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Exploring Birthparent's Experiences of Creating an Adoption Plan for Their Children with Special Needs

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Exploring Birthparent's Experiences of Creating an Adoption Plan for Their Children
with Special Needs

by

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Abstract

Very little information is available regarding the experience and needs of families who create an adoption plan for their child with disability. The purpose of this study was to learn more about the experiences of birthparents who created an adoption plan after the diagnosis of Down syndrome so as to understand their needs during the process.

Birthparents were invited to participate in the study through National Down Syndrome Adoption Network (NDSAN) by membership emails. Information about the study was made available on the organization's website and social media pages. Potential participants also learned about the study from one of the co-authors of the study. Participant inclusion criteria included individuals who were 18 years of age and older, who had created an adoption plan for their baby with Down syndrome, and who were willing to participate in the telephone interview. Semi-structured telephone interviews were conducted with five mothers who had created adoption plans for their children with Down syndrome. Conventional content analysis methods were used for systematic coding and identification of emergent themes. All five participants were Caucasian, over 35 years of age, and all but one were married and had previous children. All except one chose to create an open adoption plan. The interviews focused on three major areas: (1) families' reasons for creating an adoption plan, (2) informational and emotional needs of these families, and (3) messages to other birthparents and medical health professionals about special needs adoption. Participants reported various reasons for creating an adoption plan including unplanned pregnancy, being unprepared to raise a

child with Down syndrome, and religious and personal beliefs about termination of pregnancy. Having support of their partners, gaining acceptance from others about their decision and talking to other birthparents who have gone through the same situation were the most significant emotional needs of these birthmothers. Finding information about adoption resources was one of the informational needs experienced. Not all birthmothers interviewed received information about the option of adoption from their genetic counselors or medical healthcare providers. The birthmothers also expressed concerns that people are unaware of the option of creating an adoption plan, and suggested that more exposure is necessary. Sharing results from this study with genetic counselors and other healthcare professionals may help future birthmothers approach this option with greater ease, and hopefully help healthcare professionals provide support and referrals to clients involved in special needs adoptions.

Table of Contents

Acknowledgements	iii
Abstract	iv
Chapter 1: Background	1
Chapter 2: Exploring Birthparent’s Experiences of Creating an Adoption Plan for Their Children with Special Needs	
2.1 Abstract	9
2.2 Introduction	10
2.3 Materials and Methods	11
2.4 Results	12
2.5 Discussion.....	21
2.6 Conclusions	31
Chapter 3: Conclusions	32
References.....	33
Appendix A: Patient Interview Questions	36
Appendix B: Participant Invitation Letter.....	43

Chapter 1: Background

Receiving an abnormal prenatal diagnosis can be a very emotional time for parents as they must comprehend the implications of the diagnosis and at the same time make pregnancy management decisions. It is often difficult for parents to decide between the three available options of continuing the pregnancy and parenting the child, terminating the pregnancy or creating an adoption plan for the child. During such a sensitive and life changing time in their life, genetic counselors and other health care professionals should be able to provide parents with accurate, updated information about all available options, helpful resources and required emotional support.

The Kennedy-Brownback bill signed into law in 2008 emphasizes the necessity for up-to-date, evidence-based information and support services for Down syndrome (Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008). Subsequently, the National Society of Genetic Counselors (NSGC) published practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome. These guidelines recommend discussing all available options for pregnancy management including the option to create an adoption plan in both the prenatal and postnatal settings (Sheets et al., 2011). Population-based studies in the United States reflect a termination rate of 61% to 93% for pregnancies diagnosed with Down syndrome (Natoli, Ackerman, McDermott & Edwards, 2012). With increasing advances in prenatal testing options, more pregnancies with fetal anomalies can be detected earlier in the pregnancy. Given the termination rates of pregnancies with Down syndrome, it can be deduced that the option

of termination is well known and discussed widely by medical health professionals including genetic counselors. However, for some parents, pregnancy termination may not be an option due to moral, religious, cultural, or ethical views. In the second trimester especially, parents may feel that termination is not an option because they have already experienced fetal movement and have developed parental bonding with the pregnancy (Pryde et al., 1992). A favorable prognosis, significant uncertainty about prenatal findings, or the promise of intrauterine or neonatal therapy are other reasons parents may decide against pregnancy termination (Fonda & Mulhouser, 1995; Sandelowski & Jones, 1996). Other logistical reasons might render the option of termination unavailable, such as legal gestational age limits placed by a patient's state of residence (Fonda & Mulhouser, 1995). Accurate data are not available about how many parents choose to continue the pregnancy or terminate because they are simply not aware of the availability of an adoption option. No studies have been done to determine whether the knowledge of the option to create an adoption plan would have a significant impact on the final decision made by the parents.

Farrelly et al. (2012) analyzed transcripts from simulated genetic-counseling sessions to assess which options genetic counselors discussed with patients who receive a prenatal diagnosis of disability in the fetus. Only 13% of the 93 genetic counselors mentioned adoption. Studies from Mates (2008) and Oksala, Apse & Brewster (2007) also demonstrate that genetic counselors and other healthcare professionals lack a thorough knowledge of adoption, specifically regarding policies, resources and referrals. Thus, many healthcare professionals feel unprepared to discuss this option with patients. An unpublished thesis reported that many genetic counselors feel unprepared to equally

offer the option of adoption in addition to options of pregnancy termination and parenting a child with special needs (Perry, 2003). These studies suggest that the creation of an adoption plan is often unexplored unless a patient inquires specifically about adoption. In some cases, making an adoption plan is added as an alternative rather than an equal option to termination and parenting (Perry & Henry, 2009). Thus, patients may not receive the information needed to make an informed decision and/or families most likely find adoption-related information and support on their own.

Information-seeking is identified as one of the common coping mechanisms for patients who have received an abnormal diagnosis (Garvin & Kim, 2000). Patients who educate themselves about different options are more confident about their decision for pregnancy management and report that exploring alternative options provides at least a small element of control over a situation in which they may feel otherwise helpless (Finnegan, 1993). Parents who choose adoption after careful consideration of options usually find peace in knowing that they made an informed choice (Finnegan, 1993). Thus, as recommended in clinical practice, including adoption in the discussion of all available options is essential.

