Encyclopedia of diversity and social justice* (pp. 376-379). Rowman & Littlefield Publishers.
- Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development, 66*(3), 1-131. <https://doi.org/10.1111/1540-5834.00151>
- Hodapp, R. M., Ricci, L. A., Ly, T. M., & Fidler, D. J. (2003). The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology, 21*(1), 137-151. <https://doi.org/10.1348/026151003321164672>

- Hodapp, R. M. (2007). Families of persons with Down syndrome: New perspectives, findings, and research and service needs. *Mental Retardation and Developmental Disabilities, 13*, 279-287. <https://doi.org/10.1002/mrdd.20160>
- Hollingsworth, S. & Dybdahl, M. (2007). Talking to learn. In D.J. Clandinin (Ed.). *Handbook of narrative inquiry: Mapping a methodology* (pp. 146-176). Sage.
- Hornby, G. (1995). Fathers' views of the effects on their families of children with Down syndrome. *Journal of Child and Family Studies, 4*(1), 103-117.
- Hubbard, R. (2007). Abortion and disability: Who should and who should not inhabit the world. In Davis, L.J. (Ed.) *The disability studies reader* (2nd ed., pp. 93-104). Routledge.
- Humphreys, L., Cappelli, M., Aronovitch, E., Allanson, J., & Hunter, A. (2008). The role of women's relationships with their partners in their adjustment following prenatal genetic testing. *Journal of Applied Social Psychology, 38*(2), 482-512. <https://doi.org/10.1111/j.1559-1816.2007.00314.x>
- Isgro, K. (2016). From a caretaker's perspective: Mothers of children with Down syndrome as advocates. *Women & Language, 38*, 63-82.
- Jaeger, P. T., & Burnett, G. (2010). *Information worlds: Social context, technology, and information behavior in the age of the Internet* (1st ed., p. 214). As cited in A. Gibson (2016). Building a progressive-situational model of post-diagnosis information seeking for parents of individuals with Down syndrome. *Global Qualitative Nursing Research, 3*(1), 1-11.
- Kaposy, C. (2013). A personal experience of prenatal testing for Down syndrome. *Narrative Inquiry in Bioethics, 3*(1), 18-21. <https://doi.org/10.1353/nib.2013.0025>

- Kausar, S., Jevne, R. F, & Sobesy, D. (2003). Hope in families with children with developmental disabilities. *Journal on Developmental Disabilities*. 10(1), 35-46.
- King, G.A., Zwaigenbaum L., King, S., Baxter, D., Rosenbaum, P., Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child Care Health Development*. 32(3), 353-69. doi: <https://doi.org/10.1111/j.1365-2214.2006.00571.x>
- Kleinert, H.L., Lunney, C.A., Campbell, L., & Ferguson, J.E. (2009). Improving residents' understanding of issues, comfort levels, and patient needs regarding screening for and diagnosing Down syndrome. *American Journal of Obstetrics and Gynecology*, 201(3), e 1-328. <https://doi.org/10.1016/j.ajog.2009.05.051>
- Kozma, C. (2008). What is Down syndrome? In Skallerup, S.J. (Ed.), *Babies with Down syndrome: A new parents' guide* (3rd ed., pp. 1-44). Woodbine House.
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal of Mental Retardation*, 97, 393-404.
- Krueger, K., Cless, J.D., Dyster, M., Reeves, M., Steele, R., & Nelson Goff, B.S. (2019). Understanding the systems, contexts, behaviors, and strategies of parents advocating for their children with Down syndrome. *Intellectual and Developmental Disabilities*, 2, 146-57. <https://doi.org/10.1352/1934-9556-57.2.146>
- Lalvani, P. (2008). Mothers of children with Down syndrome: Constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities*, 46(6), 436-445. <https://doi.org/10.1352/2008.46:436-445>

- Lalvani, P. (2011). Constructing the (m)other: Dominant and contested narratives on mothering a child with Down syndrome. *Narrative Inquiry, 21*(2), 276-293.
<https://doi.org/10.1075/ni.21.2.06lal>
- Lalvani, P. & Polvere, L. (2013). Historical perspectives on studying families of children with disabilities: A case for critical research. *Disability Studies Quarterly, 33*(3).
<http://dx.doi.org/10.18061/dsq.v33i3.3209>
- Leshin, L. (2008). Medical concerns in babies with Down syndrome. In Skallerup, S.J. (Ed.), *Babies with Down syndrome: A new parents guide* (3rd ed., pp. 75-102). Woodbine House.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. University Press.
- Lytard, J. (1987). Re-writing modernity. *Substance, 16*(3), 3-9.
<https://doi.org/10.2307/3685193>
- Meekosha, H. & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights, 15*(1), 47-75.
<https://doi.org/10.1080/1323238X.2009.11910861>
- Merriam, S. B., Caffarella, R. S., & Baumgartner, L. (2007). *Learning in adulthood: A comprehensive guide* (3rd ed.). Jossey-Bass.
- Mezirow, J. (1991). *Transformative dimensions of adult learning*. San Francisco: Jossey-Bass.
- Mezirow, J. (2000). Learning to think like an adult. In J. Mezirow (Ed.) *Learning as transformation* (pp. 3-33). Jossey-Bass.
- Myers-Walls, J. A. (2017). Strengthening Family Resilience. *Journal of Family Theory & Review, 9*(4), 584-588. <https://doi.org/10.1111/jftr.12233>

National Down Syndrome Society. (2017). Down syndrome facts.

