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Adopting Children with Down Syndrome: A qualitative study of family experiences

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Honors Thesis

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### Abstract

The purpose of this study is to qualitatively investigate and compare the family beliefs, values, and perceptions of parenting of families who have adopted children with Down syndrome (DS) to parents who have biological children with DS. Participants in the study included 27 parents of biological children with DS and six parents of adopted children with DS. Participants were interviewed through a digital survey that was distributed through Qualtrics Online Survey Software. Quantitative analysis placed the participants into groups and qualitative analysis was used to identify beliefs, values, and perceptions. Results showed that while both adoptive and biological parents indicated that support services have played an important role in raising their child with DS, 100% of adoptive parents indicated a desire for the creation of additional services/programs to better serve their child with DS and only 63% of biological parents indicated the same desire. There were no significant differences in level of stress seen between the two groups, joys and benefits added to family life, or challenges faced by families. While participants from both groups reported similar values and beliefs that have contributed to their parenting decisions, themes found in motivation differed between biological and adoptive parents.

### Adopting Children with Down Syndrome: A qualitative study of family experiences

The health and functioning of any family is influenced by the characteristics that each member brings to the family system. The familial dynamic is affected by the particular attributes that each member holds, as well as the relationships between members. The addition of a child with Down syndrome can affect the family system in a multitude of ways, ranging from the level of interaction between members to the societal perception of the family (Cuskelly, Hauser-Cram, and Van Riper, 2008). Down syndrome (DS) is one of the most commonly occurring genetic chromosomal disorders, with approximately 6,000 diagnoses each year in the United States (Centers for Disease Control and Prevention, 2016). Identified before as well as at the time of birth, infants with Down syndrome typically experience a range of health issues and/or developmental differences that require medical and habilitation services, both of which can impact family systems. Given the life-long commitment to supportive living for individuals with DS, one might ask what inspires families to adopt infants and children. Certainly the answer to this question can contribute to understanding the joys as well as the challenges introduced into family systems by children with developmental needs. It also can contribute to changed societal perceptions about family life and the interwoven contributions that parents and children with DS give to lives well lived. Additionally, understanding the difficulties faced by those who have adopted children with special needs, particularly Down syndrome, can give health professionals insight into the necessity of additional, specialized services that can better meet the particular needs of these unique families.

While qualitative research has been conducted exploring the experiences of families who have biological children with DS, research that focuses on the experiences of families who have adopted children with DS is meager. However, the adoption of children with Down syndrome

has been growing in recent years, as children who were once considered “unadoptable” are finding fulfilling lives in supportive family systems (Dunlap, 2015). The purpose of the current study is to contribute to this body of literature through a qualitative investigation of family beliefs, values, and perceptions of parenting. In order to better understand these issues, both families who have adopted children with DS and those who are raising biological children with DS were included in the study. Reaching out to both kinds of families, which were spread over large geographical areas, was a difficult task. Therefore, data was collected through digital media in order to include as many families as possible. Questions were both closed-ended to establish the composition of families and open-ended to obtain descriptions of experiences and the interpretation of these by families.

### **Review of the Literature**

#### **What is Down syndrome?**

Down syndrome, or trisomy 21, is a genetic disorder resulting from abnormal cell division, leading to extra genetic material in chromosome 21 (Mayo Clinic, 2014). Both prenatal and postnatal diagnoses of Down syndrome are possible. Prenatal diagnostic tests include amniocentesis, chorionic villus sampling (CVS), and cordocentesis, typically completed during the first or second trimester of pregnancy (Mayo Clinic, 2014). Postnatal diagnosis of Down syndrome is often first based on presenting physical characteristics of a newborn, upon which health care providers will then perform a chromosomal karyotype blood test to verify the initial diagnosis (National Down Syndrome Society, 2012). While the prevalence of prenatal diagnoses of Down syndrome is increasing, the majority of cases are still diagnosed after the child is born (Staats, Goff, Springer, & Monk, 2015). Down syndrome is one of the most commonly occurring

genetic chromosomal disorders, with approximately 6,000 diagnoses each year in the United States (Centers for Disease Control and Prevention, 2016).

While the severity of symptoms varies, individuals with DS exhibit persistent intellectual, developmental, and health issues. Although each person with Down syndrome is an individual with a particular physicality, some more common physical features may include poor muscle tone, a protruding tongue, flattened facial features, and shortened height (Centers for Disease Control and Prevention, 2016). Certain health-related complications may also be present, such as heart defects, immune system abnormalities, obesity, and airway obstruction (Mayo Clinic, 2014). Despite potential health complications, the life expectancies for people with Down syndrome has increased dramatically in recent years. Today, depending on quality of health, individuals with DS may live to age sixty and beyond (Mayo Clinic, 2014). Developmental differences that can include speech, language, cognition, and motor skills, all of which can impact education and life-long work skills, are also associated with DS (National Down Syndrome Society, 2016). Identification and interventions that address development are available to families from the time of a child's birth (National Down Syndrome Society, 2016). That is good news; however, the time, energy, and fiscal commitments that are part of this life-long habilitative process can contribute to stress within family systems.

### **Habilitation Across the Lifespan**

Support to families is available in various forms throughout the life of a person with Down syndrome. For example, early intervention services are available at birth and through the first three years of life. The 'client' in early intervention is the family rather than only the child. At the age of three years, the child becomes the client as they transition into school-based

services (Paul, 2014). This can continue through age 21 as the child remains the primary focus of services as they enter life-skills training and/or supported work environments (Paul, 2014).