Many healthcare professionals are unaware about the availability of adoptive families eagerly waiting to adopt children with special needs (Lindh, Steele, Page-Steiner & Donnenfeld 2007). The possibility of creating an adoption plan is neither greatly discussed in the literature nor do medical professionals or genetic counselors have extensive training or experience regarding the adoption option (Perry & Henry, 2009). When presenting the option of adoption to patients, providers could be more helpful by having some information about available agencies and the logistics of the process.

Parents might also have questions about the families who are willing to adopt children with special needs (Finnegan, 1993). However, due to the dearth of available literature about special needs adoption and experiences of patients who have created these adoption plans, genetic counselors find difficulty in helping the parents in their decision-making process. This problem may be compounded by the social stigma about the adoption prevalent in society. In the past, attitudes toward adoption were essentially shaped by social stigmatization of young unmarried mothers who created an adoption plan for their children (Wegar, 2000). Thus, it is possible that sometimes healthcare professionals' personal views or preconceived beliefs about adoption might have an impact on their comfort level while presenting the adoption option.

In *Shattered Dreams - Lonely Choices*, Finnegan,(1993) described experiences of several birthparents who had created adoption plans for their children with special needs and were informed by their healthcare providers that adoption was not an option, as nobody would want to adopt a child with special needs. However, there has been a major change in adoption practices in the United States regarding the characteristics of children who are considered 'adoptable'.

In the past, children with developmental, physical, or intellectual disabilities were considered 'unadoptable' and often remained in institutions for life. Until the mid-twentieth century, children were regularly screened to determine if they had any characteristics that made them unsuitable candidates for adoption (Riley & Vleet, 2012). Peter and Joyce Forsythe of Ann Arbor, Michigan, were instrumental in bringing the change in the definition of 'adoptable' commonly accepted by several adoption agencies. They faced challenges while adopting a child from several public adoption agencies and

realized that there were several ‘unadoptable’ children waiting on agencies’ waiting lists but the agencies did not consider them as a ‘right candidate’ for Forsythe’s request of adoption, as these children had disabilities. After this experience, they were determined to change the definition of ‘adoptable’ and formed the Council on Adoptable Children (COAC). Due to the efforts of COAC and other adoption agencies, today all children are considered adoptable, irrespective of their health or special needs status (Sullivan, 1996). These attitudes and practices have changed; most children are not institutionalized and most agencies strive to place all their children with a good family. Most adoption agencies (and those involved in the adoption) consider full disclosure of these special needs as necessary to achieve the most desired adoption outcomes.

With these changes, numbers of special needs adoptions have increased and many families are waiting to adopt a child with special needs (Riley & Vleet, 2012). These families may feel physically, emotionally, or financially better prepared to parent a child with special needs for countless reasons. Gallinger (2012), who in her study interviewed adoptive parents of children with special needs and found that previous experiences with individuals with special needs and religious beliefs are the most motivating factors for them to adopt a child with special needs. Glidden (1990) found that adoptive families may not experience the severe initial reactions of shock, denial, despair, and depression that birth parents often do in parenting a child with a disability. These findings are thought to stem from the fact that adoptive parents make a conscious decision to parent children with special needs and can decide the extent to which they feel comfortable with their ability to care for a child with a particular disability. Typically, adoptive parents also have time to prepare for the child’s arrival and health needs, while birthparents may not

have this opportunity (Perry & Henry, 2010).

While little information has been gathered about families who create an adoption plan for their child with special needs, literature about the characteristics and experiences of families who have chosen adoption for their children without special needs is readily available. The National Survey of Family Growth (NSFG) provides insight about determining factors which affect adoption plans created by unmarried mothers (Riley & Vleet, 2012). Bacharch, Stolley & London (1992) found that the creation of adoption plans is far more prevalent among white women than black women, with an extremely low level of adoption plans among Hispanic mothers. Further, this study demonstrated that creation of an adoption plan for a child born to a never-married white woman is associated with several factors such as availability of abortion, high level of maternal education, and costs of becoming a parent. Difficulties in obtaining abortions and delays in recognizing pregnancy are also the primary factors contributing to the incidence of late abortion and are likely to contribute as well to the decision to create an adoption plan. The women who placed their children for adoption waited until later in their pregnancies to contact or enter assistance programs than women who keep their babies. In the NSFG survey of 2002, demographics of adoptive and birthmothers were compared (Riley & Vleet, 2012). They found that adopting mothers are more likely to be white, currently married, and older and to have a higher family income and years of education as compared to the birthmothers. Thus, race, religion and financial stability are the types of variables that differentiate women who seek abortion from those who give birth and place a child for adoption.

Before deciding upon the adoption plan, birthparents need to find out about the procedures for adoption and different types of adoption options available. Many parents when offered adoption often think of a single, pregnant, teenage girl who relinquishes all rights to her baby never to see and hear about the baby again (Finnegan, 1993). Some birthparents choose to have no contact with their child as it is too painful for them to have continued contact. They may choose to create a closed adoption plan. Some parents choose open adoption and mostly can decide what level of contact they want to maintain with the baby and the adoptive family. One study which surveyed the attitudes of adoptive mothers towards birthmothers, adoptive children, and parenting found that ongoing contact between adoptive mother, adoptive children and birthmother is often beneficial for the triad (Lee & Twaite, 2000). However, it is important for parents to carefully examine their feelings about the openness of an adoption plan before choosing an adoptive family, as each family is different and has different coping mechanisms to deal with the separation from their child.

The decision to place a child for adoption is a difficult decision for patients (Winkler, Brown, van Keppel, & Blanchard, 1988). Patients may not discuss their feelings for fear that their emotions are inappropriate or abnormal. Many birthmothers report that they were not fully prepared for the strong emotions that accompany their decision to create an adoption plan (Wiley & Baden, 2005; Winkler et al., 1988). Many birthparents feel that the child will have a better life in an adoptive home and are putting the child's best interests ahead of their own when they make the decision to place the child for adoption (Clutter, 2014). Other reasons birth parents place their children for adoption include societal and family attitudes, personal goals and ambitions, and

socioeconomic situations (Clutter, 2014). Parents who decide to place their child for adoption begin to plan for a great loss in their own lives with the hope that the decision will result in a better life for their baby and for themselves. The birth and the actual surrendering of the baby may prompt various phases of grief for the birth parents (Romanchik, 1999).

