Motivations and Characteristics of Families who Adopt Children with Special Needs: A Qualitative Study

Master’s Thesis

Presented to

The Faculty of the Graduate School of Arts and Sciences
Brandeis University

Department of Biological Sciences, Program in Genetic Counseling

Gretchen Schneider, MS, CGC, Advisor

In Partial Fulfillment of the
Requirements for the Degree
Master of Science

By
Bailey Gallinger

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ABSTRACT

Motivations and Characteristics of Families who Adopt Children with Special Needs: A Qualitative Study

A thesis presented to the Genetic Counseling Department of Biological Sciences, Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Bailey Gallinger

A substantial body of research on special needs adoption characterizes the adoption process itself and the outcomes. However, much of this research lacks an in-depth view of the adoptive families. Genetic counseling should include discussing the option of adoption with clients who learn pre- or postnatally of a diagnosis or suspected disability, and deeper insight into families who adopt children with special needs will aid this discussion. The goal of this study was to understand the motivations and experiences of families who adopt children with special needs. We conducted semi-structured interviews with twelve mothers who adopted children with a variety of special needs. The interviews focused on three major areas: (1) Motivations for adopting a child with special needs, (2) Acceptance of the adoption among others, and (3) Messages to others about special needs adoptions. We analyzed and coded interview transcripts using grounded theory. Participants reported numerous motivations including previous experiences with individuals with special needs and religious beliefs. Although some mothers experienced initial negative reactions, overall they felt that their other children, family members, and friends accepted their decision to adopt a child with special needs.
The adoptive mothers felt no negativity toward the children’s birth mothers; rather, they were extremely grateful for their decisions. The mothers also expressed concerns that people are unaware of the many families waiting to adopt children with special needs, and more exposure is necessary. Our findings provide valuable insight into families who adopt children with special needs, and this may in turn help birth parents who are considering making an adoption plan. Sharing results from this study with genetic counselors and other health professionals can help them approach this option with greater ease, and hopefully help them provide support and referrals to clients involved in special needs adoptions.

Keywords: adoption; special needs; private adoption; international adoption; disabilities; adoptive families; birth parents; genetic counseling
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INTRODUCTION

Special needs adoption has distinguished itself as a unique type of adoption since the 1960s. Approximately 30-50% of children awaiting adoption have a developmental disability (Henry & Pollack, 2009). The phrase ‘special needs’ within the foster care system refers to sibling groups, children with disabilities, children with mental health issues, and older children (Denby, Alford, & Ayala, 2010). However, in private domestic adoption, ‘special needs’ often refers to children with intellectual and/or physical disabilities.

There is a substantial body of research on special needs adoption. Much of this research characterizes the adoption process itself and the outcomes of special needs adoption. Research on the process addresses the challenges of caring for children with special needs and important steps to be considered with special needs adoption.

While a great deal of research focused on the adoption process, much less work explored the perspectives of the adoptive and birth parents. Lindh, Steele, Page-Steiner, & Donnenfeld (2007), studied adoptive parents’ motivations for choosing to adopt a child with Down syndrome using quantitative methods. The quantitative measures used in this research and other similar studies do not richly capture the adoptive parents’ perspectives and motivations, nor do they address adoption of children with a broader scope of special needs. To better understand these parents’ characteristics and motivations, they should be given the opportunity to openly and freely answer the question, ‘Why?’

The limited qualitative research that does exist includes a study of parents who adopted children with special needs from the foster care system (Denby, et al., 2010). This study focused
largely on whether the adoption was completed and how challenges within the foster care system affected the adoption process. Also, the term ‘special needs’ in this study referred to the children listed in the aforementioned definition. Although this study attempted to address parental motivations for adopting children with special needs, the results concentrated on reasons for adoption discontinuation and flaws within the foster care system of the United States.

A qualitative study focusing solely on parents and their reasons for adopting children with physical and intellectual disabilities is still needed to understand their motivations. Involving parents who have adopted both privately and internationally can remove confounding factors that result solely from adoptions within the foster care system.

The lack of insight into adoptive parent motivations has a direct impact on the genetic counseling process. If a client learns there is a prenatal diagnosis or suspicion of a physical and/or developmental disability, a genetic counselor must ensure that the client knows all of her options to make an informed decision about how to proceed. These options include: continuation of the pregnancy and parenting the child, termination of the pregnancy, and continuation of the pregnancy and making an adoption plan. Yet genetic counselors often feel unprepared to discuss the option of adoption when counseling clients (Perry & Henry, 2010). Farrelly et al., (2012) analyzed transcripts from simulated patient genetic-counseling sessions to see which options counselors discussed with clients if a fetus was diagnosed with a disability; only 13% of the 93 genetic counselors mentioned adoption. Studies that explore adoptive parents’ motivations and characteristics would better equip genetic counselors with answers to clients’ questions about who would want to adopt a child with a disability, in turn dispelling some misconceptions while the client considers this option.
The goal of this study is to better understand the perspectives, motivations, and experiences of families who adopt children with special needs through private adoption. Understanding these families can help genetic counselors and other health care professionals provide better care and support to both birth parents and adoptive parents of children with special needs.
METHODS

Brandeis University’s Institutional Review Board approved the study.