**Early intervention.** Early intervention can greatly benefit infants and children with DS as many individuals experience developmental delays in areas such as gross and fine motor abilities, language skills, social development, and self-help skills (National Down Syndrome Society, 2012). Although the acquisition of developmental milestones may be on a delayed timeline in comparison to typically developing children, the milestones reached by infants and children with Down syndrome can be comparable in type and sequence when intervention is employed. Early intervention is recommended to begin shortly after birth and may continue until age three (National Down Syndrome Society, 2012). Under the Individuals with Disabilities Education Improvement Act (IDEA) of 2004, a child typically undergoes a transdisciplinary evaluation conducted by members of a birth-to-3-team, upon which an Individualized Family Service Plan (IFSP) is developed (Paul, 2014). The IFSP, developed to highlight a child's distinct needs, the family's needs, and the ways in which these needs will be met, is in place until a child reaches age three (Paul, 2014). The IFSP team directly involves family members in the planning, prioritizing, and creation of service goals, representing a family-centered approach to care (Paul, 2014). Members of the intervention team of health care professionals may include a speech language pathologist, physical therapist, occupational therapist, or other health specialist, depending on a child's particular need. The intervention role of a speech language pathologist during this time may include physiological aspects, such as those associated with feeding and oral movement; interpersonal interactions that promote communication and language development; and early auditory processing/awareness skills (National Down Syndrome Society, 2012). Furthermore, a physical therapist may target a child's ability to walk or crawl despite poor

muscle tone, while an occupational therapist might target the grasping and releasing of objects (National Down Syndrome Society, 2012).

**Educational services.** These manners of intervention typically continue beyond the early intervention stage into school age, when an Individualized Education Plan (IEP) is implemented. Rather than skills of early development, the IEP focuses on methods of intervention that will maximize a child's academic success, such as literacy skills addressed by a speech language pathologist, behavioral and classroom participatory activities associated with special education, and sensory and motor skills development that is addressed by occupational therapists, physical therapists, and through adaptive physical education (National Down Syndrome Society, 2012; Paul, 2014). The IEP is developed by a team of professionals in conjunction with parents, is reviewed annually or at the parents' or teachers' requests, and is updated tri-annually (United States Department of Education, 2007). As can be seen, parents continue to be heavily involved in the educational planning for their children.

The role of the parent extends beyond the IEP process. Like any other child, those with DS have homework assignments and extracurricular activities that involve parents on a regular basis. The amount of time spent to accomplish tasks or spent in communication with school personnel can be time intensive. This is especially true as school children with DS progress through the educational system, including shifts into middle school, high school, and career training. This last step usually occurs during the ages of 16-21 years, at which time the focus of intervention may shift to an Individual Transition Plan (ITP) (Paul, 2014). This type of service plan is designed to help make a transition and integration into a life of independence, community participation, and/or vocational choices, if these are viable options (Paul, 2014).



**Adult years.** Adults with Down syndrome sometimes continue to receive intervention services throughout the lifetime, as health care professionals remain in partnership with families to provide the best quality of life for each client. Intervention services may be administered throughout any stage of life for a person with Down syndrome, although the focus and goal of intervention changes with an individual's age, health, development, and acquisition of skills.

### **Family Adjustment**

As can be seen from the preceding description of services, individuals with DS are supported across the lifespan. A history of such support has led to societal recognition of the potential for individuals with DS to lead productive and fulfilling lives. They can be entrepreneurs, artists, writers, television and movie actors, graduate from college, have romantic relationships, and contribute to the communities in which they live (Banks 2016; Zahneis, 2016a; Zahneis, 2016b). Such successes do come with a cost of time and emotional energy from families. Therefore, the adoption of a child with DS is truly a family affair and one that will require adjustments.

**Parents.** The health and functioning of any family is influenced by the characteristics that each member brings to the family system. The familial dynamic is affected by the particular attributes that each member holds, as well as the relationships between members. The addition of a child with Down syndrome can affect the family system in a multitude of ways, ranging from the level of interaction between members to the societal perception of the family (Cuskelly, Hauser-Cram, and Van Riper, 2008). One area of the family dynamic that can be affected by the addition of a child with Down syndrome is the level of parental stress and psychological well-being. Many studies reveal that parents of children with Down syndrome experience lower levels of well-being, in reference to stress and depression, than parents of typically developing children

of similar ages (Habib, Jameel, and Fazal, 2015). Furthermore, longitudinal studies have shown that levels of stress in mothers of children with Down syndrome often continue to increase significantly as the child ages, specifically between the infant and middle childhood period (Eisenhower, Baker, and Blacher, 2005). In the majority of studies conducted with families of children with Down syndrome, the mothers take on the primary child care role (Cuskelly, Hauser-Cram, and Van Riper, 2008). However, while research on fathers of children with Down syndrome is less abundant, data has suggested that fathers of children with Down syndrome often take on a higher level of involvement in child care than do fathers of typically developing children (Hedov, Wikblad, and Anneren, 2006). Another aspect of the parental role that can be influenced by the addition of a child with Down syndrome is the parents' amount of confidence in their parenting abilities. While levels of satisfaction with the parenting experience are shown to be similar to parents of typically developing children, parents of children with Down syndrome have been shown to have less confidence in their ability to parent correctly and effectively (Gilmore and Cuskelly, 2007). This data is important, as parenting confidence is tied to an individual's identity and perception of self. Although mothers may encounter lower levels of parenting confidence with heightened levels of stress, Poehlmann and colleagues found that mothers perceived their child with Down syndrome as possessing very positive traits that helped maintain deep relationships between family members and close others (2005).

**Siblings.** Regarding the siblings of children with Down syndrome, many positive outcomes have been shown. While typically developing siblings may have difficulty adjusting to their new sibling initially, further research shows that the typically developing siblings later have positive self-concepts, as they have acquired additional strengths by learning and growing alongside a child with a developmental disability (Skotko and Levine, 2006). Findings suggest

that the relationships developed between siblings of children with Down syndrome are most often of comparable quality to the relationships between all typically developing siblings, with no meaningful adjustment differences found (Cuskelly and Gunn, 2006).

