

**THE SOCIAL AND FAMILIAL HISTORY OF DOWN SYNDROME IN THE UNITED STATES WITH CURRENT PERSPECTIVES**

by

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The societal and familial perspective of individuals with Down syndrome over the past 100 years was analyzed to discover how the United States as a society values interactions with these individuals during different ages in their life span. By completing a literature review, and conducting online Qualtrics surveys and personal interviews, we further explored the experience of parents of children with Down syndrome. Through thematic analysis with survey and interview data, we found parents experience high overall life satisfaction. However, parents' experiences varied during different life stages of their child, with changing needs for their child and specific complications with other members of society, such as healthcare professionals, family, and peers.

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## **PREFACE**

As someone who works with the pediatric disability community, it has been an enlightening and exciting period for me to work on a project that can impact their lives and my own. My future aspirations of becoming an early intervention occupational therapist have inspired me to learn more about the experience of the parents with whom I will be working with.

This study will hopefully enlighten healthcare professionals to the problems that parents face, and help parents realize that they have shared experiences with others from whom they can learn from.

I would like to give special thanks to my thesis director, Dr. Roxanna Bendixen for teaching and guiding me each step of the way. I would also like to thank Dr. Alyson Stover for believing in my project and supporting my work throughout the entirety as the co-chair, as well as the rest of my committee team, Kelly Fill and Sheryl Zellis for being an integral part of my thesis. I also wish to thank the University of Pittsburgh, and all the professors and administration who have made this BPhil degree a possibility for me.

## **1.0 LITERATURE REVIEW**

### **1.1 INTRODUCTION**

This literature review focuses on the medical and social perceptions of raising children with Down syndrome over the past 100 years. Using the social disability model, it analyzes how societal institutions and social support has aided or hurt their experience, and how it influenced their perspective. We also examine how society has viewed parents of children with Down syndrome. The review is structured by life stages to examine how age is a factor in parent's well-being, and how society views individuals with Down syndrome during the different ages in their life.

The classification of Down syndrome began in 1866 by a British physician, John Langdon Down (Down, 1866). Down syndrome was first classified by physical characteristics and almost 100 years later, in the late 1950's, Jerome Lejeune discovered the cause to be genetic and almost always spontaneous. Lejeune found that individuals with Down syndrome have three copies of chromosome 21 instead of two, and gave Down syndrome a new name: Trisomy 21 (Lejeune et. al, 1960). Individuals with Down syndrome have shared but wide-ranging phenotypes. All individuals have a cognitive delay of varying degrees, and many will have hypotonia, and congenital heart defects (Antonarakis, Lyle, Emmanouil, Dermitzakis, Raymond

& Deutsch, 2004). Down syndrome is the most common genetic cause of cognitive delay and intellectual disability (Povee, Roberts, Bourke & Leonard, 2012).

Research has been medically focused and shaped how society views individuals with Down syndrome. However, as more recent information emerges about the quality of life of individuals with Down syndrome and their family, the focus has been centered on the wellness model instead of the biomedical model. These changing views in society may have impacted the way families and healthcare professionals view raising a child with Down syndrome. The purpose of this review is to observe the transformation that has or has not happened in society and within the United States (U.S.) for individuals with Down syndrome and their family members.

## **1.2 LANGUAGE**

The language we use towards individuals with Down syndrome may represent how we view that individual. Language is how individuals “shape our realities and perceive the world.” (Mackelprang & Salsgiver, 2016). In 2017, we use the medical term “Trisomy 21” or more casually and interpersonally we use the phrase “Down syndrome.” We use person-first language to talk about individuals with disabilities, so that their individuality is seen before their disability, such as “individual with Down syndrome.” These are socially acceptable today, but throughout the years the accepted terminology has changed. In the early 20th century, “mongols” and “imbeciles” were the terms to refer to Down syndrome or an intellectual disability (Swanberg & Haynes, 1919). Throughout the 20th century these terms were used along with “mental retardation” to refer to individuals with intellectual disabilities. Over the past 100 years, research

articles have used these terms because they were deemed socially acceptable at the time. These terms are not included in this research article due to the derogatory meaning that they carry today. Currently, we use person-first language to reflect that the individual with a disability is more than the medical terminology and lives a multifaceted life (Mackelprang & Salsgiver, 2016).

### **1.3 POPULATION**

In 1919, there was a total population estimate of 5,000 to 15,000 individuals with Down syndrome in the US, but this estimate was based on approximation; no thorough analysis or survey had taken place (Swanberg & Haynes, 1919). In 1946, it was estimated that 7,000 infants with Down syndrome were born each year (Ingalls, 1947) with an increase of approximately 1,000 births by 1953 (Kramer, 1953). In 1958, the survival rate of infants with Down syndrome was four times higher than in 1929 (Carter, 1958). Yet 1960 to 1975 the number of Down syndrome births every five years respectively in the U.S. dropped from 5,741 in 1960 to 3,112 in 1975 (Adams, Erickson, Layde & Oakley, 1981). The expected drops in live births could be explained partially by the increase in prenatal diagnoses for women older than thirty-five during this time frame (Adams, Erickson, Layde & Oakley, 1981). However, from the early 1980's to early 2000's there was an increase in prevalence of live births. From 1980 to 2006 the prevalence of live births went from 1 in 1,000 down to 1 in 691, therefore increasing the number of individuals with Down syndrome born each year (Adams, Erickson, Layde & Oakley, 1981; Baird & Sadovnick, 1989; Dent & Carey, 2006; Parker et. al, 2010). The primary population

decrease and secondary population increase can be explained partially by the change of termination rates (Sheets et. al, 2011; de Graaf, Buckley & Skotko, 2016)

Termination rates in the 1980's to 1990's after a prenatal diagnosis of Down syndrome were about 92% in the U.S. (Mansfield, Hopfer & Marteau 1999). Through the years of 1995 to 2011, this termination rate was reported to drop between 67% to 85% (Natoli, Ackerman, McDermott & Edwards, 2012). In 2010, it was predicted that the population of individuals living with Down syndrome was 206,366 which was a dramatic increase from 1950 when the total population was predicted to be 49,923 (de Graaf, Buckley & Skotko, 2016), but was also a decline from the estimated population in 2008 of 250,700 (Presson et al., 2013). In a recent survey (N=73), over 56% of mothers who have a child with Down syndrome report that they worry noninvasive prenatal testing will lead to a decrease in resources and increase in stigma for the Down syndrome community (Kellogg, Slattery, Hudgins & Ormond, 2014).

Throughout the years the live birth rate of infants with Down syndrome and the population estimates have fluctuated due to various social factors. These social factors include: 1) the increased survival rate of children with Down syndrome (Kucik, Shin, Siffel, Marengo & Correa, 2013), 2) the increase in life span for individuals with Down syndrome from a pediatric age to 30 years to 60 years or more, (de Graaf, Buckley & Skotko, 2016), 3) increase in maternal age (Skotko, 2009; Mathews & Hamilton, 2016), and 4) increase in the availability of prenatal diagnosis testing (Sheets et. al, 2011).

## 1.4 PRENATAL

As prenatal screening for Down syndrome has evolved, the way society views screening has changed. Before screening existed, prevention was the main priority (Benda, Dayton & Prouty, 1943). Medical professionals attempted to find "cures" to prevent Down syndrome through biological research (Benda, Dayton & Prouty, 1943). In the 1950's, the genetic cause, an extra chromosome 21, was discovered (Lejeune et. al, 1960) and by the late 1960's, amniocentesis and fetal karyotyping was available to screen for fetal Down syndrome. Only women aged over thirty-five years were offered the screening until the 1980's when the testing was offered more widely (Palomaki, 1995). In 2009, about 88.3% to 95% of women felt they could have received better knowledge about the advantages and disadvantages of participating in the prenatal tests before completing them (Driscoll, Morgan & Schulkin, 2009; Seror & Ville, 2009).

Prenatal testing has also led researchers to question whether the testing prompts discrimination against the population as there has been a decrease in prevalence of individuals with Down syndrome when there statistically should be an increase in prevalence due to increasing maternal birth age (Skotko, 2009). From 1989 to 2005, there was a 49% difference in the number of babies with Down syndrome born and the number that would have been born if prenatal diagnosing did not exist (Skotko, 2009; Egan et al., 2008; Egan et al., 2004). In 2009, it was suggested that the birth incidence may decrease further due to testing, and we have seen since then a roughly 44,000 decrease in the population (Skotko, 2009; Presson et al., 2013; de Graaf, Buckley & Skotko, 2016), prompting researchers to continue to question whether the birth incidence of Down syndrome in the United States will continue to decrease or if there will be changes in the trend (Skotko, 2009; de Graaf, Buckley & Skotko, 2016).

## **1.5 POSTNATAL**

In 1947, after mothers received postnatal diagnoses, physicians were recommending families spend time away from their infant with Down syndrome so they may have time to grieve (Aldrich, 1947). Several years later, the World Health Organization (1954) recommended the family keep children with intellectual disabilities in their home, but also offered the possibility of institutionalization if the disability was severe. In 1960, infants with Down syndrome were more commonly being put in foster placement and eventually transferred to an institution based on the recommendations of the physicians (Centerwall & Centerwall, 1960). When compared at two years old, children, independent of their IQ, who were placed in institutions were found to have lower physical and intellectual ability than infants who were raised at home (Centerwall & Centerwall, 1960). By the late 1970's, physicians recommended that infants with Down syndrome live with their families at home (Emde & Brown, 1978). In 2017, infants with Down syndrome are no longer placed in hospital institutions, but like any other baby, most are put into foster care or coordinated care with adoption agencies, if the family chooses not to take the baby home.

## **1.6 DELIVERING THE DIAGNOSIS**

Following the discovery of prenatal screening, physicians struggled with how to tell parents that their child is going to have Down syndrome. Many mothers seemed to lack knowledge of Down syndrome and relied on the physician to relay the information. However, many practitioners appeared to have medical knowledge of Down syndrome, but lacked experience with people with

Down syndrome, often resulting in unbalanced information for the mother (Williams, Alderson & Farsides, 2002). Skotko and colleagues (2009) stated that the physician with the most knowledge about Down syndrome should request to meet the patient and her partner in a private setting as soon as possible to sensitively and patiently discuss raising a child with Down syndrome (Skotko, Kishnani & Capone, 2009). Reportedly, diagnosis topics with the parents needed to include discussion about their child's ability to participate in education, employment, and relationships, in addition to awareness of the national and local Down syndrome resources available to them (Sheets et al., 2011).

If a mother is never prenatally screened, and gives birth to a child with Down syndrome, physicians rely on physical characteristics and genetic testing to clarify the diagnosis. Informing the mother of the diagnosis is recommended to occur as soon as possible after recognition of physical characteristics by a physician, and a second meeting to be held once the karyotype results are complete (Dent & Carey, 2006). Such parent-based meetings need to provide balanced information, private setting, and non-judgmental manner (Sheets et. al, 2011).

To further prepare future physicians to comfortably deliver a balanced Down syndrome diagnosis, interactive, online training programs are being developed and researched (Lunney, Kleinert, Ferguson & Campbell, 2012). In particular, education for obstetricians and gynecologists is especially important. An estimated 40% of OB-GYNs feel their training for delivering a Down syndrome diagnosis is insufficient (Driscoll, Morgan & Schulkin, 2009). While the biological and physical characteristics are important to inform parents, recent research highlights the necessity to include information about the everyday life of a family who has a child with Down syndrome.

## **1.7 YOUNG CHILDHOOD AND PARENTAL WELL-BEING**

In 2000, some birth mothers were found to have high depression scores when they first received the diagnosis, but scores were found to diminish and depressive symptoms improve over time (Flaherty & Glidden, 2000). A portion of these mothers' depression may be linked to postpartum depression which typically affects 13% to 19% of all mothers (O'Hara & McCabe, 2013). Adoptive parents may not experience this initial depression and have been reported as a group to have very low rates of depression (Flaherty & Glidden, 2000). Parents who adopt babies with Down syndrome, when compared to babies with other developmental delays, score similar positive family dynamics (Corrice & Glidden, 2009).

## **1.8 YOUNG CHILDHOOD AND PARENT EXPERIENCES**

Intellectual disability is a characteristic feature of an individual with Down syndrome and can present differently throughout the lifespan and from individual to individual. Infants with Down syndrome can be tested immediately, but the IQ of young children depends on their functional ability to participate in activities (Rihtman et al., 2009). Cognitive developmental delays become more prevalent as they age, but the functional achievements will be retained (Dameron, 1963; Rihtman et al., 2009). These intellectual disabilities may cause parents to encounter unexpected challenges. Parents' attachment and levels of well-being have been affected by the ability to adapt to their child's intellectual disability.

Several older studies agreed the importance of the role of the caregiver in the child's social development, but disagreed on how mothers with Down syndrome appeared to interact

with their children. Over 30 years, based on a study by Mahoney in 1985 and his colleagues, 25% of the child's development depended on the mother's interactions (Mahoney, Finger & Powell, 1985), and researchers looked more in-depth into mother behaviors. While their study and other studies in the 1980's concluded mothers needed to be less direct and more supportive, Crawley and colleagues contrasted this, and positively reported mothers of children with Down syndrome as more sensitive (Crawley & Spiker, 1983).

In 1990, mothers reflected on how they felt about their own parenting abilities. Mothers who had an infant with Down syndrome reported stronger feelings of competence than mothers who did not have a child with a disability, however this decreased as the child became older (Haldy & Hanzlik, 1990). Mothers may have felt influenced by their child's development or outside social factors.

In 1995, mothers of toddlers with Down syndrome were thought to overcompensate for their child's disability and control their child's play (Cielinski, Vaughn, Seifer & Contreras, 1995). However, in 1998, while mothers of young children were found to be more vocally directive than mothers of children without a disability of the same age, the vocal direction was a result of the developmental level of their child. Parents vocal directive decreased as their child became older, but parents who had a child with Down syndrome were able to adapt for the developmental age instead of the age in years (Roach, Barratt, Miller & Leavitt, 1998). Mothers of young children with Down syndrome were also found to participate in more supportive play, by offering small guidance to optimize their child's success (Roach, Barratt, Miller & Leavitt, 1998). These studies focused on the parent's personality traits and attitudes towards their young child with Down syndrome, which can be a reflection on their mother-child relationship, as well as the attitude towards mothers of children with disabilities.