While there may be similarities in the motivations and emotional adjustments of birthparents that create adoption plans for their children with and without special needs, it is difficult to generalize about the experiences and emotional impact of all birthparents. The lack of insight into motivations and experiences of birthparents may have an impact on the genetic counseling process; as such information may be helpful to the genetic counselor when working with patients faced who may choose to consider an adoption plan.

Chapter 2: Exploring Birthparent's Experiences of Creating an Adoption Plan for Their Children with Special Needs¹

2.1 Abstract

Little information is available regarding the experience and needs of the families who create an adoption plan for their child with disability. The purpose of this study was to learn more about the experiences of birthparents who created an adoption plan after the diagnosis of Down syndrome to understand their needs during the process. Birthparents who had created adoption plans for their child with Down syndrome were invited to participate through the National Down Syndrome Adoption Network (NDSAN) by email to the membership. Information about the study was also made available on the organization's websites and social media pages. Potential participants also learned about the study from one of the co-authors of the study. Participant inclusion criteria included individuals who are 18 years of age and older, who have created adoption plans for their child with Down syndrome, and who were willing to participate in a telephone interview. Semi-structured telephone interviews were conducted with five mothers who had created an adoption plan for their baby with Down syndrome. Conventional content analysis methods were used for systematic coding and identification of emergent themes. All five participants were Caucasian, over 35 years of age, well educated, and all but one were married and had previous children. All except one chose to create open adoption plan. The interviews focused on three major areas: (1) how did the families learned about

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the option of creating an adoption plan, (2) their reason for creating an adoption plan, (3) informational and emotional needs of these families, and (4) messages to other birthparents and medical health professionals about special needs adoption. Not all birthmothers interviewed had received information about the option of adoption from their genetic counselors or medical health providers. Participants reported various reasons for creating an adoption plan including unwanted pregnancy, being unprepared to raise a child with Down syndrome, and religious and personal beliefs about termination of pregnancy. Having the support of their partners, gaining acceptance from others about their decision, and talking to other birthparents who have gone through the same situation were the most important emotional needs expressed by these birthmothers. Finding information about adoption resources was one of the greatest informational needs. Birthmothers also expressed concern that people were unaware of the option of creating an adoption plan and expressed that more exposure is necessary. Sharing results from this study with genetic counselors and other health professionals may help future birthmothers approach this option with greater ease and hopefully help healthcare professionals provide support and referrals to clients interested in exploring special needs adoptions.

2.2 Introduction

Parents who receive a diagnosis of their baby's disability either through prenatal diagnosis or at birth are often faced with difficult decisions regarding the pregnancy or their child. To fully support these parents, they should receive accurate information about all the available options along with the emotional support required to help them cope with these life-altering circumstances (Sheets et al., 2011). Previous studies have suggested

that the option of an adoption is not routinely discussed as an equivalent option when faced with the decision regarding the outcome of the pregnancy (Mates 2008; Oksala et al., 2007). Because very little information is available regarding the experience and needs of these families genetic counselors and healthcare professionals may not understand what forms of support may be helpful for birthparents who create an adoption plan for their child with a disability or special needs.

The purpose of this study was to explore the experiences of birthparents who have created an adoption plan for their children with Down syndrome in order to determine the following objectives: a) to learn how they learned about the option of creating an adoption plan; b) to characterize their reasons for pursuing this option, and c) to identify their emotional and informational needs throughout the process. The experiences shared by participants in this study may be useful in educating genetic counselors and other healthcare professionals about the adoption of children with special needs in order to improve the support and resources provided to future families.

2.3 Materials and Methods

2.3.1 Participants. Eligible birthparents were invited to participate in the study through the National Down Syndrome Adoption Network (NDSAN) by emails to their members. (Appendix A). Information about the study was also made available on the organization's websites and social media pages. Potential participants also learned about the study from one of the co-authors of the study. Participants inclusion criteria included individuals who are 18 years of age and older; who have created an adoption plan for their child with Down syndrome; and who were willing to participate in an in-person or telephone interview lasting no more than 60 minutes.

Semi-structured telephone interviews were conducted with each participant separately and were digitally recorded. Personal identifiable information was not transcribed in order to further protect the participants' privacy and confidentiality. This study was approved by the University of South Carolina Institutional Review Board in November, 2014.

2.3.2 Statistical Analysis and Statistical Methods. Verbal responses from each interview were transcribed and analyzed to identify emergent themes (Ryan & Bernard 2003; Bradley, Curry & Devers 2007; Taylor & Gibbs 2010). Conventional content analysis methods were used for systematic coding and identification of emergent themes (Hsieh & Shannon, 2005). Data was independently coded by the investigator with regular inter-coder consistency checks and discussion of discrepancies.

2.4 Results

2.4.1 Participation invitation response. Five participants responded to the study invitation and contacted the lead investigator.

2.4.2 Demographics. Four of the five participants interviewed in the study were married females with prior children before the creation of an adoption plan. The demographic characteristics of the participants are listed in Table 2.1. No difference was found in the experiences of birthmothers or in their attitudes towards adoption based on their religious affiliation, marital status, financial status, or education. The participants ranged in ages between 36 to 41 years of age. All adoption plans were created after the prenatal diagnosis of Down syndrome. Four of the five participants created open adoption plans while one created a closed plan. Most of the adoption plans were created recently within the span of 7 months to 3 years prior to the time of this study. Table 2.2

summarizes the time elapsed since the adoption, maternal age at the Down syndrome diagnosis, number of children the birthmother had prior to the child with Down syndrome and the type of adoption plan created.

Table 2.1: Summary of Participants Demographics

Birthmother	Race	Religious affiliation	Marital status	Education	Income	Insurance policy
1	Caucasian	Catholic	Married	Bachelors	75-100K	Employer provided
2	Caucasian	Church of Christ	Married	Bachelors	75-100K	Employer provided
3	Caucasian	Evangelical Christian	Divorced	Some college	50-75K	Employer provided
4	Caucasian	Catholic	Married	Some college	75-100K	Self-covered
5	Caucasian	Catholic	Married	Bachelors	50-75K	Employer provided

Table 2.2: Summary of Participant Information Relevant to Adoption

Birthmother	Time since adoption (months)	Maternal age (at the time of diagnosis)	No. children before the child with Down syndrome	Type of adoption
1	12	47	2	Open
2	11	35	1	Open
3	8	41	0	Closed
4	18	45	3	Open
5	40	41	2	Open

2.4.3 Qualitative analysis. The interview discussions focused on four main areas: (1) reasons for creating adoption plan, (2) factors instrumental in finalizing adoption plan, (3) emotional and informational needs during the process and (4) messages to healthcare providers and other parents who are considering an adoption option. We identified recurrent themes using codes to categorize the participant’s remarks under these areas of discussion.