**Family life.** When the family as a whole is investigated, families commonly report that a child with Down syndrome adds positive values and experiences to the family life that would not have occurred without the specific child's presence. For example, some families report "increased feelings of empowerment, personal growth, and a rearrangement of priorities" that they associate with the presence of their child with Down syndrome (King et al., 2006, p. 353-369). While many families of individuals with Down syndrome associate positive personal and relational outcomes with their experience, additional studies have shown that these same families can have a lower quality of life in the areas of health, financial security, career stability, and social support than families with all typically developing children (Cuskelly, Hauser-Cram, and Van Riper, 2008). These findings reveal that the journey of families of individuals with Down syndrome is multifaceted, containing both experiences of intense struggle and great satisfaction.

### **Adoptive Families**

Adopting children with special needs can pose its own array of adventures and challenges that may differ from those experienced by families with biological children who have special needs. This issue is important, as the recent increased availability of funds in the United States "to support special needs adoptions has spurred on an increase towards more special needs adoptions" (Child Welfare Information Gateway, 2012). Although this type of adoption has increased, it has unfortunately been accompanied by "an increased rate in post-adoptive problems, including an increase in disrupted and dissolved adoptions" (Reilly & Platz, 2004). Failed placements of children with special needs, including adoption disruptions or dissolutions,

can likely have a negative impact on the children involved (Slayter, 2016). Understanding the difficulties faced by those who have adopted children with special needs, particularly Down syndrome, may give health professionals insight into the necessity of additional, specialized services that can better meet the particular needs of these unique families.

### **Becoming a Special Family**

The route to becoming a family that includes a child with DS is different for biological parents than adoptive parents. For biological parents, it can be an unknown until the birth of the infant, leaving them little time to adjust and pre-plan. For those who have had amniocenteses and made the decision to keep their infants and for adoptive parents, they have begun the process of being a special family prior to the arrival of the child. This often involves contact with support groups.

The period following diagnosis can often be overwhelming and emotional for families, as there is a great deal of uncertainty about the future of their child and family system. It is normal for parents to go through stages of grief and it is imperative that families know they are not alone. Connecting with other parents of children with Down syndrome can be remarkably beneficial at the time of diagnosis and throughout a child's life, as other families can offer insight into the joys of this new journey, along with understanding of the different trials that might be faced. Some communities offer local Down syndrome parent support groups, although the availability of these services differ from place to place. Organizations such as the National Down Syndrome Society (NDSS) and Down Syndrome International (DSI) can help connect families with local support groups. These groups vary in services performed; such groups may not only connect families of children with Down syndrome together, but can also offer continuing education, sibling and extended family support, recreational and social activities,

regional conferences, helplines, partnerships with clinics, training services, workshops, and events to raise public awareness (National Down Syndrome Society, 2012). Many families also connect online, via blogs, social media accounts, and websites where individuals with Down syndrome and their families can share experiences, spread awareness, and give inspiration in a supportive community. Online resources are also available to provide medical and health information for families, as well as current research findings in the area and nonprofit advocacy. Getting involved in a form of support group is one of the best choices a family can make in order to find an invaluable source of solace and encouragement.

### **Summary and Questions of the Study**

As can be seen from this review of the literature, DS is a well-identified developmental disorder with a range of functional outcomes. Long-term supportive services beginning in infancy and extending into adulthood contribute to the maximization of these outcomes. Given this, the addition of a child with Down syndrome can affect the family system in a multitude of ways, ranging from the level of interaction between members to the societal perception of the family (Cuskelly, Hauser-Cram, and Van Riper, 2008). The route to becoming a family that includes a child with DS may be different for biological parents than adoptive parents, in part because of the time allowed to come to understand the implications of raising a child with DS and finding groups that can support your decisions, subsequent challenges, and share joyful moments and accomplishments.

While qualitative research has been conducted exploring the experiences of families who have biological children with Down syndrome, research that focuses on the experiences of families who have adopted children with Down syndrome is meager. The purpose of this study was to contribute to this body of literature through a qualitative investigation of family beliefs,

values, and perceptions of parenting. In order to better understand these issues, both families who have adopted children with Down syndrome and those who are raising biological children with Down syndrome were included in the study. The specific questions of the study are the following:

1. In what ways do the perceptions of parents differ with regard to family systems, support services, and the possibility of enhancing life if a child with DS is biological versus adopted?
2. Are perceived levels of stress higher in parents of biological children with DS versus parents of adopted children with DS?
3. What positive effects on family life are seen from raising a child with DS? Are these perceived effects similar or different between biological and adoptive families?
4. What challenges do families face when raising a child with DS? Are these perceived challenges similar or different between biological and adoptive families?
5. What motivated families to raise a child with DS? Were motivations and values similar or different between the two groups?

## **Methodology**

### **Participants**

Twenty parents of individuals with DS were sought to participate in this study. A mix of biological and adoptive parents were sought through nomination and social media contact. There was no control for the age of the children with DS, the composition of the family, socioeconomic status, or regional area in which they reside.

### **Materials**

A digital interview that included both closed and open ended questions was developed from the literature and distributed through Qualtrics Online Survey Software Program. The closed ended questions identified families as biological versus adoptive and provided background information on the child and family, along with services the child has received. The open ended questions elicited values, beliefs, and perceptions about parenting and raising a child with DS.

### **Procedures**

In this study, parents of adopted children with DS were interviewed in a digital questionnaire format in order to assess their personal reasons and/or motivation for adopting a child with DS. Additionally, parents of both biological and adopted children with DS were interviewed in the same format in order to assess their perceptions of (a) the positive benefits of raising a child with DS and (b) the possible challenges faced when raising a child with DS. A script was developed that introduced the study via social media. A link at the end of the script opened the informed consent page followed by the questionnaire described above. The electronic survey engine Qualtrics was used to deploy the digital interview.