As infants become toddler-aged the bond between mothers and children with Down syndrome may change. In 1999, Atkinson and colleagues tested the attachment level in mother and child with Down syndrome using the “Strange Situation” (Atkinson et. al, 1999). Measuring the children’s attachment level, 47% were unclassifiable and 40% were secure. The mothers who had secure attachment with their toddlers were reported to be the most sensitive of all the mothers in the study. While there were links between cognitive development of the infant and security level, mother insensitivity may have played a role in restraining the attachment (Atkinson et. al, 1999). Also in the late 1990’s, mothers found to have an increase in stress seemed to be positively correlated with a stronger temperament of their child with Down syndrome (Stores, Stores. Fellows & Buckley, 1998).

From the 1980’s to the 1990’s, research focused on the characteristics of the mothers and their effect on their child’s development. Within the past 5 years, research has analyzed the relationship dynamic more than the mother’s characteristics. The mother’s age, education, and social support contributed to their interactions with their child (Mitchell, Hauser-Cram, Crossman, 2014), and the mother’s ability to positively cope affected the quality of relationship with the child, especially when mothers felt that there was hope for the future (Cless, Goff & Durtschi, 2017). In Australia, researchers expressed that the relationship between mother and child should be understood as a dynamic interaction, and that the mother’s parenting is affected by her social support, financial stress, and spirituality (Pillay, Girdler, Collins & Leonard, 2012). To help mothers raise their child, and subsequently improve the growth of their child, programs and healthcare professionals need to address the mother’s holistic needs (Pillay, Girdler, Collins & Leonard, 2012).

## 1.9 EARLY INTERVENTION THERAPY

To encourage a child to reach her or his own potential, parents find therapies and other resources to help their child become more independent. In 1983, parents who participated in early intervention therapy sessions with their infants with Down syndrome regarded the experience as positive. However, they requested health care providers be more flexible to families' schedules and sensitive to their needs (Sloper, Cunningham & Arnljotsdottir, 1983). Early intervention programs were found to give parents hope and a more optimistic approach to raising their child (Hanson, 2003). When early intervention incorporates play, children with Down syndrome can practice their social skills, which is important for their inclusion in the community (Iarocci, Virji-Babul & Reebye, 2006). By 2012, it was found that infants need interaction, especially with a caregiver, to promote their intellectual growth and connection with that individual, who will provide them with the care that they need (Sullivan, Perry, Sloan, Kleinhaus & Burtchen, 2011).

Today, therapists continue to recommend successful programs for infants with Down syndrome, such as "Tummy Time" which involves lying infants on their stomachs to promote exploration of their environment (Wentz, 2017). Once again, research found parents requesting healthcare providers provide more reasonable exercises to practice in the home. While "Tummy Time" has been mostly positive, parents felt the exercises were too long (Bartlett, Schelin & Roman, 2017). Over time, parents have had positive experiences with early intervention therapy, but felt the programs or providers may be unrealistic or inflexible.

## 1.10 SCHOOL YEARS

As children grow, relationships with their mothers, fathers, and siblings differ among each other. Parents generally want the best for their children and family, but may be divided on the integration of a child with Down syndrome into their family and society. This transition has been increasingly positive throughout the last 50 years. In 1959, 66% of families adjusted positively, however, other parents denied the disability or struggled to support the child due to financial difficulty (Schipper, 1959). In the late 1980's, parents opted for their child to undergo plastic surgery (Arndt, Lefebvre, Travis & Munro, 1986) and felt that their children should be on birth control or sterilized (Pueschel & Scola, 1988). This reflects the parents' feelings of pressure for inclusion for their child, as well as the level to which they thought they could participate in society if they were "normalized." By the 1990's, both parents who had a child with Down syndrome and parents who did not have a child with a disability had the same level of satisfaction in their family dynamics (Van Riper, Ryff & Pridham, 1992). In 2011, parents have not only integrated their child into the family, but report a sense of pride in their child with Down syndrome for teaching their family patience and love (Skotko, Levine & Goldstein, 2011).

As parents raised their children, stress became a factor. It is a natural reaction to children growing older and undergoing change. The main factors of stress in parents who have children with Down syndrome are related to the child's temperament, behaviors, and independence, as well as the family relationships, socio-economic factors, and the individual's coping strategy (Sloper, Knussen, Turner & Cunningham, 1991; Cuskelly, Chant & Hayes, 1998; Stores, Stores, Fellows & Buckley, 1998). In 1989, mothers felt that their stress appeared periodic and intense as their child with Down syndrome grew older (Damrosch & Perry, 1989). The mother's coping

strategies and social support influenced the development of the child's independent social interaction skills (Turner, 1996).

Adolescents with Down syndrome and their parents both experience stress and have a particularly difficult time during this life stage (Merrick, Kandel & Vardi, 2004). In 1999, mothers reported additional stress and lower levels of well-being if they were the one providing direct care to a child with Down syndrome and simultaneously received low partner support (Roach, Osmond & Barratt, 1999). Social support can come from families, friends, or other members of the community. Mothers feel a stronger sense of well-being when they have a good relationship with their child with Down syndrome's healthcare provider, and will more likely see other health-related professional help (Van Riper, 1999). The healthcare provider can help improve the mother's well-being and consequently improve the child's.

In the 21<sup>st</sup> century, research began to compare mothers who had children of different disabilities. Mothers with children with Down syndrome reported less stress than parents who had children with different disabilities (Hodapp, Ly, Fidler & Ricci, 2001) and less anxiety or distressed feelings than did mothers who had children of unknown diagnoses (Lenhard, Breitenbach, Ebert, Schindelbauer-Deutscher & Henn, 2005). In 2007, income level was found to be one of the most important indicator levels of stress (Stoneman, 2007). Income level can be important in depression and levels of sensitivity due to the impact it has on other factors in the parents' lives (Stoneman, 2007). Lower income levels can translate to working longer hours or more physically demanding jobs, living in a stressful environment, and having less accessibility to necessary health services. Around the same time period, mothers with young toddlers reported a lower level of stress than did mothers of toddlers of different developmental delays, however reports are inconsistent (Most, Fidler, Laforce-Booth & Kelly, 2006).

While parents undergo stress and make sacrifices, parents who have a child with Down syndrome reported to be less likely to divorce than parents who had children with different disabilities or children without disabilities (Urbano & Hodapp, 2007). Typically, parents who had children with Down syndrome who had divorced were less educated, younger, and their child with Down syndrome was two-years-old or younger (Urbano & Hodapp, 2007).

Mothers with children with Down syndrome were often compared to mothers with children without a disability as well. Mothers with school-aged children with Down syndrome felt more insecure about their ability as a parent than mothers who did not have a child with a disability, even though their actual parenting abilities were similar (Haldy & Hanzlik, 1990). They also spent less time in paid-work than did mothers who had children without disabilities (Barnett & Boyce, 1995). Both mothers and fathers spent most of their time taking care of their child with Down syndrome and less time on social activities (Barnett & Boyce, 1995). This may show the amount of work a child with Down syndrome requires, but may also demonstrate the need for more flexible work opportunities, social support services, and respite care. Parents continue to report a need for consistent and efficacious social services for their child and themselves (Siklos & Kerns, 2006).

Research about the wellbeing of fathers of children with Down syndrome has been neglected. Fathers feel stress as well, but it grows at a slower and steadier pace than the mother's stress (Damrosch & Perry, 1989). The fathers who were participating in the care of their child with Down syndrome perceived more parental competence than the mothers reported (Roach, Orsmond & Barratt, 1999).

Parents can find ways to effectively balance their own lives, and manage a family with a child with Down syndrome, by trusting in themselves as a parent, taking care of their own well-

being, and taking action to protect their social ties, including their marriage (Scorgie, Wilgosh, Sobsey & McDonald, 2001). Acting as an advocate for their child also has familial benefits (Scorgie, Wilgosh, Sobsey & McDonald, 2001). Parents with a child with Down syndrome are motivated to find programs to promote their child's well-being. Involvement with professional support was commonly addressed. Parents most often want to be involved and informed about their child's therapy (Siklos & Kern, 2006). They also have the desire for their child's teacher to understand their problems (Siklos & Kern, 2006). Parents learn to adapt over time while raising a child with Down syndrome. They create a different world-view and new aspirations for themselves and their child. They have a change in their belief system and re-prioritize what is important in their lives and their family's lives (King et. al, 2006).

## **1.11 ADULTHOOD**

Research regarding adults with Down syndrome began around the 1960's and became more popular in the 1980's as individuals with Down syndrome began living longer. In 1920, only about 15% of children lived to 10 years old compared to 1960 when 70% of children lived past 10 years old, and 1980 when almost 90% of children lived past 10 years old (de Graaf, Buckley & Skotko, 2016). The research in the 1980's often centered on the physiological changes and treatments for adults with Down syndrome. In the 1990's more sociological and psychological research regarding these individuals and their parents was occurring.

As children with Down syndrome became adults, parents felt their child became less dependent and had less or non-existent negative behaviors (Holmes & Carr, 1991). While many children still rely on some form of help from their parents, they live mostly independent lives

(Alderson, 2001). Parents most often help in the form of doing household chores and promoting health-seeking behaviors (Holmes & Carr, 1991). Adults with Down syndrome often reported that social supports and inclusion in society became important for their well-being (Alderson, 2001). In the literature, employment was another avenue of inclusion for individuals with Down syndrome in addition to independent living. Brown (1994) encouraged parents to allow their child to choose options in a field they are interested in, even if it is less traditional as they would see greater motivation to participate in work and related programming (Brown, 1994).

In 2010, the mean age of life expectancy for individuals with Down syndrome was 50 years old (de Graaf, Buckley & Skotko, 2016). As the population becomes older, communities need to have increased geriatric support and access to healthcare services. Older adults tend to experience declining health, especially aging individuals with Down syndrome who are already susceptible to many conditions. Screening for these diseases can help improve their quality of life (Van Allen, Fung, & Jurenka, 1999). Interestingly in 2011, physicians who felt uncomfortable working with individuals with Down syndrome were most often physicians who worked with adults (Pace, Shin & Rasmussen, 2011). This demonstrates the need for physician training for multiple areas of specialties and across the lifespan, not just obstetricians and pediatricians.

Adults with Down syndrome are more likely to experience Alzheimer's disease and dementia and the onset is sooner than adults without Down syndrome (Wisniewski, Wisniewski & Wen, 1985). Hence, it may be important to assess for this diagnosis as these individuals age. In Ireland, adults with Down syndrome who have Alzheimer's disease are more often going to have additional physical and mental health co-morbidities, such as depression (McCarron, Gill,

McCallion & Begley, 2005). Recognizing the symptoms in adults with Down syndrome is important so it can be detected and treated early.

Hanson studied the experiences of parents of a child with Down syndrome once they became an adult. Parents felt their child could accomplish more than what they were expecting, however they were concerned that their grown child's social network remained mainly within the family, as they had difficulty creating friends and relationships (Hanson, 2003). In additional research, mothers who remained optimistic as their children became adults, expressed greater well-being (Greenberg, Seltzer, Krauss, Chou & Hong, 2004). They also reflected on how their child's life positively impacted their own, and how their child taught their whole family influential life lessons (Skotko, Levine & Goldstein, 2011; Skotko, Levine & Goldstein, 2011; Hanson, 2003).

## **2.0 METHODS**

### **2.1 QUALTRICS**

To better understand the most current social and familial perspective of Down syndrome, we implemented parent-based online surveys. We anticipated the surveys would provide us the most up to date information, and allow us to specifically analyze gaps in previous research. Qualtrics, an online survey system, was used to create the surveys and collect survey data. This platform allowed participants to easily access our surveys and enabled us to safely store our participants' data. The survey questions were created on April 5<sup>th</sup>, 2017 in Microsoft Word, and were added into Qualtrics system on May 7<sup>th</sup>, 2017 following IRB approval.

Three separate surveys were created in Qualtrics: 1) Qualtrics Parents Survey, a survey for parents with a child(ren) with Down syndrome, 2) Qualtrics Healthcare Professionals Survey, a survey for healthcare professionals who work with patients with Down syndrome, and 3) Qualtrics Telephone Interview Response Survey, a short survey to opt for a telephone interview. In the consent form, there was an option for participants to choose "IF YOU WISH to be contacted for a follow-up telephone interview, please select this and proceed to the following web link to provide your contact information." If the participant chose this option, they would be directed to a separate webpage, unconnected to their original survey. In this new webpage, the participant was prompted to give their name, telephone number, email address, and to state

whether they were a parent or healthcare provider. Once the participant clicked submit, they were sent back to the previous page to continue their original survey.

The surveys were available to the public on August 25<sup>th</sup>, 2017. The Qualtrics Telephone Interview Response Survey was closed on September 28<sup>th</sup>, 2017 and the Qualtrics Parents Survey and Qualtrics Healthcare Professionals Survey were closed on October 10<sup>th</sup>, 2017.

### **2.1.1 Participant Recruitment**

For the Qualtrics Parents Survey, we included participants who were biological or adoptive parents of a child(ren) with Down syndrome. For our Qualtrics Healthcare Professional Survey, we included healthcare professionals who have worked with at least two patients with Down syndrome. For both surveys, the participants had to be from, and currently living, in the United States of America. The survey was open to participants on August 25<sup>th</sup>, 2017, and the first survey was taken on August 28<sup>th</sup>, 2017.

For recruitment, we used the Global Down Syndrome Foundation's resource of "Local Down Syndrome Organizations" and emailed more than 300 Down syndrome organizations across the fifty states. The distribution among these states varied from as few as one organization in Hawaii, to twenty-eight organizations in California. Some of the organizations no longer had updated information on the Global Down Syndrome Foundation's website, therefore our emails were rejected by 31 email addresses. We also contacted Pennsylvania healthcare groups that were not on this list, including: Theraplay and Pottstown Medical Specialists, Inc. Emails to these organizations requested they disseminate the email to individuals in their organization who would be interested in taking one of the surveys, or knew someone who might be interested. An IRB-approved flyer was attached to the email for organizations to hand-out during meetings.