<https://www.ndss.org/about-down-syndrome/down-syndrome-facts>

Natoli, J. L., Ackerman, D. L., McDermott, S. and Edwards, J. G. (2012). Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995–2011). *Prenatal Diagnosis*, 32, 142-153. <https://doi.org/10.1002/pd.2910>

Neely-Barnes, S., Graff, C., Roberts, R.J., Hall, H.R., Hankins, J.S. (2010). It's our job: Qualitative study of family responses to ableism. *Intellectual and Developmental Disabilities*, 48(4), 245-258. <https://doi.org/10.1352/1934-9556-48.4.245>

Nelson Goff, B. S., Springer, N., Foote, L. C., Frantz, C., Peak, M., Tracy, C., & ... Cross, K. A. (2013). Receiving the initial Down syndrome diagnosis: A comparison of prenatal and postnatal parent group experiences. *Intellectual & Developmental Disabilities*, 51(6), 446-457. <https://doi.org/10.1352/1934-9556-51.6.446>

Nelson Goff, B. S., Monk, J. K., Malone, J., Staats, N., Tanner, A., & Springer, N. P. (2016). Comparing parents of children with Down syndrome at different life span stages. *Journal of Marriage and Family*, 78 (4). <https://doi.org/10.1111/jomf.12312>

Norton, M., Dyches, T.T., Harper, J.M., Roper, S.O., & Caldarella, P. (2016). Respite care, stress, uplifts, and marital quality in parents of children with Down syndrome. *Journal of Autism and Developmental Disorders*, 46, 3700-3711. <https://doi.org/10.1007/s10803-016-2902-6>

Olshansky, S. (1962). Chronic sorrow. A response to having a mentally defective child. *Social Casework*, 43, 190–193. <https://doi.org/10.1177%2F104438946204300404>

- Patrick-Ott, A. & Ladd, L.D. (2010). The blending of Boss's concept of ambiguous loss and Olshansky's concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health, 5*, 73-86.
<https://doi.org/10.1080/15401381003627327>
- Phillips, B.A., Conners, F., & Curtner-Smith, M.E. (2017). Parenting children with Down syndrome: An analysis of parenting styles, parenting dimensions, and parental stress. *Research in Developmental Disabilities, 68*, 9-19.
<https://doi.org/10.1016/j.ridd.2017.06.010>
- Piepmeyer, A. (2012). Saints, sages, and victims: Endorsement of and resistance to cultural stereotypes in memoirs by parents of children with disabilities. *Disability Studies Quarterly, 32*(1). <http://dx.doi.org/10.18061/dsq.v32i1.3031>
- Piepmeyer, A. (2015). Would it be better for her not to be born? Down syndrome, prenatal testing, and reproductive decision-making. *Feminist Formations, 27*(1), 1-24. <https://doi.org/10.1353/ff.2015.0004>
- Pinnegar, S. & Daynes, G. (2007). Locating narrative inquiry historically. In. Clandinin, D.J. (Ed.). *Handbook of narrative inquiry: Mapping a methodology* (pp. 3-34). Sage.
- Poehlmann, J., Clements, M., Abbeduto, L., & Farsad, V. (2005). Family experiences associated with a child's diagnosis of fragile X or Down syndrome: Evidence for disruption and resilience. *Mental Retardation, 43*, 255-267.
[https://doi.org/10.1352/0047-6765\(2005\)43\[255:FEAWAC\]2.0.CO;2](https://doi.org/10.1352/0047-6765(2005)43[255:FEAWAC]2.0.CO;2)