### **Analysis**

Analysis included quantitative demographics, which was used to describe the participants and place them into groups for analyses. Qualitative analysis, specifically abstracting of narratives and themes, was used to identify beliefs, values, and perceptions.

## **Results**

### **Demographics**

Participants in the study were required to be parents and/or guardians of either biological or adopted children with DS. The Institutional Review Board (IRB) approved 40 participants to

be included in the study; there were 33 total participants in the study. Of these participants, six were parents of adopted children with DS, while 27 were parents of biological children with DS. The participants varied in residential location and socioeconomic status. Seventeen participants (51.52%) had a child with DS who was 0-2 years of age, 11 participants (33.33%) had a child with DS who was 3-5 years of age, four participants (12.12%) had a child with DS who was 6-9 years of age, and one participant (3.03%) had a child with DS who was 10-13 years of age. All participants who had an adopted child with DS completed their adoption process when the child was between 0-2 years of age. Fourteen participants (42.42%) had a child with DS who was male, while 19 (57.58%) had a child with DS who was female. Twenty-seven participants (81.82%) had other children, varying from two to eight children total. Six participants (18.18%) had no other children. In regard to individuals living in the home, 100% of families had a mother living in the home, 96.97% had both a mother and father living in the home, 63.64% had other children living in the home, 9.09% had a grandparent living in the home, and 6.06% had an uncle living in the home. Out of 33 families who participated in the study, 30 (90.91%) consider the mother to be the primary caregiver, while one (3.03%) considers the father to be the primary caregiver. Two families (6.06%) consider the mother and father to be equal caregivers to their child with DS. All individuals who personally completed the survey were mothers of children with DS.

### **Question One**

The first question of the study asked in what ways the perceptions of parents differ with regard to family systems, support services, and the possibility of enhancing life if a child with DS is biological versus adopted. Items nine, ten, and eleven on the questionnaire were used to answer this question. Ninety-six percent of biological parents indicated that support services or



programs have played an important role in raising a child with DS. Similarly, 100% of adoptive parents indicated that support services and programs have played an important role in their lives. Biological parents indicated physical therapy as being the most helpful service, followed by social media groups, occupational therapy, and speech-language therapy. Adoptive parents indicated that speech-language therapy was the most helpful service, followed by social media groups, occupational and physical therapy, local support groups, and blogs (See Table 1 below). When asked, themes about why the programs and services indicated were helpful were similar across parents of both biological and adoptive families. Parents indicated that early intervention and therapies have aided in their child's development and growth of new skills. Additionally, for almost all participants, social media has provided a community of other parents who can relate to their experiences and provide emotional support. The majority of parents communicated that social media groups have helped them feel connected, even when there are no physical support groups in their residential area. These social media communities also provide an opportunity for learning, in that parents ask each other questions and relay experiences and knowledge to one another. Participant responses showed that emotional support proved to be just as essential as physical, developmental, and academic support for their families. As one participant stated, "My core group of friends (on social media) feel like family and are often going through very similar emotions, challenges, and celebrations as I am."

Table 1

*Most Helpful Services to Families of Children with Down syndrome (DS)*

|  |                            | Is your child with DS your biological child or your adopted child? |               | Total |
|--|----------------------------|--|---------------|-------|
|  |                            | Biological child   | Adopted child |       |
| What services and/or programs have been the most helpful to your family? | Speech-language therapy    | 20   | 5             | 25    |
|  | Occupational therapy       | 21   | 3             | 24    |
|  | Physical therapy           | 23   | 3             | 26    |
|  | Local support groups       | 14   | 3             | 17    |
|  | Parent groups              | 13   | 1             | 14    |
|  | The National DS Society    | 7  | 2             | 9     |
|  | The Special Olympics       | 2  | 0             | 2     |
|  | Social media groups        | 22   | 4             | 26    |
|  | Cite/State DS Associations | 9  | 1             | 10    |
|  | Family support groups      | 5  | 0             | 5     |
|  | Counseling                 | 1  | 1             | 2     |
|  | Blogs                      | 11   | 3             | 14    |
|  | Websites                   | 5  | 2             | 7     |
| Other  | 5                          | 1  | 6             |       |
|  | <b>Total</b>               | 26   | 6             | 32    |

*Note.* Responses in the “Other” category included ABA therapy, Gigi’s Playhouse, NDSC (National Down Syndrome Congress) Convention, Canadian Down Syndrome Society, family friends, and local school district.

The next item on the digital interview targeted services that parents would like to see created or make available for their children. One-hundred percent of the adoptive parents indicated that there are services they would like to be created to better meet the needs of their children, in comparison to 63% of biological parents indicating the same desire (See Table 2 below).

Table 2

*Number of Parents of Children with DS Who Desire the Creation of Additional Services*

|  |     | Is your child with DS your biological child or your adopted child? |               | Total         |
|--|-----|--|---------------|---------------|
|  |     | Biological child   | Adopted child |               |
| Are there any types of programs or services that you would like to be created in order to better serve your child with DS? | Yes | 17<br>62.96%   | 5<br>100.00%  | 22<br>68.75%  |
|  | No  | 10<br>37.04%   | 0<br>0.00%    | 10<br>31.25%  |
| Total  |     | 27<br>100.00%  | 5<br>100.00%  | 32<br>100.00% |

*Note.* Percentages for each group indicated in blue.