### **2.1.2 Qualtrics Parent Survey**

The survey questions were aimed to better understand the participant's experience of raising a child with Down syndrome, and to understand their perspective of the social and professional support in their lives. There were 125 responses completed by survey closure. After analyzing the surveys, 9 surveys were blank and unusable for our research, therefore deleted. Of the 116 surveys remaining, an additional 39 surveys were unusable, because only demographic information was provided before they exited the survey. An additional 3 surveys were deleted, because the participants were not born in the United States, or currently residing in the United States. Seventy-four surveys were remaining and used for analyses. Of these 74 surveys, 13 of the surveys reported demographic data, and information about their child when they were 0 to 3 years old, but did not respond at the 4 to 6 life stage range or further, even though their child was at least 4 years or older as reported in the demographics section. We kept the data from these surveys to get more in-depth information on the lifespan from 0 to 3 years old. In our data set there were 61 fully complete surveys.

Parent surveys were categorized by different age groups: 0 to 3 years of age, 4 to 6 years, 7 to 21 years, and over 21 years old. These age periods signify different societal markers within our modern society including early intervention, young childhood, school years, and adulthood. There were three additional categories: demographics, caregiver questions, and overall parenting experience. Parents answered questions in each life stage until it reached their child's age. For example, a parent with a 14-year-old child would answer the 0 to 3 years' life stage, 4 to 6 years' life stage and 7 to 21 years' life stage, but not over 21 years old life stage.

The questions in the survey were a combination of quantitative and qualitative questions. The qualitative questions prompted for short answer responses. All parents were requested to complete the consent form, 19 demographic questions, 3 caregiver questions, and 7 overall parenting experience questions. All survey questions can be found in the appendix under “Qualtrics Parents Survey.”

### **2.1.3 Qualtrics Healthcare Professional Survey**

These survey questions were aimed to better understand the healthcare professional’s comfort level, experience, and advocacy for individuals with Down syndrome. There were 21 responses by the time the survey closed. Of the 21 responses, 4 surveys were unusable, because only the demographic portions of the survey were completed. Of the 16 responses, an additional 2 responses were unusable, because they did not meet the survey requirements. In the one survey, the participant was an educator, not a healthcare provider. In the other survey, the participant was not from, and did not practice, in the United States. This left us with 14 completed surveys that we used for analysis.

The questions in the survey were a combination of quantitative and qualitative questions. The qualitative questions prompted for short answer responses. The healthcare professional survey was not divided by age, but instead by categories that gaged their participation with their patients with Down syndrome. The survey included a consent form, 9 demographic questions, 6 patient-professional relationship questions, 3 clinic setting questions, 3 caregiver questions, 4 referral questions, 6 clinician education questions, and 2 genetic testing questions. The participants were asked to complete all 33 questions. All survey questions are listed in the appendix under “Qualtrics Healthcare Professionals Survey.”

## 3.0 RESULTS

### 3.1 SURVEYS

**Table 1.** Participant Responses

	<b>Total Participant Responses</b>	<b>Number of participant's Children Currently in that Life Stage</b>	<b>Average Age of child (years)</b>	<b>Range of ages (years)</b>
Life Stage 0 - 3	61	11, *13	2.3	1.8 – 3.5**
Life Stage 4 - 6	50	10	4.6	4 - 5
Life Stage 7 - 21	40	32	13.5	7 - 21
Life Stage Above 21	8	8	28.2	22 - 47

\* = Participants whose child was over 3 years old, but only completed the first life stage 0 – 3

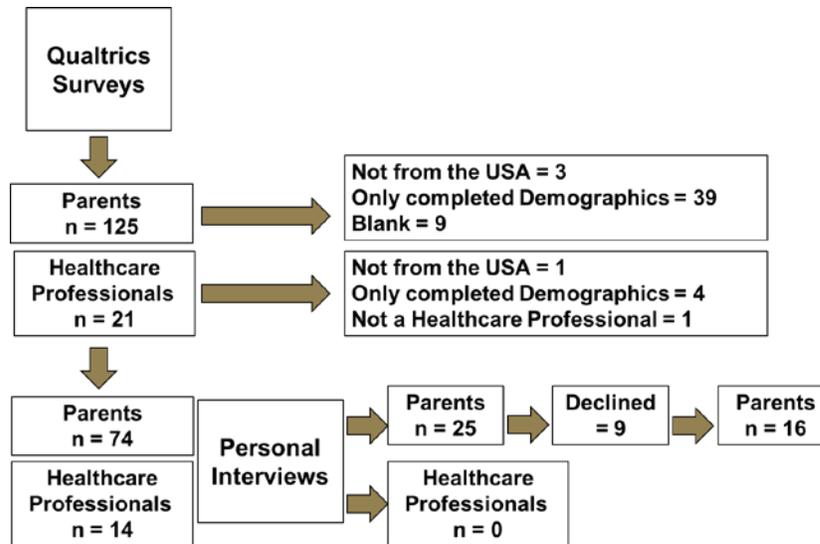
\*\* = Participant reported 3.5 and only answered the life stage 0 – 3

**Table 2.** Participant Survey Duration

	<b>Number of Questions</b>	<b>Average Time to Complete (hh:mm:ss)***</b>	<b>Average Time Excluding Largest Outlier hh:mm:ss)***</b>	<b>Range of Time to Complete (hh:mm:ss)***</b>
Life Stage 0 - 3	39	32:19, *18:56	20:46, *11:01	00:11:35 -02:27:55
Life Stage 4 - 6	49	46:23	32:28	00:11:08 -02:51:42
Life Stage 7 - 21	61	04:47:42	01:56:10	00:11:03 - 93:25:41
Life Stage Above 21	73	03:31:14	01:49:37	00:11:36 - 15:22:33

\* = Participants whose child was over 3 years old, but only completed the first life stage 0 – 3

\*\*\* = The duration of the survey includes active and inactive periods from which it was started.



**Figure 1.** Participant Methods: Qualtrics Survey and Personal Interview

### 3.1.1 Parents: Demographics

Demographics for parent respondents follow in Table 3.

**Table 3.** Parent Demographics

		<b>n</b>	<b>%</b>
<b>Age</b>			
	Min	28	
	Max	87	
	Mean	48	
<b>Gender</b>			
	Female	70	95%
	Male	4	5%
<b>State by Region</b>			
	Northeast	15	20%
	Mid-West	18	24%
	South	29	39%
	West	12	16%
<b>Environment</b>			
	Urban	6	8%
	Suburban	53	72%
	Rural	14	19%
	Other	1	1%
<b>Ethnicity</b>			
	African American	2	3%
	White	68	92%
	Other	4	5%
<b>Partner</b>			
	Yes	69	93%
	No	5	7%
<b>Current partner is biological or adopted parent</b>			
	Yes	68	99%
	No	1	1%
<b>Live With Partner</b>			
	Yes	67	97%

	No	2	3%
<b>Partner from US</b>			
	Definitely Yes	67	97%
	Probably Yes	1	1%
	Definitely Not	1	1%
<b>Partner Gender</b>			
	Male	66	96%
	Female	3	4%
<b>Partner Ethnicity</b>			
	African American	3	4%
	White	60	87%
	Asian	2	3%
	Native Hawaiian or Pacific Islander	1	1%
	Other	3	4%
<b>Child Adopted</b>			
	Yes	4	5%
	No	70	95%
<b>Child Lives with You</b>			
	Yes	70	95%
	Different house with other biological or adoptive parent	2	3%
	Different house with a different family member	1	1%
	Other	1	1%
<b>More than One Child With DS</b>			
	Yes	3	4%
	No	71	96%
<b>Age of Child with DS</b>			
	0 to 3	10	15%
	4 to 6	11	16%
	7 to 21	44	59%
	Older than 21	9	10%
<b>Other Children</b>			

	Yes	62	84%
	No	12	16%
<b>Number of Children Total</b>			
	1	1	2%
	2	19	31%
	3	24	39%
	4	13	21%
	5	2	3%
	6	0	0%
	7	2	3%
	8	1	2%
<b>Live Close to Extended Family</b>			
	Yes	45	61%
	No	29	39%
<b>Primary Caregiver (n = 70)</b>			
	Yes	63	90%
	No	7	10%
<b>Caretaking Equally Distributed (n = 68)</b>			
	Definitely Yes	20	29%
	Probably Yes	12	12%
	Might or Might Not	6	9%
	Probably Not	10	15%
	Definitely Not	20	29%
<b>No Longer Primary Caregiver (n = 73)</b>			
	Definitely Yes	3	4%
	Probably Yes	2	3%
	Might or Might Not	3	4%
	Probably Not	1	1%
	Definitely Not	64	88%

### **3.1.2 Parents: Responses**

For each life stage, parents responded to qualitative, short-answer response questions. The questions were based on describing their experiences, and how they perceived social supports in their life. A thematic analysis was used to determine themes throughout each life stage.

#### **3.1.2.1 Life Stage 0 to 3**

Parents reported their child with Down syndrome's top three strengths when the child was in the 0 to 3 years' life stage. The majority of parents reported a positive personality and temperament (81%). The top characteristics reported were socialness, curiosity or eagerness to learn, affectionate, and their positive demeanor and happiness. There were also mentions of determination and easy-going personalities. In contrast, parents reported the most challenging characteristics of their child during this time were their ability to reach milestones (85%). Of those milestones, parents reported speech and communication (51%), physical milestones such as walking and gross motor skills (51%), and feeding (31%) as the most common challenges.

The parents' reported experiences related to what they found to be their child's strengths and weaknesses. There was a positive relationship with their children regarding their personality traits bringing "happiness" and "joy" to them and their family. However, many parents did not instantly feel that after birth. After they received the diagnosis, they grieved their loss of expectations. One parent reported, "I have realized that DS [Down Syndrome] isn't scary... it is totally manageable." Many regretted originally grieving, and they felt they learned life lessons such as patience. One parent stated, "Initially, there was profound shock at his diagnosis, made

immediately after birth, and deep grief, for all the things he would ‘never be.’ However, I immediately fell in love with him and fully embraced caring for him. He was, and still is, an absolute delight and one of the greatest things that has ever happened to me.”

During this life stage, parents whose child had a medical difficulty had greater stress. They worried about their child’s health, and felt they were constantly researching, advocating, and attending numerous medical appointments. One parent stated, “This stage was challenging mainly from a medical perspective. In spite of all the medical struggles, he has been our happiest and most easy-going baby and toddler.” Parents generally worried about navigating the healthcare system to get the services they needed. One parent reported, “The first year was the hardest just trying to figure out what support my daughter needed and then advocating for her so she could get that support.”

Most parents utilized early intervention therapy to help their child reach developmental milestones. They put a lot of time and effort into helping their child succeed, and became worried when they were not catching up to other children. They also felt extremely rewarded when they reached a milestone, and thanked therapy services. One parent reported, “Once home, we had an amazing feeding therapist, in addition to helping my daughter learn to eat and drink, she truly set the positive tone for how we view our daughter and the diagnosis.” Another parent reported that their early intervention team, “became to be like family. We continue to reach out to them when we have questions.” Parents reported positively on the hope their health care providers gave them, and the openness of dialogue.

Parents felt that their healthcare providers shaped the way they view their child, but sometimes it created a negative impact. One parent reported, “One geneticist told us in the hospital, ‘she may be able to learn certain things but she will never be able to find her way out of

a burning building.’ Now I’ve got that image stuck in my head for the rest of my days.” Another parent reported, “I expected my child to be treated like any other child and that is certainly not the case. I must do a lot of research and advocacy for my child to counter the discrimination in these settings.”

However, they also felt overwhelmed constantly attending appointments or seeing visiting therapists in their home. Other parents reported “A life surrounded and controlled by appointments.” Another parent expanded on this idea, “It has been hard to bond with him because there are so many other people called in his care. Sometimes I felt like they had more rights to decide what was going on with him than I did.” Parents felt overwhelmed by appointments, felt healthcare professionals were taking their autonomy, and at times felt discriminated against. One parent commented, “It was not our child that was challenging, it was the outside world and the lack of acceptance of someone not like them!”

These parents also reported on the desire to be connected to other parents who had children with Down Syndrome, and commented on feeling more overwhelmed or alone during this life stage. Having a healthcare provider connect them with another parent who had a child with Down syndrome during a prenatal diagnosis, or right after birth, was a positive experience for parents during this life stage. Parents living in rural areas were more likely to connect online to these individuals as opposed to parents living in urban and suburban areas. One parent reported the importance of “finding a community of families with babies with Down syndrome in order to have shared experiences on the journey.”

Parents described how they perceived their partner’s experience during this life stage. Parents commented that their partner had a similar experience to their own whether it was positive, negative, or mixed (36%). Others reported their partner was supportive or loving

towards their child since the beginning (23%). Parents also reported that their partners worked often and were constantly exhausted or stressed (13%), or the partner's experience was initially frustrating or challenging, then they became accepting (9%). Parents reported their partner continued to have difficulty or had fear (9%).

When parents compared their other siblings to their child with Down syndrome during the life stage of 0 to 3, parents commented that it was a similar experience, with the exception of the milestones, medical challenges, and appointments. Parents most often responded that their other child(ren) accomplished their milestones quicker (38%), and how that created less stress. However, they also reported how that made milestones less celebratory. One parent reported on the perceived difference between the children, "we learned how quickly and easily many milestones are reached but that children have their own individual needs regardless of having a 'diagnosis' or not." Parents commented how they had less fear of medical symptoms and the health of their child without Down syndrome (10%). They also reported that due to having less symptoms, there was less coordination of therapists and specialists (10%). One parent reported her experience as "it was a joy to raise all my children. I didn't worry as much about some things with my typical children." Parents commented that the bond between the siblings was positive, and they benefited or supported each other (16%).