2.4.3.1. Reasons for creating adoption plan for the child. Three major themes emerged when discussing the underlying reasons for creating an adoption plan for a child with Down syndrome.

Not prepared to raise a child with special needs/ Down syndrome.

All of the participants felt that they were not mentally prepared or equipped to raise a child with special needs/ Down syndrome. Birthmother 01 said, *“I don’t have that much energy. I am still at work. Oh my goodness. We will have to get a bigger house. That will be a lot of work. I am just not ready for this.”* Birthmother 03 said, *“The adoption plan was decided strictly because the child had Down syndrome.”* Birthmother 05 said, *“The diagnosis was Down syndrome and it was emotionally devastating. Adoption was my only hope and I suddenly had a purpose and I could go through it.”*

Unplanned pregnancy

Two of the participants felt that one of the reasons that they created an adoption plan for their child with Down syndrome was that they were not planning to have further children. Birthmother 01 stated, *“It was unplanned pregnancy. I was shocked to find out that I was pregnant number one, we did not want any more children, we were happy with two. That’s all what we wanted.”* Birthmother 05 also cited similar reasons as she did not want to be pregnant in the first place and adoption seemed the right option when it was first mentioned.

Termination of pregnancy was not an option due to religious/ personal reasons

Religious and personal beliefs about termination of the pregnancy were among the reasons why most birthparents considered an adoption option. Birthmother 01 said, *“I am Catholic. Abortion wasn’t really an option.”* For other birthmothers termination of the

pregnancy was not an option due to their personal opinion about abortion. Birthmother 04 said *“I think the worse thing to do would be the abortion. You would have to live with that guilt forever from what I have read and heard.”* Birthmother 03 stated, *“I had decided that if the child is strong enough then I’ll carry it to term but I’ll not take the decision to kill the child.”* Birthmother 05 decided against termination of the pregnancy after she heard the details of the procedure involved. *“That (abortion) was my initial thought. Then the genetic counselor told me this is not as simple as I thought. This was my 24-weeks living, breathing pregnancy. She explained to me what the process was and I didn’t want it.”*

2.4.3.2 Factors instrumental in finalizing adoption plan. Three major themes emerged when searching for factors which helped birthparents while finalizing their plan of creating an adoption plan for their child.

Finding the “right” adoptive family

All of the participants mentioned that finding the right home and loving family for their child was instrumental in finalizing their decision. Birthmother 01 said, *“He’s going to be with someone who is prepared...who will love him unconditionally and that’s what you want for any child.”*

Having control over choosing the right family for their child was an important factor too. Birthmother 02 said, *“We were choosing an option where there were people who were gonna love him. It wasn’t abandonment... We had tons and tons of choices.”*

Birthmother 03 stated, *“I heard a man say, “thank you” and realized it was the adopting father that had come into the room to hold the child and had calmed the child.*

Knowing this I then knew the child had a great father and I found even more peace with my decision.”

For some birthparents it brought closure to their decision. Birthmother 05 said, *“that was for an absolute closure. I was absolutely 100% comfortable with that decision.”*

Most birthparents had specific criteria while choosing the family and finding a family which matched their requirements was helpful for them as they progressed with their adoption decision. Birthmother 04 said, *“They were also Catholic and when we met with them I felt they were just good people. And they had no other reason than to just help. They just wanted to love my child.”*

Birthmother 02 stated, *“We found a wonderful family in Missouri .We spoke to the family at length. (We) asked them a few questions, religious questions especially. We wanted to make sure that he would have same kind of religious upbringing that he would have had here with us.”*

Putting their child’s best interest /needs above their own

Creating an adoption plan was the most painful and difficult decision that the birthparents had to make and the strong belief that this decision was for their child’s best interest was instrumental in their decision making process. Birthmother 01 said, *“He’s not a toy, he’s a life. We have to think what’s best for him. You get over it, you will adjust. It’s not about us. That’s when it’s easier to make the decision.”* Birthmother 02 stated, *“I took the best decision that I could in that situation. But it’s much better than the abortion.”*

Recognizing their inability to parent a child with special needs

One birthmother expressed that meeting with families of children with disabilities to understand what is involved with raising a child with Down syndrome was an important aspect of their decision making process.

Birthmother 05 stated, *“That’s what my husband wanted....The biggest thing is that it’s very time consuming. We not knowing the severity how it is going to be affected... that was always an unknown. It depends on her severity. She could be in diapers till she is 20 or 5. Those are all factors that helped us to understand the dynamics of Down syndrome and how it would affect her life and ours.”*

2.4.3.3 Emotional and informational needs during the process. Three major themes emerged when analyzing the emotional needs birthmothers experienced during the adoption process.

Husband’s/partner’s support in the decision

Two of the birthmothers felt that having a partner’s consensus and full support was most helpful while they were coping with the situation emotionally. Birthmother 02 said, *“The fact that me and my husband were truly together on this decision (was most helpful).”* Some birthmothers did not get the support they required from their partners, either because their husbands/partners had not come to the terms with the diagnosis and the decision of adoption or were not there for them by choice. Birthmother 01 felt that her husband wasn’t there for her emotionally and that made the process harder as she had to struggle on all fronts, including gathering information and dealing with her own emotional upheavals during the entire adoption process.