- Powers-Albanesi, H. P. (2017). Encountering disability studies in the social sciences (2016 Western Social Science Association's Presidential Address). *The Social Science Journal*, 54, 1-3. <https://doi.org/10.1016/j.soscij.2017.01.006>
- Ricci, L.A. & Hodapp, R.M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: Perceptions, stress and involvement. *Journal of Intellectual Disability Research*, 47(4-5), 273-84. <https://doi.org/10.1046/j.1365-2788.2003.00489.x>
- Ridge, T.K. (2013). *Paternal response to a prenatal diagnosis of Down syndrome and reflections on raising their child* (Publication No. 3689822) [Doctoral dissertation, Massachusetts School of Professional Psychology]. ProQuest Dissertations & Theses Global.
- Risdall, D. & Singer, G.H.S. (2004). Marital adjustment in parents of children with with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95-103. <https://doi.org/10.2511%2Frpsd.29.2.95>
- Roets, G, Goodley, D., & Van Hove, G. (2007) Narrative in a nutshell: Sharing hopes, dreams, and fears with self-advocates. *Intellectual and Developmental Disabilities*, 45(5), 323-334. [https://doi.org/10.1352/0047-6765\(2007\)45\[323:NIANSH\]2.0.CO;2](https://doi.org/10.1352/0047-6765(2007)45[323:NIANSH]2.0.CO;2)
- Sauer, J. (2013). What's behind the curtain? A family's search for an inclusive Oz. *Review of Disability Studies*, 9(2&3), 41-53.

- Sauer, J. & Ferguson, P. M. (2013). Writing the global family, international perspectives on disability studies and family narratives. *Review of Disability Studies, 9*(2/3), 5-9.
- Saul, R.A. & Meredith, S.H. (2016). Beyond the genetic diagnosis: Providing parents what they want to know. *Pediatrics in Review, 37*(7), 269-278.
<https://doi.org/10.1542/pir.2015-0092>
- Scorgie, K., Wilgosh, L., Sobsey, D., & MacDonald, J. (2001). Parent life management and transformational outcomes when a child has Down syndrome. *International Journal of Special Education, 16*(2), 56-67.
- Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin, 32*(1), 84-110.
- Scorgie, K. & Wilgosh, L. (2008). Reflections on an uncommon journey: A follow-up study of life management of six mothers of children with diverse disabilities. *International Journal of Special Education, 23*(1), 103-114.
- Shakespeare, T. (2007). The social model of disability. In Davis, L.J. (Ed.) *The disability studies reader* (2nd ed., pp. 197-204). Routledge.
- Sheets, K.B., Best, R.G., Brasington, C.K., & Will, M.C. (2011). Balanced information about Down syndrome: What is essential? *American Journal of Medical Genetics, 155A*(6), 1246-1257. <https://doi.org/10.1002/ajmg.a.34018>
- Skotko, B.G. (2005). Prenatally diagnosed Down syndrome: mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics and Gynecology, 192*(3), 670-677. <https://doi.org/10.1016/j.ajog.2004.11.001>

- Skotko B.G., Kishnani P.S., & Capone, G.T. (2009a). Postnatal diagnosis of Down syndrome: Synthesis of the evidence on how best to deliver the news. *Pediatrics*, *124*, 751–758. <https://doi.org/10.1542/peds.2009-0480>
- Skotko, B. G., Kishani, P.S., & Capone, G. T. (2009b). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medicine*, *149A*, 2361-2367. <https://doi.org/10.1002/ajmg.a.33082>
- Skotko, B.G., Levine, S. P., & Goldstein, R. (2011). Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics, Part A*, *155*(10), 2335-2347. <https://doi.org/10.1002/ajmg.a.34293>
- Solnit, A., & Stark, M. (1961). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*, *16*, 523–537. <https://doi.org/10.1080/00797308.1961.11823222>
- Song, J, Mailic, M.R., & Greenberg, J.S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. *Social Science and Medicine*, *217*, 152-158. <https://doi.org/10.1016/j.socscimed.2018.09.044>
- Stone, N.D. & Parnicky, J.J. (1966). Factors in child placement: Parental response to congenital defect. *Social Work*, *1966*, *11*, 35-43. <https://doi.org/10.1093/sw/11.2.35>
- Stoneman, Z. (2007). Examining the Down syndrome advantage: mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research*, *51*(12), 1006-1017. <https://doi.org/10.1111/j.1365-2788.2007.01012.x>

- Urbano R.C. & Hodapp, R.M. (2007). Divorce in families of children with Down syndrome: A population-based study. *American Journal on Mental Retardation*, 112, 261–274. [https://doi.org/10.1352/0895-8017\(2007\)112\[261:DIFOCW\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2007)112[261:DIFOCW]2.0.CO;2)
- Van Riper M. (2007). Families of children with Down syndrome: Responding to a “change of plans” with resilience. *Journal of Pediatric Nursing*, 22, 116–128. <https://doi.org/10.1016/j.pedn.2006.07.004>
- Van Riper, M., & Choi, H. (2011). Family-provider interactions surrounding the diagnosis of Down syndrome. *Genetics in Medicine: Official Journal of the American College of Medical Genetics*, 13(8), 714-716. <https://doi.org/10.1097/gim.0b013e3182209f21>
- Walsh, F. (2003). Family resilience: a framework for clinical practice. *Family Process*, 1, 1-18. <https://doi.org/10.1111/j.1545-5300.2003.00001.x>