Parents discussed their perceptions of their extended family's experiences. A quarter of participants reported that extended family lived farther away, or they did not see them often (25%). Of the families who lived relatively near to their extended family, they reported similar experiences to what parents have reported about their own experiences, whether or not is within the same family. Many felt extended family members were accepting (59%), 48% of which reported they were supportive from the beginning, and 11% who first felt grief then later on

acceptance. There were also perceived mixed feelings from different members of the family (21%). On the other end, parents felt extended family was uninvolved (11%) and few felt they were unsupportive (4%)

Parents reported on their additional services during this life stage, and the majority of individuals reported about their early intervention therapists (77%). Early intervention therapy was reported positive 71% of the time, and was reported negative 29% of the time. Parents felt therapists encouraged their child's development, and provided social support for the parent by providing them hope. One participant said, "Their opinions helped me shape my views and expectations I had of my daughter." Many parents had to search through multiple therapists before finding ones that worked well with their family. Most of the parent's negative responses about therapists were due to feeling overwhelmed by scheduling appointments, always attending appointments, and learning how to understand the system. Other parents reported that their therapists often canceled appointments and did not communicate well.

Parents also discussed their experience with other healthcare professionals. Parents most commented on the healthcare professionals and the provider team as positive (51%). The negative aspects parents described were the professionals' lack of updated information (16%) and not seeing the individual before the diagnosis (10%). Other parents commented on receiving negative information during a diagnosis and feeling their child was discriminated against.

### **3.1.2.2 Life Stage 4 to 6**

Parents reported the top three strengths of their child during the ages of 4 to 6. They again expressed socialness and curiosity, and this time they reported milestones. They reported similar scores in both socialness, 38% compared to 32% and in curiosity, 16% compared to 22%. While parents regarded reaching milestones as a challenge in the life span of 0 to 3, for this age group

parents regarded walking and gross motor skills (30%) and language and communication (28%) as a strength, demonstrating a greater satisfaction of improvement in these areas.

The parents reported the top three challenging characteristics of their child. Similar to the life stage of 0 to 3 they reported milestones, however gross motor skills were no longer on the list. The previous milestones that were mentioned again were speech and feeding. Speech was reported 42% of the time compared to 51% and feeding was reported 10% of the time compared to 31%. Speech was still the biggest difficulty, but parents also expressed challenges with wandering, health related issues, unsuccessful toilet training, and fine motor skills.

Parents reported on the support they received from their partners and extended family. Of the participants that reported that they currently had a partner, most commonly they had the same experiences when their child was younger, and participants felt their partner was generally supportive and accepting of their child. Fewer participants felt their partner was frustrated or constantly working or uninvolved. Of the participants that reported they had extended family living close to them, most commonly participants reported their extended family has been supportive and accepting. Fewer participants reported that the family was unsure how to act, or they had mixed attitudes towards their child.

Of the parents that reported they had other children who were currently or previously aged in the 4 to 6 lifespan, they most often reported on that their other children had no issues, with the exception of the parents who reported they had another child with a disability. They reported additional stress in raising their children without Down syndrome.

Participants reported their child's experience with day services during this life stage. Parents reported utilizing many different types of settings, such as developmental schools, private schools, public schools, Montessori schools, and daycares. Regardless of setting, 74% of

responses were positive, 14% were negative and, 8% were mixed. The parents who responded negatively felt teachers had low expectations of their child, had difficulty finding teachers that accepted their child, or the parent had difficulties finding a place that would accept their child. One parent reported “It did take 14 calls to other schools who turned us down first without even meeting our daughter before we found one to take her.”

Parents reported on their experiences with additional services. Parents most often participated in continued therapy either outside or inside the school environment. One parent commented, “Life revolving around therapies was improving as fewer therapies were needed.” Parents also did not specify what additional services they had, but reported fair to excellent experience (29%). Fewer parents reported their child no longer had additional services.

Parents also commented on their experiences with the healthcare professionals. During this life stage, many parents reported positive relationships with their healthcare professionals (60%), which is an increase from the previous life stage (51%). Most parents who reported it was positive, felt that their healthcare experience was the same during this life stage as it was in the previous life stage. A parent reported, “His healthcare team remained the same, and we are still very pleased with all of them.” The other parents who reported positive commented that their health care experience as “being better”, either with the same or different providers. One parent stated, “We finally had the right doctors and they are all great.” Another parent reported, “It is better. We became more educated and knew what to help the doctors with.” Some parents reported that their healthcare professionals were knowledgeable, while others reported that they were not knowledgeable about Down syndrome. Parents who reported that they had a mixed experience with healthcare professionals often reported that they had positive relationships with certain providers, but negative experiences with others. This was mixed among different

healthcare professions. Fewer parents had a completely negative experience (10%), those who did felt they had to do a lot of research and advocating for their child.

### **3.1.2.3 Life Stage 7 to 21**

Similar to the previous two life stages, we see a continuing strength of their child relating to their socialness with a slight decrease from before. We also see a shift in speech as more parents report it as a rewarding characteristic, and fewer parents report it as a challenging characteristic. During this life stage, parents most often believed their child's strength to be their socialness. Interestingly, 23% of our parents believed language and speech were a strength, in contrast to 28% who continued to feel challenged by their child's speech. As their children became older and entered school, parents less often reported milestones and focused on personality and behaviors as challenges, such as their stubbornness and their negative behaviors or defiance.

Parents most often found their partners experience during the life stage of 7 to 21 the same as their experience in the previous life stage. Other parents reported support and love as well as frustration. Parents and partners' experiences were more divided during this life stage as some felt challenges were decreasing, while others thought they were increasing. One parent exclaimed, "We love her more during this stage because we know she is not going to die, she will eat and communicate more. More joy." Another parent reported, "Our child's lessening physical needs and greater independence skills eased the load on both of us." Parents with more challenges reported, "Problems and challenges with how to teach skills/discipline/motivate" and another parent said, "Very stressful. Especially the defiance." Children who began to show stronger negative behaviors created more difficulty for parents who were less able to enjoy the child's increase in independence and achievement of milestones.

Parents had mixed reactions about their other children during this life stage. Parents reported they had similar challenges with their other children that they had for their child with Down syndrome, such as “tween moodiness.” Parents felt that their other children had additional difficulties that their child with Down syndrome did not have. This became even more prevalent for parents who had children whose disability appeared right before or during this life stage. One parent felt their other child “felt left out” while someone else’s child was “learning to appreciate and understand the complexities his sister has and challenges she faces.” Other parents felt their other child(ren) had positive experiences and no issues during this life stage.

If parents had extended family relatively near them during this life stage, they reported their experiences. Parents mentioned that supportive family who were nearby during previous life stages moved away, and so they no longer provided that extra support (15%). Parents also started reporting that family that was previously supportive, stay supportive, however they were less able to understand or interact with their child during this life stage. Similar to previous life stages, several parents continued to report that their extended family was supportive and accepting, no involvement, or showing the same level of support that was shown during previous life stages.

Outside of family support, parents described the support they received from their child’s education professionals. Professional specialties varied, because parents chose a variety of settings for their child during this time frame including special needs schools (20%), a special education classroom in a mainstream school (34%), an inclusive classroom in a mainstream school (33%), and “other” (12%). Parents who reported other, most often taught their child in their home. Including all the settings, parents most often reported having a mixed experience (50%). They felt some teachers or staff were more supportive and invested than others, and this

varied within a classroom or across different grades and classrooms. One parent reported, “It depends on the year, I felt some were very engaged and others did not care about him because he was lower functioning.”

Parents also reported a generally negative experience (20%) due to discrimination from the teachers or a lack of education and training in working with individuals with Down syndrome or disabilities. One parent stated, “Low, low, low expectations. Most concerned with getting them through the system and off the schools’ books without caring about maximizing her learning.” Other parents repeated how they go to court or file complaints about their school. One parent stated, “There were some civil rights issues with denial in equal participation in some general electives that had after school hours, which were only resolved after I filed a complaint.” Other parents state the difficulty they have in communicating their concerns with educational staff. One parent stated, “Teachers never give the parents credit for knowing the child best, so my opinion was just that, an opinion. It was hard.”

A few parents reported a positive experience (15%) due to the accommodations and support of the educational professionals; although parents also felt they had to often fight and advocate for their child to get the services they needed and lawfully deserved (20%). This varied and included changing schools to get services or taking extra time to work with staff who were less knowledgeable. One parent stated, “The administration doesn’t really know what they’re doing but they will let us lead the way. And honestly, my husband and I barely know what we are doing. Head and hearts lead the way.” Another parent stated, “I pushed very hard for inclusion and they met me every step of the way. Our schools, staff, and administration is amazing.”

Parents also described their child's relationships with their peers and classmates. Generally, they categorized two types of interactions, their child's interaction with their classmates overall, and their child's personal friendships, but the responses were mixed. Several parents mentioned that their child was very popular and described as the mayor at school. Other parents described that "Some students were accepting, others were not. It seems to depend on whether they have been around people with special needs or not." More parents replied similar responses, prompting for better education of disabilities to other classmates. Other common response parents had was their child was supported by classmates, but as they became older they had less friendships or invites to events outside of school. One parent reported, "They are wonderful to her at school and at school functions, but no one calls to invite her to movies or a party, so she is a bit isolated." Parents also reported their child was supported by classmates, but their friendships came from other children who had Down syndrome or disabilities, and not from children who were seen as "typical." One parent reported, "Typical kids usually reject him, but he is very good with other children with disabilities. He knew the typical kids were rejecting him so he stayed away from them. He really enjoys being around other teens with Down syndrome at events." A few parents reported that their child had negative school experiences, such as bullying.

Parents also reported on the additional services their child received during this life stage. Parents most often commented on their child receiving therapy during this time (39%), and other parents reported clubs and sports (15%), or no activities (13%).

The majority of parents reported having positive relationships and experiences with healthcare professionals (72%), which is an increase from the previous life stage of 4 to 6 (60%). Some of those individuals admitted to taking extra time to find more responsive healthcare

providers. Parents also reported negative experiences (10%) based on their healthcare provider's outdated knowledge and language. Most commonly, parents reported having to see healthcare professionals less during this stage, "Medically things have stabled out since the early years and we are on a quarterly basis, but we still encounter lots of outdated language and thinking about DS." Parents who reported negatively, also often discussed the discrimination they felt. One parent reported, "Our physician had a couple of instances where I can tell she has some stereotypes of kids with DS that are just not true. She had him evaluated for autism because he 'wasn't happy all the time like other DS kids.' He is not autistic."

#### **3.1.2.4 Life Stage Above 21**

Parents who had a child over the age of 21 expressed the strengths and challenges of becoming adults. Of the 8 responses from parents, 4 reported their child's ability to work (50%) as a strength, and 3 reported their child's socialness and friendliness (38%). Parents' results about the challenges were less cohesive, and they reported differing challenging characteristics. Parents commented that their child would "lack" a skill that was expected at this age, such as communication, ability to handle money, sense of time, and having interests. The other two parents commented that either their child was stubborn or "resistant to try new things."

When parents expressed their experience, they most often reported positive experiences (40%). One parent commented, "I love him so. He is happy and that's the important thing." Another parent commented, "We are just starting out, but I see a lot of growth with the immersion into the adult world of work and activities for those over 22." One parent reported neutral feelings. The two parents who had negative experiences expressed differing reasons. One exclaimed, "It is a challenge to keep up with all his activities as I have to provide transportation to and from each activity. We are still working on life skills to help him be more independent."

Another parent was concerned that their child seemed to be less interested and communicate less with others than he used to and said, “frustration in trying to understand just what is going on in his mind or self-contained world. To reach out to him to make sure he knows how much he is loved.” Parents’ experiences varied on their child’s participation in work, education, or with peers.

For the parents who had a partner during this life stage, three reported their partner had similar experiences to their own, positive (50%), and three reported their partner as supportive, especially in terms of daily needs or job training (50%). The majority of parents during this life stage reported not having any other children, and not living close to extended family members.

Parents also discussed their child’s work experiences with their boss and staff. Two parents reported that their child was currently in a vocational training program. One parent reported he does not participate regularly due to the child’s own accord, and the other participates in two different programs that both are of interest to him. Four parents reported their experiences with their bosses, one stating that “most bosses have been supportive, and have created encouraging work environments so far.” Two of the parents reported that their child has two different jobs. If their child participated in non-paid positions, they reported their experience has been positive.

Parents reported mixed experiences with peers during this life stage. Four parents reported that they had positive peer experiences, two parents further described the experience, exclaiming that their child had good relations with both individuals with and without disabilities. One stated that while he “interacted appropriately with people of all ages, with and without disabilities” that their son’s friends were all from the disability community. Two parents reported that they don’t have friends outside of their family members. One parent explained, “It was hard

at first as his peers went off to college and he didn't. Trying to find people his age to hang out with is hard. He has started doing things with his peers at work." Another parent stated that "as she got older, her typical friendships faded." Adulthood friendships and relationships change as they adjust to a new lifestyle.

### **3.1.2.5 Overall Parent Experiences**

#### ***Life Satisfaction***

Parents commented on their overall perception of their child's life satisfaction. Out of the 61 parents, 7% reported slightly satisfied, 31% reported moderately satisfied, and 62% reported extremely satisfied. Parents also reported their own life satisfaction. Out of the 61 parents, 3 reported less than slightly satisfied. Of these who reported, one individual chose "neither satisfied nor dissatisfied", another chose "slightly dissatisfied", and one chose "moderately dissatisfied". Of the 58 parents that reported satisfaction, 10% reported "slightly satisfied", 49% reported "moderately satisfied", and 36% reported "extremely satisfied."