Non-judgmental approach of others and respect for their personal decision

Most birthmothers feared the tone of judgment when they shared their decision of adoption with others. All wished that other people did not judge them as parents because of their decision and were more accepting and respectful of their choice. Fear of feeling judged was one of the main reasons why all the birthmothers felt difficulty in sharing this decision with their immediate family members, friends, and co-workers. This was also the reason why all birthparents decided to share this information only with select people. Birthmother 01 said *“Telling family members and public was hard. It was really hard. Everyone gets to judge you. Whether you know it or not but you are judged. All those moms are judging me ...”* Birthmother mother 03 said, *“Everyone had their opinion and deep need to share it with me.”* Birthmother 04 stated, *“I actually did not share this information, tried avoiding people, stayed at home. I didn’t want people to ask me questions and everyone would talk about it and they will not understand ‘cause they will never be in the same situation that I am in.”* One birthmother who had a positive experience during delivery from the hospital staff who were supportive and sensitive to her emotional status said, *“That was a big factor making the situation better. It was a good memory in the entire horrible one.”*

Talking to other birthparents

Most of the birthmothers felt talking to other birthparents who have gone through the same situation as theirs was very helpful. Birthmother 02 said, *“We also spoke to both of them (birthmothers) before we told our families; that made a big difference because they have gone through the same. They were able to (understand us). Talking to them really helped me to make progress on my decision.”* One birthmother did not get the

opportunity to talk to other birthparents and felt talking to someone who had gone through what she experienced would have been helpful.

2.3.3.4. Informational Needs. Two major themes emerged when assessing the informational needs that birthparents experienced during the adoption process.

Finding out about adoption option

Not all birthmothers were presented with the adoption option as they met with their medical healthcare providers during the prenatal diagnosis of Down syndrome. Three of them received this information from their genetic counselor and two of them found out on their own from a Down syndrome information book or the internet.

Connecting with other parents

One birthmother stated that she wished the hospital or the genetic counselor could have connected her with the parents who have a child with Down syndrome to understand what is involved in raising a child with special needs.

2.3.3.5 Messages to healthcare providers and to other birthparents. Two themes emerged from the messages birthparents had for healthcare providers which they thought would be helpful in care of other birthparents.

Be Compassionate and open-minded and recognize birthparent's needs.

Most birthparents wanted their healthcare providers to be nonjudgmental, compassionate, and respectful toward their decision. Two birthparents mentioned that it would have been great if the genetic counselor would have followed up with them after the diagnosis of Down syndrome about their decision. They felt they were left alone to fend for themselves since they had not chosen one of the more common options of termination or continuing the pregnancy. Birthmother 04 stated, *“It’s important that you*

keep talking to the parents until they make a decision. Don't give up on them." It is critical for healthcare providers to recognize that these patients are in a vulnerable position and healthcare providers should be sensitive toward their situation. One of the birthmothers who had created a closed adoption plan for her child got to know information about the child even though she had specifically requested against it, due to miscommunication between the people within the organization. She had many similar experiences where people who were involved in her care were unaware of her situation. She stated, *"There should be one point of contact in the medical profession so that the right hand knows what the left hand is doing."* On the other hand, parents who received caring help from medical professionals greatly appreciated the unbiased support.

Be informed about all the available options

Most birthparents stated that presenting all the available options to the parents is essential, as one of the options might be a right option for that particular family in certain circumstances.

2.3.3.6 Messages to Birthparents. One primary and important theme emerged from participant's comments about ways that birthparents can have a better experience.

Educate yourself about adoption and be open to learning more before making a decision

For some birthparents, adoption did not come across as the right option when it was mentioned the first time. Most of the birthparents advised that parents should weigh all their options after gathering the maximum possible information. Birthmother 02 said, *"People are going to be so much more supportive than you would ever dream. To be open."* Birthmother 03 stated, *"I believe that adoption is a beautiful thing and if you're*

persistent you'll find the right family and be able to have peace and resolution with your decision.” Birthmother 05 said, “Don't make the rash decision until you have all the information on the table. You might uncover something that might change your decision.”

2.5 Discussion

The purpose of this study was to explore the experiences of birthparents who have created an adoption plan for their children with Down syndrome in order to determine how they learned about the option of creating an adoption plan, to characterize their reasons for pursuing this option, and to identify their emotional and informational needs throughout the process. The five qualitative interviews with birthmothers performed provided an in-depth view of the experiences and issues surrounding creating an adoption plan for their child with Down syndrome. Creating an adoption plan was an important and emotional decision for these participants. This study determined the main factors which were instrumental in their decision-making process. The participants also shared messages they wanted to convey to other prospective parents and healthcare professionals about special needs adoption experiences.

Every family or individual had their own reasons behind creating an adoption plan. Birthmothers in this study decided to create an adoption plan for three primary reasons. All the birthmothers explained that the adoption plan was created based on the diagnosis of Down syndrome, as they felt unprepared to raise a child with special needs. Before coming to this conclusion, they had acquainted themselves with Down syndrome and associated health conditions. One of the birthmothers recounted her experience of how her husband constantly wished that the baby had mosaic Down syndrome which they understood had milder range of health concerns. The unpredictability of spectrum of

the severity of the health concerns associated with Down syndrome was an important factor she considered while making the decision.

One of the other reasons given by the birthmothers for creating an adoption plan was that the pregnancy was unexpected and not desired at that juncture in their life. Two of the birthmothers in the current study mentioned how the pregnancy news had taken them by surprise and they did not wish to be pregnant at that time. Some of these birthmothers stated that they were simply not ready to give the support and commitment required for parenting at that stage in their lives. A recurring theme with all of the participants in the current study was that they felt that they did not have all the resources or were not equipped emotionally to raise a child with special needs.

Religious beliefs and personal views about pregnancy termination also had an impact on the birthmother's decision for creating an adoption plan. The major themes seen in the birthmother's discussions of their reasons for creating an adoption plan for their child with Down syndrome were similar to findings in previous studies of birthmothers who had either created an adoption plan for their typically developing children without Down syndrome (Clutter, 2014). For some patients for whom termination of pregnancy is absolutely not an option but who have concerns regarding their ability to raise a child with special needs, creating an adoption plan can be a fitting alternative. Healthcare professionals, including genetic counselors, should recognize and acknowledge this and explore the patient's views about the option of creating an adoption plan.

All the birthmothers interviewed in the study stated that creating an adoption plan for their child was one of the most difficult decisions in their life. For most birthmothers,

it was an option that they had never heard before and they needed time to come to peace with their decision. For most of them, adoption was not a clear decision from the first day. As they educated themselves further about adoption and processed the information, they felt more strongly about this option.

The birthmothers in this study felt that by creating an adoption plan and finding a family who would take care of their child, they were acting in their child's best interest. A previous study which explored experiences of birthmothers who had created an adoption plan for their children without special needs also found that birthmothers believed they were creating a better opportunity for their children and putting their interest ahead of their own interest (Clutter, 2014). The birthmothers felt that the benefits of adoption outweighed the challenges of pregnancy, birth, and difficult emotional transitions. They wanted their children to have a loving family unit, stable life and home, provision for their needs, best life possibilities, and better life than what they could give to them (Clutter, 2014). All these desires were consistent with those reflected by the five birthmothers in the current study.