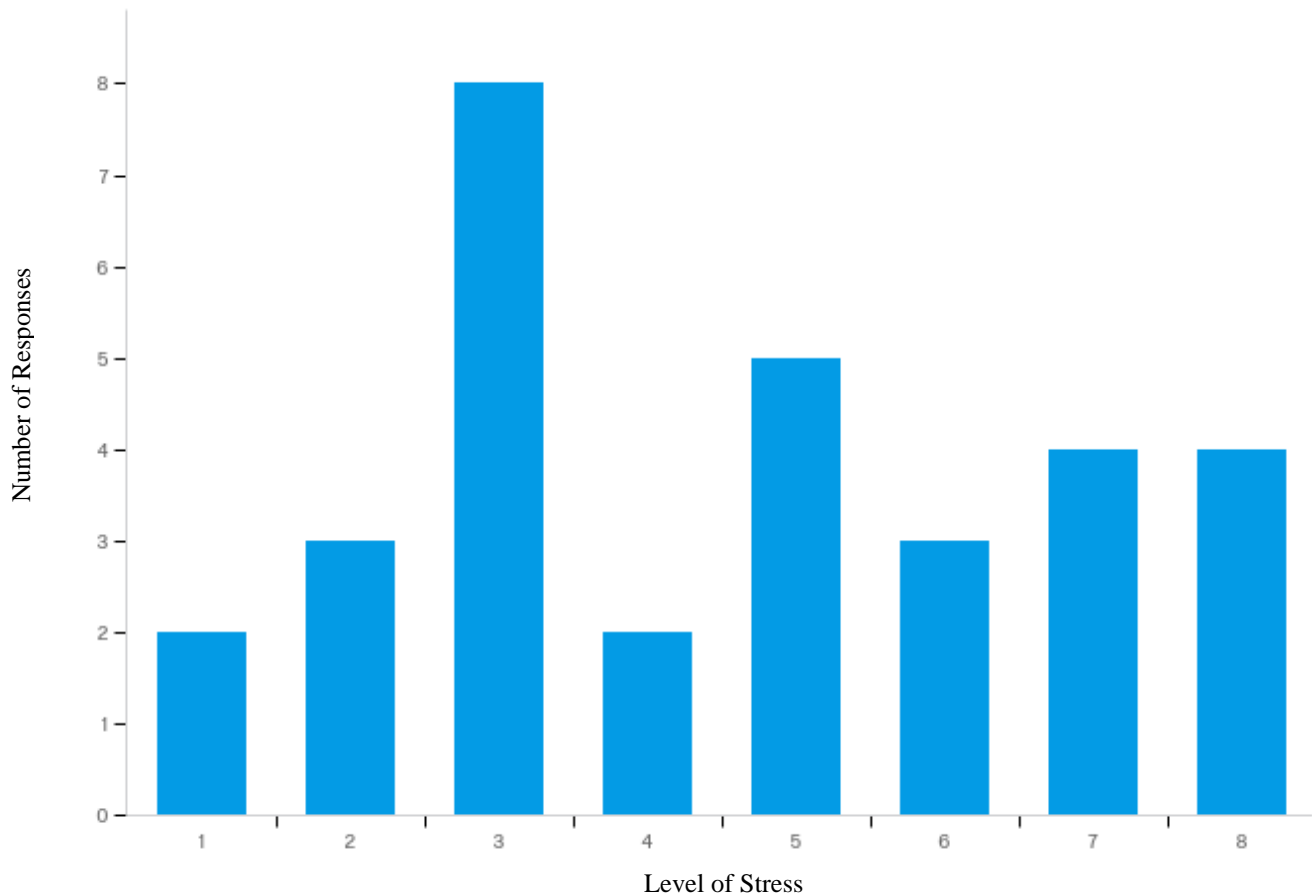
If parents indicated that they would like additional services to be created to serve their children and families, they were then prompted to describe the services they desired. There were both similarities and differences in the responses of the two groups. One theme found from both biological and adoptive families indicated that there were little to no services in their area that provide support, training, or vocational opportunities for individuals with DS once they reach adulthood. Parents would like more support to help their children learn life skills and integrate into society once they leave the school system. Another response that was seen from both biological and adoptive parents was the desire for therapy clinicians to better train parents to incorporate therapy into the family's daily routine, in order to enhance progress and functionality of skills. Additionally, parents from both biological and adoptive families indicated that programs directed toward siblings of children with DS could be beneficial. Parents suggested that they would enjoy classes to educate typically-developing children so that they can better understand the differences, development, and needs of their sibling with DS. Parents also suggested the creation of programs where their children without DS could meet with other siblings of children with DS, to vent, share feelings, and discuss opinions in a safe environment.

A type of service that was requested exclusively by biological families involved after-school programs and recreational activities. Although many families with DS are finding inclusion for their children in the school system, many would like to see more after-school programs that are accepting of their children's differences and provide accommodations and modifications that would allow their children to participate more fully. A type of service that was requested exclusively by adoptive parents was counseling services that are appropriate for children with DS. As some adopted children have had traumatic experiences prior to adoption, parents desire counseling services that are appropriate for their child's level of cognition, speech, and language.

While both adoptive and biological parents indicated that support services have played an important role in raising their child with DS, 100% of adoptive parents indicated a desire for the creation of additional services/programs to better serve their child with DS and only 63% of biological parents indicated the same desire. However, the descriptions of services given by biological and adoptive parents who do desire additional services contained many common themes.

### **Question Two**

The second question of the study asked if perceived levels of stress are higher in parents of biological children with Down syndrome versus parents of adopted children with Down syndrome. Item 16 on the questionnaire was used to address this question. On average, biological parents indicated their level of stress as a parent being 4.6, while adoptive parents indicated their level of stress as being 4.8 (See Figure 1 below). There were no significant differences in level of stress seen between the two groups.



*Figure 1.* Parental Level of Stress on 0-10 Scale. Figure includes results from both biological and adoptive families of children with DS (31 total responses).