**Table 4.** Overall Life Satisfaction

	<b>Extremely Satisfied</b> %	<b>Moderately Satisfied</b> %	<b>Slightly Satisfied</b> %	<b>Neither Satisfied or Dissatisfied</b> %	<b>Slightly Dissatisfied</b> %	<b>Moderately Dissatisfied</b> %	<b>Extremely Dissatisfied</b> %
<b>Life Stage 0 – 3 (n= 7)</b>							
Perceived Child’s Life Satisfaction	<b>86</b>	<b>14</b>	0	0	0	0	0
Parents Life Satisfaction	<b>57</b>	<b>29</b>	<b>14</b>	0	0	0	0
<b>Life Stage 4 – 6 (n = 6)</b>							
Perceived Child’s Life Satisfaction	<b>67</b>	<b>33</b>	0	0	0	0	0
Parents Life Satisfaction	<b>33</b>	<b>50</b>	0	0	<b>16</b>	0	0
<b>Life Stage 7 – 21 (n = 29)</b>							
Perceived Child’s Life Satisfaction	<b>52</b>	<b>41</b>	<b>7</b>	0	0	0	0
Parents Life Satisfaction	<b>33</b>	<b>55</b>	<b>17</b>	0	0	<b>3</b>	0
<b>Life Stage 21+ (n = 7)</b>							
Perceived Child’s Life Satisfaction	<b>43</b>	<b>29</b>	<b>29</b>	0	0	0	0
Parents Life Satisfaction	<b>57</b>	<b>42</b>	0	0	0	0	0

## *Rewarding and Challenging Life Stages*

**Table 5.** Life Stages Rewards and Challenges: Perceived for Child

	<b>Life Stage 0 - 3</b>	<b>Life Stage 4 - 6</b>	<b>Life Stage 7 - 21</b>	<b>Life Stage Above 21</b>
	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
<b>Life Stage 0 – 3</b>				
<b>Life Stage 4 – 6, n = 6</b>				
Most Rewarding	17	100	X	X
Most Challenging	100	0	X	X
<b>Life Stage 7 – 21, n = 29</b>				
Most Rewarding	21	31	66	X
Most Challenging	21	24	52	X
<b>Life Stage 21 Above 21, n = 7</b>				
Most Rewarding	0	29	29	71
Most Challenging	0	29	57	14

**Table 6.** Life Stages Rewards and Challenges: For the Parent

	<b>Life Stage 0 - 3</b>	<b>Life Stage 4 - 6</b>	<b>Life Stage 7 - 21</b>	<b>Life Stage Above 21</b>
	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
<b>Life Stage 0 – 3</b>				
<b>Life Stage 4 – 6, n = 5</b>				
Most Rewarding	40	60	X	X
Most Challenging	100	0	X	X
<b>Life Stage 7 – 21</b>				
Most Rewarding, n = 25	28	36	64	X
Most Challenging, n = 27	44	29	37	X
<b>Life Stage Above 21, n = 5</b>				
Most Rewarding, n = 5	0	40	60	20
Most Challenging, n = 7	14	14	57	43

### 3.1.3 Healthcare Professionals: Demographics

Demographics for parent respondents follow in Table 7.

**Table 7.** Healthcare Professionals Demographics

<b>Healthcare Professional Demographics</b>		<b>n</b>	<b>%</b>
<b>Age</b>			
	Min	25	
	Max	57	
	Mean	38.3	
<b>Gender</b>			
	Female	12	86%
	Male	2	14%
<b>Region of Practice</b>			
	Northeast	9	64%
	Mid-West	4	29%
	South	0	0%
	West	1	7%
<b>Environment</b>			
	Urban	3	21%
	Suburban	9	64%
	Rural	2	14%
	Other	0	0%
<b>Ethnicity</b>			
	African American	0	0%
	White	12	86%

	Asian	1	7%
	Other	1	7%
<b>Region of Clinical Degree</b>			
	Northeast	8	57%
	Mid-West	3	21%
	South	2	14%
	West	1	7%
<b>Area of Specialty</b>			
	Pediatrics	5	36%
	Therapy (OT,PT,SLP, EI)	5	36%
	Other	2	14%
<b>Duration of Practice</b>			
	< 1 year	1	7%
	1 - 5 years	4	29%
	6 - 10 years	2	14%
	10 - 15 years	2	14%
	>20 years	5	36%
<b>Number of Patients</b>			
	1	0	0%
	2 to 4	1	7%
	5 to 10	2	14%
	11 to 20	4	29%
	21 to 50	6	43%
	> 50	1	7%
<b>Age of Patients with Down Syndrome</b>			
	0 to 3	12	86%
	4 to 6	12	86%
	7 to 21	12	86%
	> 21	1	7%
<b>How often do you see your patients with Down syndrome?</b>			
	Every day	0	0%

	2 to 3 times a week	5	36%
	Once a week	8	57%
	Every other week	1	7%
	Once a month or longer	0	0%
<b>Session duration when compared to other patients</b>			
	Same	10	71%
	Longer	3	21%
	Shorter	0	0%
<b>Most common conditions treated</b>			
	Heart defects	6	43%
	Vision	6	43%
	Deafness	4	29%
	Infections	1	7%
	Hypothyroidism	1	7%
	Blood disorder	1	7%
	Hypotonia	11	79%
	Spine condition	3	21%
	Disrupted Sleep	4	29%
	Dental Disease	1	7%
	Epilepsy	1	7%
	Digestive Disorder or celiac disease	3	21%
	Mental Health	2	14%
	Emotional or behavioral problems	7	50%
	Other	5	36%
<b>Healthcare Setting</b>			
	Outpatient	7	50%
	School-based	5	36%
	Home	2	14%
	Other	2	14%

### 3.1.4 Healthcare Professionals: Responses

Healthcare professionals reported details on their interactions with the patients and caregivers on a professional basis. Of the 14 responses, the range in which it took to complete surveys was 3 minutes, 24 seconds to 23 minutes, 29 seconds. The average time it took to complete the survey was 9 minutes and 31 seconds. Excluding the largest outlier, the average time for survey completing was reduced to 8 minutes, 27 seconds.

Healthcare professionals reported who they most often talk to when they meet their patients with Down syndrome. One provider spoke to the patient most often (7%), 4 responded they spoke to the caregiver the most often (29%), 8 responded they spoke to both equally (57%), and 1 responded other (7%). When that provider expanded upon other they reported, “Depends on the cognitive status of the patient. Generally, the patient first, then caregiver as needed.” Healthcare professionals reported they most often speak to the mother (100%), with a few who noted that they also speak to the fathers (21%), grandparents (7%), and hired caretakers (7%).

Healthcare professionals were asked how they communicate with their patients with Down syndrome. Healthcare professionals chose English ten times (71%), American Sign Language was chosen three times (21%), and Assistive technology such as picture boards and Augmentative Alternative Communication (ACC) devices was chosen 3 times (21%). Parents regard speech as one of the most prevalent, lifelong challenges of their child, so the ability to incorporate various language devices can make the session more comfortable and successful for patients and parents.

Healthcare professionals also responded on accommodations they make for their patients with Down syndrome. Of the 14 survey responses, 3 reported “none” (21%), and 7 responded with the various accommodations they have made (64%). Of the 7 that made accommodations, 3

reported they only make accommodations when there is an individual need of their patients. The other 4 reported “behavior modifications,” “visual schedules, lots of verbal cuing, frequent praising,” “increased time for travel, modifications to PE,” and “increased time and effort for task completion.”

Healthcare professionals reported how often they refer their patients with Down syndrome to other professionals. Referrals can reduce the time that parents put into researching needed services and opportunities. The majority of healthcare professionals responded “definitely yes” (64%), others reported “probably yes” (29%), and “probably not” (7%). When asked to expand on what type of local services they referred their patients to, we received a variety of responses, such as Down syndrome organizations, Special Olympics programs, educational institutions or staff, or services such as “adaptive dance class” and “parent support groups.” Healthcare professionals discussed other health services that they referred their patients to, such as therapy services, specialists, and nutrition. Therapy was reported by 65% of our healthcare providers, and this may have been the result of the majority of our participants being in the field of pediatrics.

Healthcare professionals discussed how they advocated for their patients with Down syndrome, with no mutual consensus. Twelve of the fourteen participants’ answers were related to their practice and community. Participants answered, “giving them a voice,” “school opportunities,” and “by providing them with the skills to be successful.” Of the responses that related to independence and adaptations, healthcare professionals reported, “Needed adaptation in school and home,” “Assist with their independence and get support where needed,” “big supporter of the R-word initiative, promoting self-advocacy, promoting independence,” and “Encouraging adaptive recreation activities in the community.” Other healthcare professionals

responded about helping the child obtain additional services, such as “advocate with parents for communication needs,” “Ensuring therapy coverage and getting physiatrist referrals when ready,” and “I helped to make sure that they receive the services that they need when they transition out of early intervention. And I keep an eye out for other services if they need as they develop in the zero to three program.” Healthcare professionals also discussed their connection to the community, “Locally, regionally, and nationally lead organizations that participate in advocacy for people with Down syndrome,” and “testify before the state legislature, write to my US senators and representative.” Healthcare professionals demonstrated the interpretation of advocacy and the wide-variety of options available, even in a small sample size.

Healthcare professionals also reported when they received educational services directly about Down syndrome. Of the fourteen professionals, twelve reported that it occurred in a broader educational service (86%), one reported that it was an independent course about Down syndrome (7%), and one reported “other” (7%). The majority of healthcare professionals responded that the most recent educational service was in the past five years (93%), and only one participant reported that it has been over five years (7%). Of the participants who reported the educational service occurred less than five years ago, 69% reported it occurred within the last two years, and 38% reported it occurred within the last year.

Healthcare professionals were asked how knowledgeable they felt about the Down syndrome community. No healthcare professionals reported that they were “not knowledgeable at all” (0%), six reported they felt “slightly knowledgeable” (43%), four reported they feel moderately knowledgeable (29%), three felt very knowledgeable (21%), and one felt “extremely knowledgeable” (7%). They were also asked how knowledgeable they felt about the family dynamics when there is a patient with Down syndrome. Again, no healthcare professionals

responded “not knowledgeable at all.” The responses were similar to the community responses, five felt “slightly knowledgeable” (36%), five felt “moderately knowledgeable” (36%), three felt “very knowledgeable” (21%), and one felt “extremely knowledgeable” (7%). Healthcare professionals were asked to report how knowledgeable they feel about a patient with Down syndrome’s holistic needs. In these responses there was a greater increase in moderately knowledgeable, alluding to a possible greater understanding of the needs of the patient rather than the family and disability community components. Again, no healthcare provider responded “not knowledgeable at all”. One provider responded “slightly knowledgeable,” nine responded “moderately knowledgeable,” three responded “very knowledgeable,” and one responded “extremely knowledgeable.”

Healthcare professionals were also asked to report what they believe to be the comfort level of their patient with Down syndrome. They reported that the patient felt “neither uncomfortable nor comfortable” (21%), “moderately comfortable” (43%), and “extremely comfortable” (36%). Healthcare professionals were asked to report their own comfort level when providing treatment to a patient with Down syndrome. Of the fourteen professionals, thirteen responded they felt a variation of comfortable (93%). Of those thirteen professionals 2 responded with “slightly comfortable” (15%), four felt moderately comfortable (31%), and seven felt “extremely comfortable” (54%). The one provider who did not feel comfortable reported they felt “extremely uncomfortable” (7%).

Healthcare professionals were asked about the possibility of eliminating Down syndrome with genetic testing and modern day medicine. Of the fourteen healthcare professionals, three responded “definitely not,” (21%) five responded “probably not,” (36%) and 6 responded “probably yes,” (43%) and no one responded “definitely yes” (0%). When further asked whether

they believed we should promote the possibility of eliminating Down syndrome, one healthcare professional responded yes (7%), eight responded no (57%), three did not report an answer (21%), and 2 responded with “other” answers (14%). The individual who reported yes explained, “While parents love their children unconditionally there are so many challenges that come along with having a child with Down syndrome.” Of the professionals who responded “no”, two of the individuals alluded to positive characteristics. The other six expressed opinions of ethics. One individual said, “To say we eliminated a population seems unethical. Providing patients and families with resources for is a much better option than doing genetic modifications, tests, etc.” Another provider said, “Why should the life of a person with Down syndrome be any less valuable than mine?” For the two individuals who responded “other,” one reported “Not sure how you can eliminate a chromosomal defect,” questioning the probability, while the other had a mixed response, “I think it would be great if there was a way to prevent a genetic malformation to plow each individual the best possible scenario in life however people with DS can be productive individuals in society and they are really loving too.”

## **3.2 INTERVIEWS**

### **3.2.1 Parent Interviews Demographics**

Demographics for parent respondents follow in Table 8.

**Table 8.** Parent Interview Demographics

	State	Location	Age of child	Adopted or Biological	Siblings	Mother or Father	With Adopted or Biological Partner?
<b>Interview 1</b>	Missouri	Suburban	2	Adopted	3	Mother	Yes
<b>Interview 2</b>	North Carolina	Suburban	2	Biological	1	Mother	Yes
<b>Interview 3</b>	Michigan	Rural	2.5	Biological	4	Mother	Yes
<b>Interview 4</b>	Florida	Urban	2.75	Biological	1	Mother	Yes
<b>Interview 5</b>	Virginia	Suburban	11	Biological	1	Mother	Yes
<b>Interview 6</b>	California	Suburban	2	Biological	2	Mother	Yes
<b>Interview 7</b>	New York	Suburban	10	Biological	1	Father	No
<b>Interview 8</b>	North Carolina	Suburban	14	Biological	1	Mother	Yes
<b>Interview 9</b>	Pennsylvania	Suburban	12	Biological	3	Mother	Yes
<b>Interview 10</b>	Montana	Rural	4	Biological	6	Mother	Yes
<b>Interview 11</b>	North Carolina	Suburban	5	Biological	3	Mother	Yes
<b>Interview 12</b>	Pennsylvania	Urban	6	Biological	1	Mother	Yes
<b>Interview 13</b>	Wyoming	Rural	2	Biological	3	Mother	Yes
<b>Interview 14</b>	Wisconsin	Suburban	5	Biological	1	Mother	Yes
<b>Interview 15</b>	Alabama	Suburban	18	Biological	1	Mother	Yes
<b>Interview 16</b>	Virginia	Urban	21	Biological	0	Mother	No

### 3.2.2 Themes

Five themes emerged from the interviews with parents who had children with Down syndrome: medical experience, expectations, individuality, connectivity, autonomy. The medical experience encompasses the child’s physical health, as well as the experience with the healthcare professionals in regards to the child’s health. Expectations were the standards and goals in which parents, healthcare professionals, and educators believed the child was capable of achieving. Individuality was the parents experience in regard to the child’s identity. Connectivity was the ability to create deeper connections with others through experiencing challenges and rewards. Autonomy was the parents' rights and responsibilities of their child and having a level of control over a situation.