Finding a loving family who is well-prepared to take care of their child seemed to be paramount in finalizing their decision to create an adoption plan. Similarly, all the birthmothers appreciated the peace of mind they achieved knowing their birth children were safe, thriving, and growing. All these birthmothers also mentioned that they had strict criteria for selecting the adoptive family and were happy that they had control over choosing the right family for their child. Lee and Twaite (1997) found that a good, open relationship between adoptive mother and birthmother has a positive influence on the biological mother, on the adopted child, and on the parenting relationship between

adoptive mother and child. Four of the five birthmothers in the current study indicated that maintaining continued contact with the adoptive family provided them reassurance that their child was taken care of and was well accepted and loved in his/her new family.

The majority of the interviews concentrated on exploring the emotional and informational needs of birthmothers during the process of creating an adoption plan. Emotional needs of these birthparents were finding good support from their partner, wanting other people to be accepting and non-judgmental about their decision, and talking to other birthparents who had gone through a similar experience as theirs.

Many of the birthmothers stated that their families and communities were surprised and concerned when they first learned about the adoption. Most of them shared this information with immediate family members first and decided to withhold the information until the adoption procedure was completed. Some birthmothers had to consider how they would tell others who had not known about the pregnancy or adoption because the birthmothers did not know the level of support others would give. Two of the birthmothers decided not to share this information with the community, as they thought people would not be able to understand their decision. All birthmothers felt judged for their decision to make an adoption plan instead of parenting. In her book, *Shattered Dreams - Lonely Choices*, Finnegan (1993) described experiences of birthparents of babies with special needs and explained how society expects parents with children who have special needs to parent the children. For most of these mothers, being a birthmother and having made an adoption decision was very hard emotionally. Even those who had a strong sense that adoption was the best choice still had difficulty. Thus, medical professionals and those involved in the care of these parents must be sensitive and

supportive of the birthmothers' decision and remain non-judgmental in their actions and words.

Birthmothers may need help when they decide to share the information with their children, family members, and significant others. Genetic counselors can provide guidance and support as the birthmothers explain the situation and their decision to others. In the current study, one birthmother explained that sharing adoption information with her father was difficult for her, and that her genetic counselor was a great help and even offered to be there as she shared the information with her father.

Birthmothers echoed that support from their spouse was an important factor while they made the decision. Some birthmothers in this study indicated that their partners took a longer time to come to terms with the decision, indicating that different people have individual needs and cope with the same situation on different timelines and in their unique way. Also, it is important for medical professionals to recognize and prepare couples for varying coping processes as both partners may not have the same opinion or views about the situation. Addressing these issues in a counseling session can make a difference to the patients, as most birthmothers indicated that having their partner's support in such a crucial stage in their life was very important to them.

Talking to other birthparents was also an important source of support in the birthparent's decision-making process. They were able to discuss various issues with these parents as they felt those who had a similar experience would understand their situation better than anybody else. As recommended in the NSGC statement for communicating the prenatal and postal diagnosis of Down syndrome, it can be useful for parents to have the opportunity to speak to others who have been through a similar

experience (Sheets et al., 2011). Therefore, genetic counselors may benefit from having contact information of birthparents who are willing to talk to others about their experience in creating an adoption plan for their child with Down syndrome or other special needs conditions and may wish to connect these parents with the local adoption agency experienced with special needs adoptions.

Two informational needs of the birthmothers were realized. The first one was information about the option of creating an adoption plan. Two out of five birthmothers did not get the information about the option of adoption after the diagnosis of the Down syndrome from their healthcare provider and had to find out the information on their own. These birthmothers felt alone while they struggled with finding more information. Three birthmothers who were given information about adoption received it through their genetic counselor and felt that the counselor provided them with the required resources and connected them with the adoption agency. Practice guidelines published by National Society of Genetic Counselors (NSGC) state that all available options for pregnancy management including the option to create an adoption plan in both the prenatal and postnatal settings should be discussed with patients (Sheets et al., 2011).

One of the birthmothers stated that they had an opportunity to meet the families who were raising children with Down syndrome. Interacting with those families and having that perspective also helped her and her husband finalize their decision. Providing opportunities for birthparents to educate themselves about the diagnosed condition is very important, because as they learn more about the condition, the more they feel confident about their decision.

One study which focused on the experiences of healthcare providers while providing the option of adoption and related information revealed that 39% of them did not offer the option of adoption, as they did not think of it or they lacked information and resources which would help them to discuss that option (Oksala et al., 2007). The current study findings where two of five were not offered the option of creating an adoption plan from either their healthcare providers or genetic counselors was consistent with the study published in 2007. Another study by Perry (2003) revealed that 5% of genetic counselors agreed that an informational website on the option of adoption would be useful for expectant parents as well as healthcare professionals. They reported feeling unprepared to provide referrals to clients in such situation. Thus increasing availability of resources can bring greater awareness among patients and health care providers. Henry & Perry (2010) recommended that genetic counselors and other healthcare providers involved in the care of patients facing prenatal and postnatal diagnosis of special needs familiarize themselves with local adoption agencies and organizations. They also recommend that national organizations such as the NSGC should seek to collaborate with experts in the field of adoption to encourage continuing education opportunities through conferences and other professional developmental opportunities.

Another informational need stated by some of the birthmothers was to connect them with the parents who have raised a child with Down syndrome and those who have created an adoption plan for their children with Down syndrome. Genetic counselors should feel comfortable referring their clients to local adoption agencies and other professionals for support if they do not have the resources to connect their clients with these parent groups.

Birthmothers were also asked to share suggestions for other expectant birthparents considering the decision to create an adoption plan as well as healthcare professionals involved in their care. All of the birthmothers interviewed wanted prospective parents who were considering adoption for their child to be open-minded toward adoption and weigh all their options before making the final decision. Some birthmothers had dismissed the option of creating the adoption plan when it was first presented to them and only after careful consideration and after acquiring more information did they realize that this was the right option for them. Genetic counselors should be aware and inform expectant parents who are considering this option that there are families who are not only willing, but are also grateful for the opportunity to parent children with special needs including Down syndrome.