### Question Three

The third question of the study sought to understand the perceived positive effects of raising a child with Down syndrome. When reporting the joys and benefits that families have experienced with the addition of their child with DS, the responses of all parents, whether biological or adoptive, contained very similar themes. Almost every parent, both biological and adoptive, said that their child with DS has taught them how to slow down and enjoy simple moments and accomplishments in life. Parents feel that they now focus on what truly matters, rather than getting caught up in superficial worries. The majority of biological and adoptive parents also expressed that having a child with DS has brought them into a fulfilling community

of other families who are now their close, supportive friends. Thirdly, parents repeatedly reported that their child has enabled them to see beauty in others that they did not notice before and to appreciate individual differences. For most participants, raising a child with DS has opened their family's mind and the mind of their community to the diversity of human development. Lastly, a commonality among both groups of participants was that raising a child with DS has helped them improve as individuals, including increasing their patience, kindness, empathy, compassion, and respect for those they come in contact with. In terms of joys and benefits added to family life, there were no significant differences between the two groups.

*Themes in Reported Benefits of Raising a Child with Down syndrome (DS)*

| <b>Biological and Adoptive Families</b>                          |
|--|
| Rearrangement of priorities                                      |
| Joining a supportive community                                   |
| Learning to appreciate individual differences                    |
| Increased personal attributes of patience, kindness, and empathy |

**Question Four**

The fourth question of the study asked about challenges or adventures that families face when raising a child with Down syndrome. Biological parents and adoptive parents reported many of the same challenges and adventures experienced with the addition of a child with DS.

By far, the most common theme among both biological and adoptive parents was that it is challenging to watch their child experience a myriad of health complications, including surgeries, challenges with weak immune systems, and feeding complications, as well as handle the effects of their child's developmental delays on everyday life. The second most common theme reported by parents of both groups was being overwhelmed by the amount of therapies and services their child requires, along with the financial strain this can bring. Many parents feel that managing the substantial amount of therapy appointments needed to address their child's developmental delays leaves them with less time to meet other life obligations and enjoy family time. Other, less commonly reported challenges included facing societal misperceptions of disability, fear of the unknown when given a prenatal diagnosis, giving other children in the family the attention they deserve, and finding services near the family's residential location. There were no meaningful differences found in the challenges faced by adoptive parents compared to biological parents.

*Themes in Challenges Faced when Raising a Child with Down syndrome (DS)*

| <b>Biological and Adoptive Families</b>                 |
|---|
| Health complications and developmental delays           |
| Managing child's schedule (therapies and appointments)  |
| Facing societal misperceptions of disability            |
| Finding services near the family's residential location |

**Question Five**

The fifth question of the study explored the motivations for raising a child with Down syndrome. The purpose of this survey item was to determine why adoptive parents chose to adopt a child with DS or why biological parents chose to raise a child with DS rather than terminate the pregnancy or put the child up for adoption. The most common theme found among both biological and adoptive parents was that they attributed their decision to their personal faith, religion, and/or belief in God that encourages them to see the value and purpose in each human being. There were two common themes seen only in responses of biological parents. The first theme is pro-life values among biological parents that motivated parents to keep their child after a pre-natal diagnosis of DS. The second common theme seen in responses of biological parents is the belief that a parent should keep a child that is biologically theirs, regardless of any qualities, differences, or potential challenges. These parents reported the belief that a biological child belongs to them and no diagnosis could change that. Motivations that were seen only from adoptive parents included an individual who was a foster parent and desired to adopt children who were unable to find a home because of a diagnosis; this participant stated, "We didn't see a girl with Down syndrome. We saw (an) innocent baby that needed a home and to be loved." Another response seen only from adoptive parents included an individual who has worked with children with special needs throughout her life; this participant saw immense value in these individuals and made it her life goal to raise a child with special needs, which led to the adoption of her child with DS. While many participants from both groups reported similar values and beliefs that have contributed to their parenting decisions, some themes found in motivation differed between biological and adoptive parents.



*Themes in Parental Motivation for Raising a Child with Down syndrome (DS)*

| Biological Families                        | Adoptive Families                                  |
|--|--|
| Personal faith and/or religion             | Personal faith and/or religion                     |
| Pro-Life values                            | Foster parents adopt children unable to find homes |
| A child belongs in their biological family | Career experience with children with special needs |

**Discussion**

While qualitative research has been conducted exploring the experiences of families who have biological children with Down syndrome, research that focuses on the experiences of families who have adopted children with Down syndrome is meager. The purpose of this study was to contribute to this body of literature through a qualitative investigation of family beliefs, values, and perceptions of parenting. Results from this study show that while both adoptive and biological parents indicated that support services have played an important role in raising their child with DS, 100% of adoptive parents indicated a desire for the creation of additional services/programs to better serve their child with DS and only 63% of biological parents indicated the same desire. However, the descriptions of services given by biological and adoptive parents who do desire additional services contained many common themes. There were no significant differences in level of stress seen between the two groups. In terms of joys and benefits added to family life, there were no significant differences between the two groups. There were no meaningful differences found in the challenges faced by adoptive parents compared to biological parents. While many participants from both groups reported similar values and beliefs

that have contributed to their parenting decisions, some themes found in motivation differed between biological and adoptive parents.

Previous research has found that parents of children with DS often experience further challenges and demands than “typical” parents, due to increased medical and developmental needs of children with DS and societal perceptions of individual differences (Cuskelly, Hauser-Cram, & Van Riper, 2008). Research has also found that parents who adopt children with special needs may experience familial complications, indicated by the level of disrupted and dissolved adoptions of children with special needs (Reilly & Platz, 2004). Given these previous findings, one might assume that parents who have adopted a child with DS may experience heightened levels of stress and increased challenges, due to the combination of having a child with DS who is also adopted. However, while adoptive parents indicated further desire for additional services to meet the needs of their families when compared to biological families, this study found no meaningful differences in the type of challenges faced by parents of adopted and biological children with DS. Additionally, no significant differences were found in the level of stress reported by the two groups. This lack of heightened stress or different challenges in adoptive families could be attributed to these families’ motivations for adopting and prior experience with children with special needs. For example, some adoptive parents reported gaining experience with children with special needs throughout their lifetime, whether through life as a foster parent or a career path. These experiences prepared these individuals for raising their own child with special needs. Additionally, adoptive parents reported the belief that each person can contribute to society, regardless of disability. This belief may motivate adoptive parents to not be discouraged by their child’s limitations, but rather focus on the unique contributions and skills that their child can offer. While adoptive families may require additional services to meet their

needs when compared to biological families, adoptive parents' previous life experience and belief in their child's potential may equip them to overcome the difficult challenges they face.