### 3.2.2.1 Medical Experience

Across a child with Down syndrome's life span, the diagnosis is the first part of the journey in the parent's medical experience. Some parents received a prenatal diagnosis, and they went through a grieving process, and were able to move toward acceptance. Parents reported using that time to do extra research, look for resources, and prepare mentally. One parent reported, "If we're going to have this baby then let's get excited about it!" Another parent reported, "I think we cried for a week straight both of us and we kind of came to terms with it because we would never get rid of our baby and now were like what the hell were we so dang upset about?" It is interesting to compare these anecdotal experience with the literature reports of 67% to 85% (Natoli, Ackerman, McDermott & Edwards, 2012) who receive a prenatal diagnosis will terminate the pregnancy. The individuals in these interviews stated they would not consider an abortion, regardless of the circumstances.

In the interviews, parents who had a postnatal diagnosis also often grieved at first, then regretted doing so because they missed out on time to enjoy the child's early life. One mother reflected on her experience and said, "I would tell my, you know, newly brooding mother of a child with a disability not to cry. That it was going to be okay. So there was a lot more joy out there than I would have imagined for both of us, for her and for me." Another parent stated, "I did not enjoy her when she was first born because I was grieving over the diagnosis itself, so I'd wish to get that out of the way first, so I could enjoy her at an early age more." The diagnosis was a marker in their child's life parents often brought up on their own accord, recognizing it as a period of grief followed by acceptance.

Parents felt that the diagnosis "really sets the tone." None of the parents in the interview had a child with Down syndrome before, and some had never met someone with Down

syndrome. Many felt they did not know what this diagnosis entailed, and relied on the health care provider to relay the information to them, these individuals had great influence how parents perceive their child from birth. One parent reported on her experience with healthcare providers informing her about the diagnosis, “telling us your child’s never going to talk, they’re never going to walk, they’re never going to live independently, thank goodness we had a NICU nurse who actually had a child with Down syndrome herself and said oh no ignore all that.” Another participant expressed how a midwife told her that she knows of patients with individuals with Down syndrome, and they all love their child, to which she said, “I was really afraid I wouldn’t. I was afraid we would be like outcasts or something. I don’t know what I thought, it all sounds stupid now.” Parents wanted a diagnosis based on experience and positivity. Instead of “whispering in my room” parents wanted a “Congratulations!” and other positive expressions after the delivery. Parents want to know that “it will be okay.” The combination of not knowing what is ahead and the negative responses from healthcare professionals at the birth, pushed grief into a negative experience. Parents would advise healthcare professionals during the diagnosis to be more positive, and give well-rounded information. One parent exclaimed, “To give a fuller picture of what it looks like to have a child with Down syndrome.”

Parents all received early intervention therapies for their child. Parents expressed how they could tell when the therapist love their job versus an individual who “just shows up to their job.” When speaking about her occupational therapist, speech therapist, and physical therapist, one parent said, “the other two aren’t quite, I guess, go-get-em, she is, so we don’t feel like we always get what we wish we could get out of the other two.” Parents also reported that they had difficulty coordinating all of the therapies. Some parents had therapists visiting constantly and felt overwhelmed. Parents reported that they did not want to have therapists and doctors

constantly. Their child needs to be around other children, and less adults, so they can have normal childhood experiences. One parent expressed, “Make sure you do the ordinary in spite of all the therapies and the medical concerns and everything else you may have.”

Many parents reported medical and health difficulties from the birth through the young childhood years. Most felt that these critically ill experiences at the home or the hospital were the scariest situations. Most of the parents’ children in the interviews went to the NICU proceeding their birth and these children experienced continual health problems for the first year or two. One parent commented that it was “a 24-hour job” and another parent reported, “It’s a lot of pressure. It’s stressful to know you’re wholly responsible for all these little warning signs.” Parents commented on the seriousness of the medical issues would stop after two or three years, and they felt they were able to live a less hospital-oriented life as their child became older.

Parents want their healthcare providers not to rush them or make them feel like ‘the next person that’s coming into the office.’ and to “show that you care.” Especially when the children are at a young age, many parents took their child to see specialists, doctors, and therapists. They want them to be empathetic, show compassion, and be patient. A parent of an adult child with Down syndrome reported that her daughter expressed the desire for her provider to look her in the eye, as opposed to talking only to her caregiver. Another parent reported “I’ve noticed more healthcare providers when they are with [my son], the eye contact they make and they treat him like an individual.” Parents want their healthcare professional to interact with their child, to treat her or him as a person.

Parents most often expressed they wanted their healthcare providers to view their child as an individual. To see their personality, strengths, and weaknesses, before they see the Down syndrome. One parent reported how she changed her therapists because they did a “kind of

checklist” and “I feel like the people working with him now know him better as an individual.” They want their health care provider to have “high expectations” and to “suspend their assumptions.”

### **3.2.2.2 Expectations**

Expectations of the child with Down syndrome was highly reflected in parents and society. After the diagnosis parents expressed that “you’re grieving your expectations.” One parent explained, “Your kid, you’re going to figure out, is not going to live up to your high expectations that you have, because they’re people, so I’m experiencing what all parents will, just a little earlier.” Parents expressed creating new goals and expectations for their child. They discussed re-evaluating what success means, and to live in the present. Their future goals and expectations for their child remained the same as what most parents want for their children without a disability, “I just want him to do what he wants to do and be more independent. To be who he is. I don’t want society or even himself to hold him back.” They expressed hope that their child will receive an education, have a job, live independently, and find love. Parents also expressed that they wanted their child to be happy in whatever s/he wants to do. Parents of older children expressed their desire for their child to be included in society and in a supportive community.

Parents want their child to be happy and enjoy their loving attitude, but many stressed the importance of having their child function in society. One parent said, “Everybody said ‘Oh people with Down syndrome are so comforting and loving.’ That didn’t comfort me at all. That wasn’t enough for me. I wanted somebody who was functional in society and a good part of family. And that’s absolutely going to be the case” Another parent expressed, “My daughter is going to be a productive member of society, she will not burden the society.” Parents defined

functional success in different ways, but their main concern was their child's ability to participate in societal functions and roles.

Parents living in a rural area had expressed in greater detail the lack of expectation and inclusion for their child. They aspired for their child to achieve the same expectations as other children with Down syndrome, or any children, from suburban and urban areas. However, there was a lack of resources and understanding. Parents often had an easier time enrolling them in an inclusive school, because there were not many other options, but found the teachers lacked knowledge. One parent expressed when she wanted to learn more about Down syndrome, her library had "one or two books about what Down syndrome was and they were so outdated, and they made me really sad." Parents commented on the lack of organizations outside of the education system for their child. They believed that they needed services to help their child develop and did not want to miss on critical years of development due to the lack of options available.

Parents' advice to other parents regarding expectations were to just enjoy your child, relax, and it will be okay. They recommended to take it one day at a time, instead of always worrying about the future. Parents should not treat their child like "a special project" and to remember their life "does not have to revolve around Down syndrome." Parents expressed that they wanted their partners, families, and society to see their child as an individual first before their diagnosis. One parent expressed, "He's just like any other kid, we don't look at him any differently, and we don't treat him any differently." Another parent expressed, "I didn't understand why we needed to do anything differently with a Down syndrome girl than what we would do for anyone else." Parents advised other parents to expect their child to have their own

individuality, and that parent's experience may differ from other parents who have a child with Down syndrome.

### **3.2.2.3 Individuality**

During the interviews, parents expressed their individuality through their favorite activities. Activities were varied, with the exception of "reading books" and "playing outside." The other individuals reported swimming, listening to music and going to restaurants, playing soccer, horseback riding, theater, playing sports, playing puzzles or games, music, riding his toy car, dancing, and cooking. The diversity among these answers demonstrates that at a young and older age, individuals with Down syndrome have a wide variety of interests.

Parents believed if children with Down syndrome were included more often in society, making inclusion was an expectation, people would see them as individuals. Having individuals with Down syndrome included in education, work, and entertainment, would allow others to see Down syndrome as normal. One parent commented, "It's just a part of humanity and it's not a grave tragedy. I guess that's what I want to happen in the culture." Parents want this acceptance of Down syndrome so others see their child as "a human" or someone who "has real feelings." Parents felt their inclusion will allow others to see them as equal, and without this inclusion others will not know what to expect. One parent commented, "Sometimes people won't be able to look at him because they don't know how to react, or they don't want to act like they're being rude by looking or whatever. The not knowing for people is the scariest and once you know and you've been around him and you know that it's okay"

When parents who were asked if they could change anything about their child's life, 3 of the 16 interview participants reported they wish they could take the Down syndrome out of the child, but keep the child. When they expanded on this, they described their love of the child, but

the social factors that have impeded on their lives. One parent explained the difficulties she had with the healthcare system and the stress of advocating and keeping up with research. Another parent believed it would make the child's life easier. He said, "I'm not at school so I worry about kids bullying her, picking on her, and not assimilating her in groups. And then her speech difficulties are because of Down syndrome so she'd be able to speak better and advocated for herself better if she could speak better." He wanted her to receive more speech services, but has been having difficulties connecting with available therapists. The third parent expressed, "She has a lot of challenges to overcome, her tone issues, the social issues she might have to experience. All kinds of things, so if I could change them I know I would." Individuals wanted to keep their child, but felt Down syndrome may exclude them in society and present unnecessary issues to them.

A majority of the parents interviewed, 13, did not want to change the presence of Down syndrome, but wished for a change in a range of personal and social experiences. They wanted to change their own reaction to the diagnosis, certain parts of their school experience, more social opportunities, earlier participation in Down syndrome organizations, more services for their child, and one parent wished her daughter had a sibling. A parent exclaimed, "The hard part has been dealing with society." Another parent reported, "Don't focus on my son's disability, it is only a part of him."

The parents who expressed they would not change anything exclaimed that the child has had positive experiences with family, healthcare providers, programs, and schools, whether or not this was easy to achieve initially. They felt the child has been happy and succeeding in their goals, and their parental labor has paid off. One parent explained, "I think we've done the best

we can, each step of the way, and I think on the whole things have worked out pretty well and he's an awesome kid.”

#### **3.2.2.4 Connectivity**

Parents wanted their child to be included in society, but also wanted them to connect with others. Connectivity became prevalent in all relationships with family and professionals. Parents discussed the ability of their child to connect with others. Generally, parents who enrolled their child into an inclusive education setting, seemed to show greater academic success. However, reported increased struggles with making close, social connections. Children with Down syndrome would attend the events or clubs the school hosted, but often alone, or they lacked playdates or casual get-togethers. Their overall socialness typically remained the same for that child. One parent reported she had a “strong social game” and “she looks out for people, she’s helping people. She’ll try to include people.”

The socialness for their child seemed to change over the lifespan, and it upset many parents. As children became older, parents believed they had less causal relationships that the individual would initiate on one’s own. But if the child was involved in Down syndrome organizations or activities with other children with disabilities, they more often made those social connections.

Parents also commented on their child’s connection to her/his siblings. None of the parents expressed a negative relationship between the siblings, even if they were far apart in age. While some relationships were closer than others, many felt it encouraged the siblings to “not fear children with disabilities.” One parent said, “[they] enrich each other like any other sibling. Maybe even more so because my big girl had to grow up so much and learn to be patient.”

Their child's connections were valuable to the parent, but they also commented on their own connections. Parents felt the ability to reach out to other parents who had children with Down syndrome was a valuable resource for themselves and their children. Parents felt they could relate to and learn from the experiences of other parents. They expressed how learning from parents who had older children helped guide the way for them. In the beginning it was seen as relief, one parent explained that the hospital "hooked us up right away with a lady that lead a Down syndrome program up there and she came up to the hospital and made us feel 150,000 percent better, it was just what we needed." It was an opportunity for parents to hear advice from parents from similar situations who could understand what they were going through. Parents who were not part of an organization wished they could participate much sooner. However, some were unable to because of the hospital visits in the first two years of their child's life.

Parents felt they and their children have made friendships through Down syndrome organizations. One parent exclaimed, "All the moms hang out, we've all gone to the beach together, just the moms, and we do stuff with the kids and they go to each other's birthday parties and they've all grown up together. So she has a really nice social network there." There is a level of social support and trust that the child is in safe hands and they will always have a group of friends they can lean on when it comes to care or friendships. They felt the organizations have given them a new opportunity. A parent reported, "You go outside of your box and get involved with organizations and people that you never would normally."

Parents also discussed their partner's level of support. Parents who had similar ideas on how to raise the child tended to express greater closeness and satisfaction. One parent said, "I think my partner and I had pretty similar experiences. We're pretty much on the same page when it comes to most things, and I think we have a pretty similar perception." Another parent who

experienced more difficulties in her relationship exclaimed, “I don’t think our parenting styles are the same, I think that is confusing to her.” Raising a child with Down syndrome presents many choices of specialty services and inclusion that parents with children without disabilities do not have to navigate. So the having similar ideas of what that path should look like for that child can become a conflict within the marriage.

Parents also expressed how creating connections with their child began with milestone development. It was a challenging and rewarding time for parents who put a lot of time, effort, and services into their child’s achievement. Parents knew these were going to be delayed so they felt that “you have to appreciate it, every little thing.” Parents explained the dedication they put into these moments, “we have to really [be] so hands-on and show them on your hands and knees, we have crawled with him, we had literally had to show him how to do things more.” Parents most often mentioned walking and talking as exciting milestones. Mothers exclaimed the most rewarding experience was when their child first called her momma. Speech has been a difficult for many children in the interviews, so many parents often utilized American Sign Language for their children.