All birthmothers emphasized that healthcare professionals should be compassionate, non-judgmental, and respectful of their patients' decisions. Therefore, when discussing the option of adoption after a prenatal or postnatal diagnosis of Down syndrome or other special needs condition, genetic counselors and health care providers must be sensitive to how the birthparents feel and how others may perceive them for their decision to choose adoption. Genetic counselors can provide anticipatory guidance about what these birthparents might experience as they move along the adoption process and their ongoing support may be helpful in preventing subsequent or exaggerated feelings of isolation which birthparents typically feel. It is also important for medical health professionals and genetic counselors to use appropriate and respectful language when discussing adoption and they should be able to respond to the myths and misconceptions raised by the patients. In addition, the participants hoped that their participation in this

study would increase awareness of the option among health care providers as well as the general public. This in turn would improve understanding of the needs of the patients who are considering special needs adoption and perhaps aid in the decision-making process.

Preconceived, societal beliefs may still exist that mothers who choose to create adoption plan for their children are often young adolescent mothers or mothers who have children before marriage (Wegar, 2000). However, in the current study the participants were Caucasian, all but one was married, older than 35 years and had children prior to the creation of an adoption plan. This profile does not conform to what society may expect for an individual who would create an adoption plan. This notion was supported by the experiences of the birthparents in the current study. When asked about her initial reaction to the option of adoption, one birthmother recounted that she had out rightly dismissed it as she felt that was not an option for a couple who is married, is older, and has children. She stated *“I was like ..no...no..we are married and we have a two year old. It’s not what people of our age do.”* Thus, it is possible that clients who immediately refused the option of adoption may be basing their decision upon a preconceived or stereotypic societal perception of who is more likely to consider creating an adoption plan for their baby. Healthcare providers and genetic counselors should be aware that some patients may not consider the adoption option if they have preconceived ideas of the profile of parents who would consider adoption.

Limitations and avenues for future research

This study was limited by a convenience design and a small, homogeneous sample of Caucasian females. However, with limited literature available on this topic,

this exploratory study offers new insight into the experiences of birthparents who have created an adoption plan for their children with Down syndrome. Potential recruitment bias may have been introduced from identifying participants through only one adoption agency; however, few organizations exist which specialize specifically in Down syndrome or special needs adoption. This was an important initial investigation with a patient population which has not been studied extensively before. As with any qualitative study, results may not be generalized for the entire patient population. However, these results provide a deeper understanding of the process of creating an adoption plan after diagnosis of Down syndrome. Another limitation of this study is that it used qualitative methodology and the study's principal investigator subjectively created all coding and emergent themes after analyzing interview transcripts.

The experiences shared by these birthmothers during the study that the adoption process is a very emotional event in the birthparent's life and they are reluctant to revisit that experience. This may be a likely explanation for the limited participation response. A larger sample size would have enabled us to explore more about how these families learn about the adoption option. This study has further potential for qualitative research into the various issues identified to better understand these families and their needs. Future studies should include a larger sample size incorporating a more diverse sample of individuals who have created an adoption plan for their child with special needs not just limited to Down syndrome. This study was a sampling of parents who created adoption plans within the last seven months to three years. It would be important to see how birthparents view their experience creating an adoption plan with the passage of time and to better understand their long-term needs.

2.6 Conclusions

Experiences of birthparents who chose to create an adoption plan for their baby with Down syndrome are underrepresented and unacknowledged in current literature of the healthcare delivery system. This study explored the experiences of birthmothers who created an adoption plan for their children with special needs, specifically Down syndrome and provided insight into their emotional and informational needs during the process. Greater familiarity with the perspectives of birthparents can help genetic counselors and health care providers better support parents considering the option of creating an adoption plan. Understanding the unique informational and emotional needs will assist the provider in facilitating informed decision-making and to provide appropriate resources. Genetic counselors and healthcare providers supporting patients considering the option of adoption should include discussion of the patient's feelings about the pregnancy, raising a child with Down syndrome and pregnancy management such as their views about pregnancy termination. This study also highlighted the importance for genetic counselors and other healthcare providers to keep in mind that those families who choose an adoption plan might not always fit the preconceived idea one has about the families who would choose an adoption plan for their babies. The birthmothers in this study felt that there should be more awareness about the adoption option and that this option should not be viewed with a biased perspective.

Chapter 3: Conclusion

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Appendix A: Patient Materials

Interview Guide

Participant's name:

Date:

Demographic information

- Current age:
- Gender
 - Female
 - Male
- Race (check all that apply)
 - American Indian or Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White or Caucasian
 - Other (please specify your Race) _____
- Ethnicity
 - Hispanic or Latino
 - Not Hispanic or Latino
- What is your Religious Affiliation?
 - Buddhist
 - Catholic
 - Evangelical Christian
 - Hindu
 - Jewish
 - Mormon

- Muslim
 - Protestant
 - No religious affiliation
 - Other (please specify your Religious Affiliation)
- What is the Highest Level of Education you have completed?
 - Less than high school graduate
 - High school graduate
 - Some college
 - College graduate
 - Post graduate degree
 - What is your Marital Status?
 - Single, never married
 - Single, but living with partner
 - Married
 - Divorced
 - Widowed
 - Which state do you live or have residency in?
 - For statistical purposes, please estimate your total Annual Household Income (from all sources):
 - < \$25,000
 - \$25,000 - \$50,000
 - \$50,000 - \$75,000
 - \$75,000 - \$100,000
 - > \$100,000
 - What kind of Health Insurance Policy do you have?
 - Government sponsored (e.g. Medicaid)
 - Employer-provided (e.g. group policy)
 - Private or self-coverage
 - Do not have health insurance
 - Have you or your partner been pregnant before the pregnancy or child diagnosed with Down syndrome?
 - No
 - Yes
 - If yes: How many prior pregnancies before the pregnancy/child with Down syndrome did you or your partner have?