The results from this study correspond to previous research findings that the majority of families of children with DS have the mother as the primary caregiver (Cuskelly, Hauser-Cram, and Van Riper, 2008). Cuskelly, Hauser-Cram, and Van Riper's finding was reflected in this study's results, in that 90.91% of participants interviewed considered the mother to be the primary caregiver. However, this study's findings on siblings of children with DS differed from the findings of Cuskelly and Gunn's 2006 study. Cuskelly and Gunn found that siblings of children with DS experience levels of well-being comparable to siblings of typically developing children, with no meaningful differences. However, based on parental responses from this study, mothers express a need for the creation of "sibling group" services for siblings of children with DS. Parents indicated that a group such as this would be beneficial, because siblings of children with DS often get overlooked or overshadowed. "Sibling groups" could provide an environment for siblings to discuss feelings and challenges without feeling guilty. Feelings of being overlooked or overshadowed from siblings of individuals with DS could certainly be attributed to the level of attention and special services their sibling with DS requires, which was reflected in responses of parents. Results from this study show that experiences and emotions of siblings of children with DS may be more complex than previously reported.

This study's findings of the benefits a child with DS offers to the familial dynamic align closely with previous research. As King et al. (2006) found, families report "increased feelings of empowerment, personal growth, and a rearrangement of priorities" that they associate with the presence of their child with Down syndrome. The current study's findings reflect prior research, as the most common benefit found among both groups of families was that a child with DS

encouraged families to prioritize meaningful family experiences and encourage one another through hardship, rather than focus on superficial, fleeting details of everyday life. Likewise, participants from this study reported that their experiences as a parent of a child with DS has shaped their identity to include core values such as patience, compassion, acceptance, adaptiveness, and empathy. Based on findings from this study, while parents experience many challenges and see a number opportunities for improvement of services directed toward their unique families, the addition of a child with DS can also lead to a more positive perception of self for parents and more joyous family experiences, for both adoptive and biological families.

Results from this study can inform and do lead to steps that can be taken by members of health professions fields in order to better serve families of both adopted and biological children with Down syndrome. Many families reported a desire for improvement in the areas of vocational training for adults with DS, inclusive recreational programs, parental training for implementing therapy activities at home, counseling for adopted children with DS, and educational and support group opportunities for siblings of children with DS. By understanding additional needs of those who have both adopted and biological children with DS, health professionals may develop specialized services that can better meet the particular needs of these unique families.

### **Limitations**

Several limitations apply to this study. First, a limited number of responses were collected from families of adopted children with DS. Although the six mothers of adopted children with Down syndrome who were interviewed provided valuable information and outlooks on the subjects discussed, a larger number of responses from this group would provide a more extensive understanding of this population.

Secondly, all participants who completed the survey for this study were mothers of children with DS and almost all (90.91%) were the primary caregiver of the child. Perceptions, including perceptions of stress, further services needed, or parenting values, might differ in fathers of children with DS and/or parents who are not the primary caregiver of the child. Gathering responses from other members of these families and from families who have primary caregivers other than the mother could have contributed additional, valuable viewpoints.

Lastly, almost all families of the current study (96.97%) reported having two parents living in the home. Responses of more single parents of children with DS may have indicated further levels of stress or need for additional services to meet the needs of their children and families, as single parents may take on the majority of caregiving duties without the support of a spouse. Interviewing members of more diverse family dynamics could have supplied a more complete view of the perceptions of this population.

### **Future Directions**

In future research on this topic, it would be advantageous to interview single-parent households with biological and adopted children with DS, in order to ascertain whether the perceptions and desires of these families differ from two-parent households. Likewise, information on residential location and socioeconomic status of biological and adoptive parents of children with DS could be gathered. By determining where families of children with Down syndrome reside, researchers could gain insight into which areas of the country are lacking in services and support groups for these families. Furthermore, collecting information regarding family income could provide insight into whether the variable of socioeconomic status plays a role in parenting stress and satisfaction.

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## Appendix A

**Survey Distributed through Qualtrics Online Survey Software**

Title: Adopting Children with Down Syndrome: A qualitative study of family experiences

Principle Researcher: Emily Richter

Faculty Mentor: Fran Hagstrom

1. Who is completing this survey?
2. Is your child with Down syndrome your biological child or your adopted child?
3. At what age was your child with Down syndrome adopted?
4. How old is your child with Down syndrome currently?
5. Is your child with Down syndrome male or female?
6. Do you have any other children? How many children do you have including your child with Down syndrome?
7. Who lives in the home? Indicate all of the following.
  - Mother
  - Father
  - Other Children
  - Step mother
  - Step father
  - Grandparent(s)
  - Aunt
  - Uncle
  - Cousin(s)
  - Others (please specify)
8. Who is your child's primary caregiver?
  - Mother
  - Father
  - Step mother
  - Step father
  - Grandparent(s)
  - Aunt
  - Uncle
  - Sibling
  - Cousin
  - Other (please specify)

9. Have support services and/or programs played an important role in raising your child with Down syndrome?

10. What services and/or programs have been the most helpful? Check all that apply.

- Speech-language therapy
- Occupational therapy
- Physical therapy
- Local support groups
- Family support groups
- Parent groups
- The National Down Syndrome Society
- City or State Down Syndrome Associations
- The Special Olympics
- Social media groups
- Blogs
- Websites
- Counseling
- Other (please specify)

11. Why were these services and/or programs helpful?

12. Are there any types of programs/services that you would like to be created in order to better serve your child? If so, please describe this program/service.