As children became older they concentrated on the social and behavioral milestones they wanted their child to accomplish. One parent said, “Just watching her be a typical kid at a dance, having a good time, no Hercules effort, no coordinating, no chaperone, just sending her to the community knowing she’s safe and happy, and coming back.” Parents also comment that their child’s changes in behavior as they grew older became important to them, “her transitions are much faster, for instance a couple weeks ago the cab came a little earlier when she was eating breakfast, she got up, grabbed her book bag and walked out the door. And our jaws dropped to the floor, like a couple years ago it would have been like world war 3.” Two parents had children

who were eighteen and twenty-one and they expressed their children's ability to be included in educational and career experiences. These markers of adulthood are societal milestones reached in the next transition.

### **3.2.2.5 Autonomy**

Autonomy became a prevalent theme as there was often an imbalance in the roles and responsibilities of parents and other individuals in their child's life. Parents felt to provide their child with the appropriate services, they had to constantly fight, advocate and research, but felt they were losing their autonomy as the parent simultaneously.

Parents often had to advocate for their child to get necessary healthcare services. They feel they are constantly battling with the "system" to help their child be healthy. One parent reported, "What has been hard and what has been frustrating about the journey has been the medical care and having to fight for him to even be given a chance and I find that out outrageous that he is discounted and categorized by his looks and by his diagnoses."

The recognition of dual diagnosis has been difficult for many parents who notice other symptoms in their child, but feel they are not being addressed. One parent explains, "I hate the phrase 'That is normal for Down syndrome' because it allows you to ignore a lot of stuff that is treatable." Another parent expanded on the difficulty for her, "Dealing with medical symptoms that you run into a provider that just talks it up to Down syndrome and doesn't take the time to realize that he also has asthma and so then you end up in these situations where people keep saying, oh it's just trisomy. No other kids with trisomy don't stop breathing when they're 4, so that's the frustration." To counteract this, parents often research and show healthcare professionals current research to bring their point across. One parent said, "I think the most challenging moment I have are when I take him to get medical care and I'm having to educate

the doctors on the issues, options available, and that he deserves treatment, that part is really frustrating, but I want them to know more about Down Syndrome and talk about Down Syndrome.”

Or they will find someone who will listen to their concerns and research, and give them a more in-depth reason as to why they should or not proceed with certain testing or treatments. Many parents in the interviews talked about dual diagnoses that their child had, and how it is a constantly undermined problem that causes them frustration.

Parents express concerns for others who may not understand how to advocate or who do not understand different healthcare and education procedures, “Some of the processes are not made to be easy. And I can imagine someone with less education and less contact in bureaucracy would give up quite easily and would not get them things that their child should be able to get.” Other parents felt they have personally improved in these areas as they been raising their child, and try to disseminate this information for others to share, “We’re always finding ways to spread knowledge and support and communicate so I mean that is challenging, but it’s also very rewarding.”

Parents spend a lot of their time researching, networking, and advocating for their child, but often feel that healthcare professionals and teachers treat them subordinately. Parents feel they should be seen as the experts on their child, but feel the healthcare providers and educators believe otherwise. One parent reports, “they tell you your child is better off with therapists and teachers all day long than with you, their mother, and I disagree, I think you really have to be careful, maintain your family values, because you have all these people coming in telling you what you need to do and how you should do it. And you don’t have to.” Another parent reports similar problems during an opposing view with a school therapist, and the teachers took her side,

because she was the “expert” in that situation. Creating a defined sense of role in the child’s life was important to parents who felt their role was easily lost. One parent reported, “It’s like you’re confused and it’s great to take everybody’s opinion in, but ultimately be brave and think about what’s best for your own child.”

Parents who feel their healthcare providers have been positive, report that the best advice they received encourages their own autonomy and choices to decide how they should raise their child. A parent explains, “There’s more than one way to raise a child with Down syndrome.” “Once you get the diagnoses there are a lot of advices on how you should feel and what your path should be like and I just try to encourage them to enjoy their babies and own their own experience. So it might look like other peoples that [they] meet that have children with Down syndrome, and it might not be.” A parent who felt overwhelmed during the diagnosis, felt she received the best advice from a doctor who told her, “‘you take him home, and you love him, and you treat him and raise him like you do all your other kids.’ And like okay I can do, I can do that, that’s easy!”

## 4.0 DISCUSSION

The transitions of children with Down syndrome from birth to adulthood shift their parents' perceived strengths and challenges regarding their child, family, and society. When parents start their journey with the diagnosis, they often feel unprepared to raise a child with Down syndrome. Healthcare professionals are typically the first individuals who discuss raising a child with Down syndrome with parents and this can shape their opinions of their child. Many of the parents in our interviews reported grieving after the diagnosis, due to their altered expectations. If healthcare professionals use optimistic language, and connect them with other individuals who have children with Down syndrome, parents feel more comforted and grieve less. Healthcare professionals can take the first three years of life as an opportunity to help build confidence in the parent. Providers need to be aware of the power they have during this vulnerable time for parents.

In our surveys and interviews, parents often reported the most stress during the life stage of 0 to 3 due to the overwhelming diagnosis, health services, and searching for answers and resources. These social factors added stress to the pressure they felt to help their child achieve foundational milestones, such as walking, talking, and feeding. As the child entered the 4 to 6-year life stage, parents found their children were improving in these milestones, and worried more about their adjustment to the education system. They wanted their child to succeed in both life skills and academics. This desire continued as their child entered the 7 to 21-year life stage,

however, there was greater worry whether their child was creating social connections and friendships. When their child became over 21, parents again worried most about their inclusion in society and relationships they were creating. Throughout the lifespan parents reported their most challenging characteristic to be speech ability, and the most rewarding characteristics of their child was their positive personality, ability to socialize with others, and their increasing ability in communication, as some children overcame this barrier. They felt their child was a positive influence in their community, and desired for their community to feel the same way. It is reflected in their desire for their child to connect on a deeper level with others. By stopping the social stigma on individuals with disabilities, they will have more opportunities to create these relationships. The stigma is hidden, however, we see it as parents talk about their need to constantly research, advocate, and fight for their child to get the services they need.

Managing their child's growth with parent's own needs and desires became a balancing act. This appears to be especially important in the beginning of the child's life when parents felt overwhelmed with the new "system" that their other children did not need. Their children typically had medical difficulties and developmental delays for the first two years of life. They had to learn how to manage the rotating therapists, follow-up appointments with doctors, and the finances, while still maintaining a normal child-parent experience. As children entered the 4 to 6 age life stage, there was a more routine schedule with school, and typically less therapy and doctor visits. Parents enjoyed this transition and felt their child's life had become more normalized. Healthcare professionals should consult with parents to decide on a schedule that can help relieve some of the parents' stress. Prescribing the correct number of appointments for the child and for the parent to ensure neither is overwhelmed. One option is to decrease medical and healthcare appointments, and increase the social support programs. In the stressful life stage

of 0 to 3, parents seek extra connections and support. Having more programs available that allows parents to socialize or re-strengthen their relationships, will enhance their well-being. Especially for parents who may not have supportive extended family nearby, non-expensive or free respite care can give them the time they need.

In addition to time management, education and referrals can also ease some of the burden that parents feel. Parents often feel they need to navigate the healthcare, financial, and social support system alone. There is no universal “system” across the United States, so it is difficult for a parent to find one resource that explains all the steps they should take. Healthcare professionals should work with local Down syndrome organizations to create a guide for parents in the local area that informs them about the health, financial, educational, and social resources available for parents of children with Down syndrome throughout the lifespan.

There is a disconnect between the parent, healthcare provider, and educational professional on what each other’s role is in helping to raise a child with Down syndrome. In our interviews, parent’s felt they were losing autonomy and reported that healthcare providers and educators need to do a better job of consulting with them on the goals and future steps taken for their child. When parents noticed symptoms or behaviors in their child, they felt they were often disregarded and told “that’s Down syndrome.” Parents found this discriminatory, and want their concerns to be taken seriously. As their child becomes older, the professionals should equally include the child in the conversation.

This controversy in the parent’s view versus the professionals’ views often came down to the latest research and individuality of the child. In our interviews parents often felt they were educating the professionals about the latest research. In our survey, most of the healthcare professionals who work with children with Down syndrome did not report they felt extremely or

very knowledgeable when it came to their understanding of the Down syndrome community and family dynamics of raising a child with Down syndrome. If healthcare professionals learn the latest research then educate the parents, parents will have more time and feel less stressed. Healthcare providers will consequently feel more comfortable and knowledgeable. Disability and Down syndrome classes can be led by the workplace to ensure all employees are providing equal care and education.

Parents also adamantly discussed the possibility of elimination of Down syndrome due to genetic testing, and many cited Julian Quinones' CBS report about Iceland's nearly 100% abortion rate of Down syndrome. However, in the healthcare professional surveys, the participants were unsure whether elimination of Down syndrome was possible, creating a real disconnect between what parents and healthcare providers see as a potential problem in the future. However, both parents and healthcare professionals believed that the elimination of a disability would be unethical or unwanted. Educating healthcare professionals and educators about the most recent research can help avoid conflict and lower the stress levels of parents and influence the tone of discussions they have.

Parents felt the discrimination their child received was due to a lack of understanding and only seeing the child as Down syndrome. Parents themselves did not know what to expect when their child was born, and searched for information from research, organizations, and people. They felt they did not really know what Down syndrome was, because they never learned about it, and the unknown is scary. If disabilities studies are included in the general curriculum for young students, they will not have to face these challenges in the future when they become parents or healthcare professionals. Disabilities impacts everyone directly or indirectly. The United States Census reports that the one in five individuals has a disability. Educating children

about disabilities, including Down syndrome, can promote less social stigma and greater advocacy in the future. Parents also positively responded to the increase of Down syndrome awareness in social media on YouTube and on the television. They felt it was a positive resource for parents to understand more about the parent's experience of raising a child with Down syndrome and the quality of life that child has.

Learning about Down syndrome will help increase acceptance and reduce stigma about the disability. Parents want society to see their child first before the diagnosis and feel their inclusion in education and the community can help. Individual parents are with their child almost every day and see their personality and identity, but others who have only met a few individuals with Down syndrome may assume that is what all people with Down syndrome are like. This can occur when healthcare providers ignore parent's concerns about a dual diagnosis, or an educator writes a generic IEP. In our interviews and surveys, this caused parents' frustration and to believe that "society is the problem."

While parents want others to see their child as an individual, they also want Down syndrome to be recognized. They do not want their child to be discriminated against, but there are unique challenges to raising a child with Down syndrome that could easily be disregarded with people become "blind" to the disability. Parents may be prevented from getting the services they deserve, or having those services covered.

Parents who have children with Down syndrome have found greater satisfaction in finding supports from other parents who have children with Down syndrome or in Down syndrome organizations. This became a source of connection for parents to relate to someone who has shared experiences. Parents often reported having positive experiences learning from parents who had older children with Down syndrome, as well as, teaching parents who had

younger children than Down syndrome than they did. Parents also found the organizations to be the most updated about current events and research related to Down syndrome. The local healthcare and education systems should take advantage of this resource, and other disabilities organizations, to stay current with their practice.

Parents reported their child's life satisfaction to be slightly more satisfying than their own, but almost all parents reported their child's life and their own to be satisfying. Parents worried about their child's quality of life and almost all parents perceived them to have a moderate to extremely satisfying life overall. This varied with the parent's view of their own quality of life, which appeared to be lower. From our surveys and interviews we gather that the factors lie in the struggles outside of their child. Gathering social support from new and different sources, and maintaining the social supports with their partners and families who may not have the same perception on how to raise the child. There may or may not be professional supports available, and the process of acquiring them and financially securing them can be a stressful experience. Most importantly, being able to find a therapist, healthcare provider, or teacher that is compassionate, knowledgeable, but not authoritative is imperative.

#### **4.1 STUDY LIMITATIONS**

Selection bias may have occurred across the different populations of participants who chose and were able to participate in this study. The study had a relatively even distribution of participants across the different regions, however it lacked an even distribution in living environments: urban, suburban, rural. The ethnicity and gender diversity among the participants was also greatly weighed with white, female participants. Participants were limited to individuals who had

access to and the ability to use computers and phones. This may be a reason why there was a limited number of parents of older children with Down syndrome who participated in the surveys, due to the older ages of this population. Participants were also limited to English speakers due to the lack of translation of survey material or interview interpreters. Response bias may have occurred when discussing sensitive topics, especially during interviews when interview bias may have contributed to this. Bias may have also occurred in the interpretation of the qualitative data in the surveys and interviews. The stance of the researcher as an advocate for children with disabilities and as a future pediatric occupational therapist, may have created a subconscious bias to recognize data that pointed towards a certain conclusion.

## **4.2 FUTURE AREAS OF RESEARCH**

As individuals with Down syndrome are living longer, there needs to be more data reported on quality of life of adults who are living with Down syndrome, as well as their parent's quality of life in the United States. The current available research is limited, and the participation of parents with adult children is limited in our own research. Finding ways to connect with these adults in person, instead of online, may make future research in the older generation of this population more successful.

A topic that came up indirectly during interviews was the parent's decision and delivery of how they told their own child about their diagnosis. Analyzing the opinions of individuals with Down syndrome and their parents on the most appropriate procedures to discuss this topic, can help parents in the future navigate delivering a diagnosis to their own child.