- What were the outcomes of any prior pregnancies? Please consider newborns, miscarriages, terminations and stillbirths. (free response)
- When was the diagnosis of Down syndrome made? (month / year)
- Was the diagnosis made during the pregnancy or after birth?
- Who or what was helpful for gathering information or resources?
 - Your partner or spouse
 - Your children
 - Your or your partner's parents
 - Your or your partner's brothers or sisters
 - Other extended family members
 - Your or your partner's friends
 - Religious or Spiritual community
 - Cultural or Ethnic community
 - Genetic counselor
 - Doctor or other healthcare provider
 - Other people who have had a prenatal diagnosis of Down syndrome
 - A Down syndrome support group
 - An adoption agency
- Who or what was helpful for providing emotional support?
 - Your partner or spouse
 - Your children
 - Your or your partner's parents
 - Your or your partner's brothers or sisters
 - Other extended family members
 - Your or your partner's friends
 - Religious or Spiritual community
 - Cultural or Ethnic community
 - Genetic counselor
 - Doctor or other healthcare provider
 - Other people who have had a prenatal diagnosis of Down syndrome
 - A Down syndrome support group
 - An adoption agency

Questions

1) Explore families' experience and the process of creating an adoption plan

Could you in your own words, please tell the story about how you received the [prenatal / postnatal] diagnosis of Down syndrome.

- If Prenatal Diagnosis was done:
 - I. When the diagnosis was given, what options were presented to you?
 - II. When and how did you learn about the option of creating an adoption plan?
- If Postnatal Diagnosis was done:
 - I. When and how did you learn about the option of creating an adoption plan?

2) Understanding families reasons for choosing to create an adoption plan

- Before receiving the diagnosis, had you considered the possibility of raising a child with Down syndrome/adoption/termination?
- Did receiving the diagnosis affect your plans for the pregnancy?
- How have your plans/feelings changed?
- How did you reach your decision to create an adoption plan? Please describe the things or factors you are considering or considered when making this decision or plan for the pregnancy.
- Did talking to others about options help you make the decision to make an adoption plan?
- Did you get the opportunity to talk to other birth parents? If so, how did talking with them help you in your decision making process?
- How much did you choose to share your decision with others?

- How did you convey your decision to the other members in the family? Did you tell them in person, over the phone, via email? Why did you choose to tell them the way you did?
- How did your family react to your decision?
- If applicable: How did your partner feel about the adoption?
- If applicable: How did your other children feel about the adoption?
- What kind of reactions did you received from others that you know like friends, coworkers, acquaintances?
- What was your OBYGYN's reaction ? How did he receive your decision ?
- Tell me about the adoption plan you created.
 - I. Did you chose an open adoption or closed adoption?
 - II. Did anybody help you during this decision making?
 - III. Is there any ongoing contact with the adoptive families?

Did you make a birth plan for that day ? Made a plan for how do you want things to go that day? Whether you want to hold the baby ?/feed the baby? Did anybody helped you in that process ?

Was the hospital staff aware of the situation ? Were they supportive ?
- Please describe your experience after the adoption plan was made.
 - Potential questions.
 - I. Did you choose to see/hold baby? What was that like? Or “What feelings did you experience while holding the baby?”
 - II. Tell me about the transition (was it helpful or did it make it harder at the time of the transition)?

3) Assess informational and emotional needs of those creating adoption plans

- I can only imagine that what an emotional journey this must have been for you.

- What do you think were your biggest challenges during the entire process? In terms of support, who or what was most helpful to you?
 - I. During the adoption transition
 - II. In the long term / following the child's release
- Who or what was helpful for gathering information or resources?
 - Your partner or spouse
 - Your children
 - Your or your partner's parents
 - Your or your partner's brothers or sisters
 - Other extended family members
 - Your or your partner's friends
 - Religious or Spiritual community
 - Cultural or Ethnic community
 - Genetic counselor
 - Doctor or other healthcare provider
 - Other people who have had a prenatal diagnosis of Down syndrome
 - A Down syndrome support group
 - An adoption agency
- Who or what was helpful for providing emotional support?
 - Your partner or spouse
 - Your children
 - Your or your partner's parents
 - Your or your partner's brothers or sisters
 - Other extended family members
 - Your or your partner's friends
 - Religious or Spiritual community
 - Cultural or Ethnic community
 - Genetic counselor
 - Doctor or other healthcare provider
 - Other people who have had a prenatal diagnosis of Down syndrome
 - A Down syndrome support group
 - An adoption agency
- Was there something/someone you feel who could have helped make the adjustment easier? If so, who or what was it?

- Is there any message you would like to convey to other birth parents going through this same situation of receiving a diagnosis and considering adoption?
- Please share any other thoughts that would be helpful for medical professionals
- What would make the experience easier or less burdensome for other couples going through a similar experience?
 - I. Experience while receiving the diagnosis,
 - II. The options that were given to you and the manner in which they were given
 - III. Resources you did or did not receive

Appendix B: Participant Invitation Letter



Department of OB/GYN – Genetic Counseling

Dear Potential Participant:

You are invited to participate in a graduate research study focusing on experiences of birth parents who have created an adoption plan for their children with Down syndrome. I am a graduate student in the Genetic counseling program at the University of South Carolina School Of Medicine.

By doing this study, I hope to gain a better understanding of how you learned about adoption as an option, your reasons for choosing this option and what were your emotional and informational needs during the adoption process.

You will be asked to participate in an audio taped telephone interview lasting approximately 60 minutes. During this interview, you will be asked questions regarding your adoption experience. If you do not wish to answer a certain question, you can choose not to answer that question and continue with the rest of the interview. Your participation in this research is voluntary. At any time, you may withdraw from the study by not completing the interview.

All records containing identifying information, such as names, email addresses, telephone numbers, and home or work addresses will be kept strictly confidential during the study. All study related documents and materials (including consent forms, interview transcripts, and audiotapes) will be kept in a secure location accessible only to the student researcher, and any databases containing identifiers will be password protected using a password known only to the student researcher. Transcripts, interview notes, and audiotapes will be labeled with a coded ID number, which will be assigned to you upon enrollment into the study. All audiotapes will be destroyed after transcription of the

interviews. If you are quoted or referred to in any transcripts, written, or oral reports of the study, you will be given an alternate name. You will never be referred to by your real name or any other identifying information in any written or oral reports based on the interview. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

If you are interested and would like to participate in this study, please contact me at either the phone number or email address given below*.

Thank you for your time and consideration to participate in this interview. Your responses will help in educating genetic counselors and other healthcare professionals about Down syndrome adoption and needs of these families. If you have any questions regarding this research, you may contact either me or my faculty adviser, Victoria Vincent, MS, CGC, using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

Student Contact Information:

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