13. Are there any types of programs/services that you would like to be created to better serve your entire family? If so, please describe this program/service.

14. What positive joys and benefits has your family experienced with the addition of your child with Down syndrome?

15. What challenges or adventures has your family experienced with the addition of your child with Down syndrome?

16. On a scale of 0-10, rate your level of stress as a parent, with 0 being no stress and 10 being extreme stress.

17. What values or beliefs contributed to your decision to raise a child with DS and your actions/methods as a parent of a child with DS?

18. What values do you think are important for your child with DS, your family, and the community at large to possess for optimizing a better lifestyle?

## Appendix B

### Nomination Script

Title: Adopting Children with Down Syndrome: A qualitative study of family experiences  
Email/telephone conversation seeking nominations for the study

My name is Emily Sugg-Richter, and I am a senior honors student completing a degree in communication disorders at the University of Arkansas in Fayetteville. I am completing my honors requirements by conducting research that compares the experiences of families who have adopted children with Down syndrome to the experiences of families who have biological children with Down syndrome.

I am seeking participants through a nomination process via email or telephone calls. If you know a family who has an adopted child with Down syndrome or a biological child with Down syndrome, I would appreciate your sharing my contact information with the parent/guardian of the child. The individual with Down syndrome can be of any age and their parent/guardian will be the actual participant in the study.

There are no known risks to participants in this study.

Participation in this study is completely voluntary and the parent/guardians are free not to participate in the project. In addition, they may choose at any point during the questionnaire to not submit it, and all information entered to that point will be destroyed.

Code names will be used for all data collection and reported in an anonymous manner in any presentations or publications. All information will be kept confidential and secure to the extent allowed by applicable State and Federal law and University policy.

The results of the study may benefit the field of speech-language pathology and related health professions by contributing information about family beliefs, values, and perceptions of parenting. By understanding the possible unique challenges faced by those who have adopted children with Down syndrome, health professionals may gain insight into the necessity of additional, specialized services that can better meet the particular needs of these families.

If you have any questions about the study or this nomination process, please contact me (Emily Sugg-Richter at [elsugg@email.uark.edu](mailto:elsugg@email.uark.edu) or 870-480-3494) or my faculty mentor, Dr. Fran Hagstrom at 479-575-4910 or by email at [fhagstr@uark.edu](mailto:fhagstr@uark.edu).

## Appendix C

## Informed Consent Procedures

**Electronic Distribution****Adopting Children with Down Syndrome: A qualitative study of family experiences**

Principle Researcher: Emily Sugg-Richter

Faculty Mentor: Fran Hagstrom

*Purpose of the Study*

The purpose of the study is to better understand the experiences of families who are raising children with Down syndrome. We are particularly interested in learning about your beliefs, values, and perceptions of parenting, both in general and with regard to your child with Down syndrome.

*Description of Procedures*

You are being asked to complete a digital questionnaire containing both multiple choice and open-ended questions. The multiple choice questions will identify families as biological versus adoptive and provide background information on your child with Down syndrome, services the child has received, and functional outcomes. The open-ended questions ask about your values, beliefs, and perceptions that pertain to parenting and raising a child with Down syndrome. It will take approximately 20-30 minutes to complete the online questionnaire.

*Risks and Benefits*

There are no anticipated risks associated with participation in this study. You may gain insight about values and beliefs that guide your parenting.

*Confidentiality*

Your name will not be on the questionnaire, and the electronic link to the questionnaire cannot be traced to you or the computer upon which it was completed. This means no one will know if or how you answered the questions. The results of the study will be reported only as group information in presentations and papers. All information will be kept confidential to the extent allowed by applicable State and Federal law and University policy.

*Voluntary Participation*

Participation in this study is completely voluntary and the parent/guardians are free not to participate in the project. In addition, they may choose at any point during the questionnaire to not submit it, and all information entered to that point will be destroyed.

*Implied Consent*

By completing the questionnaire and electronically submitting it, you are implying that you are willing to participate. It also means that you understand the description of the research, including risks and benefits, confidentiality, and voluntary participation.

If you have questions about this study or seek additional information, please contact the researchers at the following address or telephone number.

**Researcher:**  
Emily Sugg-Richter, Undergraduate Student

**Administrator:**  
Ro Windwalker, CIP

Fran Hagstrom, Ph.D., Faculty Advisor  
University of Arkansas  
College of Education and Health Professions  
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Institutional Review Board Coordinator  
Research Compliance  
109 MLKG Building  
University of Arkansas  
Fayetteville, AR 72701  
Phone:479-575-2208  
irb@uark.edu479-575-4910

## Appendix D

IRB #16-11-219  
Approved: 11/28/2016  
Expires: 11/27/2017



UNIVERSITY OF  
ARKANSAS

Office of Research Compliance  
Institutional Review Board

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November 30, 2016

## MEMORANDUM

TO: Emily Sugg Richter  
Fran Hagstrom

FROM: Ro Windwalker  
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 16-11-219

Protocol Title: *Adopting Children with Down Syndrome: A Qualitative Study of Family Experiences*

Review Type:  EXEMPT  EXPEDITED  FULL IRB

Approved Project Period: Start Date: 11/28/2016 Expiration Date: 11/27/2017

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Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<https://vpred.uark.edu/units/rscp/index.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

**This protocol has been approved for 40 participants.** If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or [irb@uark](mailto:irb@uark).