## APPENDIX

**Table 9.** Qualtrics Parents Survey Demographic Questions

<b>Question</b>	<b>Optional Answers</b>
What is your year of birth?	Open-ended answer
What is your month of birth?	January, February, March, April, May, June, July, August, September, October, November, December
Were you born in the United States?	Yes, No
What is the state in which you reside?	Open-ended answer
What environment do you live in?	Urban, Suburban, Rural, Other
What gender do you identify as?	Male, Female, Other
What Ethnicity do you identify as?	White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, Other
Do you have a partner who helps take care of your child with Down syndrome?	Yes, No
Is your current partner either the biological or the adoptive parent of your child with Down syndrome?	Yes, No
Does your current partner live with you?	Yes, No
Was your current partner born in the United States?	Definitely Yes, Probably Yes, Might or Might Not, Probably Not, Definitely Not
What gender does your current partner identify as?	Male, Female, Other
What ethnicity does your current partner identify as?	White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, Other
How old is your child with Down syndrome?	Open-ended question
Is your child with Down syndrome adopted?	Yes, No
Where does your child with Down syndrome currently reside?	In the same house as you, In a different house with the other biological or adoptive parent, In a different house with a different family member, Lives independently be oneself, Lives independently with a partner or roommate(s), Lives in an assisted living facility, Other
Do you have more than one child with Down syndrome?	Yes, No
Do you live close to extended family?	Yes, No

**Table 10.** Qualtrics Parents Caregiver Questions

<b>Question</b>	<b>Optional Answers</b>
Are you the primary caregiver of your child with Down syndrome? If not, who is?	Open-ended question
If you have a partner, is the care-taking responsibility equally distributed?	Definitely yes, Probably yes, Might or might not, Probably Not, Definitely Not, Not Applicable
Were you at one time the primary caregiver, but no longer are?	Definitely yes, Probably yes, Might or might not, Probably not, Definitely not

**Table 11.** Life Stage of 0 - 3 Years Old Questions

<b>Question</b>	<b>Optional Answers</b>
Is your child currently, or has your child previously been, 0 to 3 years old?	Currently, Previously
What are the top 3 strengths of your child with Down syndrome during this life stage (0 to 3 years old)?	Open-ended answer
What is your experience during this life stage with this child with Down syndrome?	Open-ended answer
What are the top 3 challenging characteristics of your child with Down syndrome during this life stage (0 to 3 years old)?	Open-ended answer
If you have a partner, what is/was their experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have had another child who is/was 0 to 3 years old, and does not have Down syndrome, what is/was your experience?	Open-ended answer
If you live close to extended family members, what is/was their experience during this life stage with your child with Down syndrome?	Open-ended answer
If your child with Down syndrome participate(s/d) in additional services during this life stage, what is/was your experience?	Open-ended answer
What is/was your experience with your healthcare professionals involve in your child with Down syndrome's care during this life stage?	Open-ended answer
What organized activities does/did your child with Down syndrome participate(s/d) in? What was your experience?	Open-ended answer

**Table 12.** Life Stage of 4 - 6 Years Old Questions

<b>Question</b>	<b>Optional Answers</b>
Is your child currently, or has your child previously been 4 to 6 years old?	Currently, Previously, Younger than 4 years old(Will skip this section)
What are/were the top 3 strengths of your child with Down syndrome during this life stage (4 to 6 years old)?	Open-ended answer
What are/were the top 3 challenging characteristics of your child with Down syndrome during this life stage (4 to 6 years old)?	Open-ended answer
What is your experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have a partner, what is/was their experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have had another child who is/was 4 to 6 years old, and does not have Down syndrome, what is/was your experience?	Open-ended answer
If you live close to extended family members, what is/was their experience during this life stage with your child with Down Syndrome?	Open-ended answer
If your child with Down syndrome participate(s/d) in day care services or preschool during this life stage, what is/was your experience?	Open-ended answer
If your child with Down syndrome participate(s/d) in additional services during this life stage, what is/was your experience?	Open-ended answer
What is/was your experience with your healthcare professionals involved in your child with Down syndrome's care during this life stage?	Open-ended answer
What organized activities does/did your child with Down syndrome participate(s/d) in? What is/was your experience?	Open-ended answer

**Table 13.** Life Stage of 7 - 21 Years Old Questions

<b>Question</b>	<b>Optional Answers</b>
Is your child currently, or has your child previously been, 7 to 21 years old?	Currently, Previously, Younger than 7 years old (Will skip this section)
What are/were the top 3 strengths of your child with Down syndrome during this life stage (7 to 21 years old)?	Open-ended answer
What are/were the top 3 challenging characteristics of your child with Down syndrome during this life stage (7 to 21 years old)?	Open-ended answer
What is your experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have a partner, what is/was their experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have had another child who is/was 7 to 21 years old, and does not have Down syndrome, what is/was your experience?	Open-ended answer
If you live close to extended family members, what is/was their experience during this life stage with your child with Down syndrome?	Open-ended answer
Has/Did your child learn in a special education classroom, or mainstream classroom? What percentage did they participate in each setting? Select all that apply.	Special needs school: open-ended percentage, Special education classroom in a mainstream school: open-ended percentage, Inclusive classroom in an inclusive school: open-ended percentage, Other: open-ended
What has/was your experience with the faculty, administration, and staff?	Open-ended answer
What has/was your child's experience with his or her peers during this life stage?	Open-ended answer
If your child with Down syndrome participate(s/d) in additional services during this life stage, what is/was your experience?	Open-ended answer
What is/was your experience with your healthcare professionals involved in your child with Down syndrome's care during this life stage?	Open-ended answer
What organized activities does/did your child with Down syndrome participate(s/d) in? What is/was your experience?	Open-ended answer

**Table 14.** Life Stage of older than 21 Years Old Questions

<b>Question</b>	<b>Optional Answers</b>
Is your child currently, or has your child previously been, older than 21 years old?	Currently, Previously- My child has passed away, Younger than 22 years old (Will skip this section)
What are/were the top 3 strengths of your child with Down syndrome during this life stage (older than 21 years old)?	Open-ended answer
What are/were the top 3 challenging characteristics of your child with Down syndrome during this life stage (older than 21 years old)	Open-ended answer
What is your experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have a partner, what is/was your experience during this life stage with this child with Down syndrome?	Open-ended answer
If you have had another child who is/was older than 21 years old, and does not have Down syndrome, what is/was your experience?	Open-ended answer
If you live close to extended family members, what is/was their experience during this life stage with your child with Down syndrome?	Open-ended answer
If your child participate(s/d) in an educational or vocational training, what is/was your experience with the boss and staff?	Open-ended answer
If your child participate(s/d) in a volunteer (unpaid) position, what is/was your experience with the boss and staff?	Open-ended answer
If your child participate(s/d) in a volunteer (unpaid) position, what is/was your experience with the boss and staff?	Open-ended answer
If your child participate(s/d) in a work (paid) position, what is/was your experience with the boss and staff?	Open-ended answer
What has/was your child with Down syndrome's experience been like with his/her peers during this life stage?	Open-ended answer
If your child with Down syndrome participate(s/d) in additional services during this life stage, what is/was your experience?	Open-ended answer

**Table 15.** Overall Parenting Experience Questions

<b>Question</b>	<b>Optional Answers</b>
How would you rank your child’s overall life satisfaction?	Extremely satisfied, Moderately satisfied, Slightly Satisfied, Neither satisfied nor dissatisfied, Slightly dissatisfied, Moderately dissatisfied
Do you feel there has been one or more life stages in your child’s life that has been the most rewarding or pleasant for them? If yes, what life stages?	0 to 3 years old, 4 to 6 years old, 7 to 21 years old, Older than 21 years old, Not applicable
Do you feel there has been one or more life stages in your child’s life that was the most challenging for them? If yes, which life stage(s)?	0 to 3 years old, 4 to 6 years old, 7 to 21 years old, Older than 21 years old, Not Applicable
How would you rank your own overall life satisfaction?	Extremely satisfied, Moderately satisfied, Slightly satisfied, Neither Satisfied nor dissatisfied, Slightly dissatisfied, Moderately dissatisfied, Extremely dissatisfied
Do you feel there have been one or more life stages in your child’s life that was the most rewarding or pleasant for you? If yes, which life stages?	0 to 3 years old, 4 to 6 years old, 7 to 21 years old, Older than 21 years old, Not Applicable
Do you feel that there have been one or more life stages in your child’s life that was the most challenging for you? If yes, which life stage(s)?	0 to 3 years old, 4 to 6 years old, 7 to 21 years old, Older than 21 years old, Not Applicable
Is there any more that you would like to tell us about you and your child with Down syndrome?	Open-ended answer

**Table 16.** Qualtrics Healthcare Professional Demographic Questions

<b>Question</b>	<b>Optional Answers</b>
What year were you born?	Open-ended answer
What month were you born in?	January, February, March, April, May, June, July, August, September, October, November, December
What gender do you identify as?	Male, Female, Other
What ethnicity do you identify as?	White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, Other
What is the State in which you currently practice?	Open-ended answer
What type of environment do you currently work in?	Urban, Suburban, Rural, Other
What State did you get your highest clinical degree?	Open-ended answer
What is your area of specialty?	Open-ended answer
How long has your duration of practice been?	<1 year, 1-5 years, 6-10 years, 10-15 years, > 20 years

**Table 17. Healthcare Professional and Patient Relationship Questions**

<b>Question</b>	<b>Optional Answers</b>
Have you had a patient who has Down Syndrome?	Yes, No(Will end survey)
How many patients with Down Syndrome have you worked with?	1, 2-4, 5-10, 11-20, 21-50, >50
What are the age(s) of your patient(s) with Down Syndrome? Select all that apply	0-3 years old, 4-6 years old, 7-21 years old, > 21 years old
How often do you see your patient(s) with Down Syndrome?	Every day, 2 to 3 times a week, Once a week, Every other week, Once a month, Once every other month, Once a month for less than 6 months, Once a year, Once every few years or longer
Do you feel that your sessions with your patient(s) with Down Syndrome are shorter or longer when compared to your other patient(s)? Why?	Open-ended answer
What were the most common conditions you have treated while working with your patient(s) with Down Syndrome? Select all that apply.	Heart Defects, Vision Problems, Deafness, Infections, Hypothyroidism, Blood Disorder, Hypotonia, Spine Condition, Disrupted Sleep, Dental Disease, Epilepsy, Digestive disorder or Celiac Disease, Mental Health, Emotional or Behavioral Problems, Other: open-ended

**Table 18. Healthcare Professional Setting Questions**

<b>Question</b>	<b>Optional Answers</b>
What healthcare setting have you practiced in while treating a patient with Down syndrome? List all that apply.	Open-ended answer
What accommodations did you make for your patient(s) with Down syndrome?	Open-ended answer
What do you think is the comfort level for your patient(s) with Down syndrome on a scale of extremely uncomfortable to extremely comfortable?	Extremely uncomfortable, Moderately uncomfortable, Slightly uncomfortable, Neither comfortable not uncomfortable, Slightly comfortable, Moderately comfortable, Extremely comfortable

**Table 19.** Healthcare Professional and Caretaker Relationship Questions

<b>Question</b>	<b>Optional Answers</b>
When you meet with your patient(s) with Down syndrome, do you most often speak to the patient or the caretaker?	Patient, Caretaker, Both equally, Other: open-ended
How do you communicate with your patient(s) with Down syndrome? Select all that apply.	English, Spanish, American Sign Language, Assistive Technology, if yes please explain: open-ended, Other: open-ended
Who is the primary caretaker you most often speak to? Select all that apply.	Mother, Father, Sibling, Grandparent, Hired Caretaker, Other: open-ended

**Table 20.** Healthcare Professional Referral Questions

<b>Question</b>	<b>Optional Answer</b>
Do you often refer your patients with Down syndrome to other professionals?	Definitely yes, Probably yes, Probably not, Definitely not
What local, special services or local organizations have you reached out to for your patient(s) with Down syndrome?	Open-ended answer
Have you coordinated a patient with Down syndrome's care with other healthcare professionals within your workplace? If yes, please list what profession(s).	Open-ended answer
In what ways do you advocate for patients with Down syndrome?	Open-ended answer

**Table 21.** Healthcare Professional Education Questions

<b>Question</b>	<b>Optional Answer</b>
When is the last time you have received educational services directly about Down syndrome?	Within the last month, Within the last 6 months, Within the last year, Within the last 2 years, Within the last 5 years, Within the last 10 years, Over 10 years, Never
Was your most recent Down syndrome educational service an independent course or lecture, or was it part of a broader course or lecture?	Independent, Broader, Other: open-ended
How knowledgeable do you feel about the Down syndrome community on a scale from not knowledgeable at all to extremely knowledgeable?	Not knowledgeable at all, Slightly knowledgeable, Moderately knowledgeable, Very knowledgeable, Extremely knowledgeable
How knowledgeable do you feel about the family dynamics when there is a patient with Down syndrome on a scale from not knowledgeable at all to extremely knowledgeable?	Not knowledgeable at all, Slightly knowledgeable, Moderately knowledgeable, Very knowledgeable, Extremely knowledgeable
How knowledgeable do you feel about a patient with Down syndrome's holistic needs on a scale from not knowledgeable at all to extremely knowledgeable?	Not knowledgeable at all, Slightly knowledgeable, Moderately knowledgeable, Very knowledgeable, Extremely knowledgeable
How comfortable do you feel providing treatment to a patient with Down syndrome on a scale of extremely uncomfortable to extremely comfortable?	Extremely comfortable, Moderately comfortable, Slightly comfortable, Neither comfortable nor uncomfortable, Slightly uncomfortable, Moderately uncomfortable, Extremely uncomfortable

**Table 22.** Healthcare Professional Genetic Testing Questions

<b>Question</b>	<b>Optional Answers</b>
Do you feel there is a possibility to eliminate Down Syndrome with genetic testing and modern day medicine?	Definitely yes, Probably yes, Probably not, Definitely not
Do you think we should promote the possibility to eliminate Down Syndrome, why or why not?	Open-ended answer

**Table 23.** Parent Interview Questions

<b>Demographic Questions</b>
How old is your child with Down syndrome?
Do you have any other children?
Do you have a partner?
If yes, is this partner the biological or adoptive parent?
If yes, does your partner live with you or help you take care of your child with Down syndrome?
What state do you currently reside in?
Do you live in a urban, suburban, or rural area?
<b>Parent – Child Relationship Questions</b>
What does you and your child’s typical week look like?
What is your favorite activity your child does, or that you like to do with your child?
What is the most rewarding moment you have had with your child?
What is the scariest moment you have had with your child?
Is there anything you wish you could have changed about your child’s life and experiences?
What do you wish your child to do in his or her future?
What advice would you give the healthcare professionals, teachers, and other individuals’ in your child’s life?
What advice would you give other parents of children with Down syndrome?
What advice would you have given yourself while you were pregnant with (or adopting, or receiving the diagnosis for) your child with Down syndrome?

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