Study Population

We recruited participants through the National Down Syndrome Adoption Network (NDSAN) (Appendix A) using a technique known as snowball sampling, in which existing participants recruit future subjects from among their acquaintances (Goodman, 1961). We provided the NDSAN with a recruitment notice (Appendix B) to distribute to members of the organization. We also sent the recruitment notice to both active members of the adoption community and individuals already recruited for the study, to pass along to their contacts. We encouraged individuals to contact us directly by e-mail. We then completed a brief questionnaire by phone (Appendix C) to assess eligibility of the study candidates. Subject inclusion criteria included: individuals must be 18 years of age or older, must speak fluent English, must have successfully completed the adoption process of a child with physical and or intellectual special needs, must have been aware prior to the adoption plan that their adopted child has special needs, and must have adopted a child through a private adoption agency or internationally, not through the foster care system in the United States.

Twelve respondents who expressed interest were eligible for study participation, and we scheduled phone interviews at their convenience. We sent a copy of the consent form (Appendix D) via e-mail to each of the participants and collected them prior to the interviews. We offered the participants a $25 gift card as a gesture of our appreciation for their time.
**Demographics**

All twelve participants recruited for this study were females who were married to males. The participants ranged in ages from 28 to 57 years. The adoptive children of the participants ranged in ages at time of adoption, from four days to six years, and ages at time of study, from one and half to 13 years. The type of special need varied and included physical only, intellectual only, and both physical and intellectual. Four of the children had Down syndrome, five of the children had physical special needs, and three of the children had both physical and intellectual special needs unrelated to Down syndrome. Seven of the twelve participants adopted more than one child with special needs. For consistency, interviews were based around the adoption of their first child with special needs. Table 1 shows further information about the participants and their children. Table 2 shows information about the adoption process and types of adoption, as well as the make-up of the participants’ families.

**Interviews**

We designed a semi-structured interview guide with open-ended interview questions (Appendix E). The main questions on the interview guide focused on: why adoption was chosen in general, why adoption of a child with special needs was chosen, how the adoption plan came to be, other people’s reaction to the adoption, information about their child and his/her special needs, and messages they would like to send out to birth parents, adoptive parents, and the general population with regards to special needs adoptions. We designed interview questions based on previous literature regarding special needs adoption and an adoptive mother reviewed the interview guide. We used the same interview guide for each participant to ensure consistency; however, the number and type of questions asked of each participant were dependent upon the issues explored during the interview. Interview duration ranged from 35 to
60 minutes.

Data Management and Analysis

We digitally recorded all interviews and a professional transcriptionist transcribed them. We placed our data into ATLAS.ti (version 6.2), a software package for qualitative analysis of textual data (Friese, 2011). Using a methodology of ‘Coding Consensus, Co-occurrence, and Comparison’ outlined by Willms et al, (1990) and based in grounded theory (i.e., theory resultant from data and then demonstrated by characteristic examples of data) (Glaser, 1999), we analyzed our interview transcripts.

We coded interviews to condense the data into analyzable units. We assigned codes to sections of text, phrases or paragraphs based on a priori (from the interview guide) and emergent themes (Saldaa, 2009). We then further subdivided into code families to identify broader themes. If we did not identify a code in greater than seven distinct interviews, we did not include it in the analysis. We grouped transcript documents by type of adoption (e.g., international versus domestic) and the structure of the participant families (e.g., multiple adopted children with special needs) (Table 3).
<table>
<thead>
<tr>
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<th>Age of child at adoption</th>
<th>Child’s current age (years)</th>
<th>Gender of child</th>
<th>Mother’s age at adoption (years)</th>
<th>Mother’s current age (years)</th>
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<td>F</td>
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<td>36</td>
<td>Cleft lip and palate</td>
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<td>2.5 years</td>
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<td>F</td>
<td>47</td>
<td>57</td>
<td>VI + Autism</td>
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Table 1. Summary of participant demographics. DS, Down syndrome; VI, Visually impaired
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<th><strong>Child's birth country</strong></th>
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<tr>
<td>Physical only</td>
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<tr>
<td>Physical and Intellectual</td>
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<tr>
<td>0</td>
<td>3</td>
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<td>1-2</td>
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<table>
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<th>Percentage</th>
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<tbody>
<tr>
<td>0</td>
<td>5</td>
<td>41.7</td>
</tr>
<tr>
<td>1-2</td>
<td>3</td>
<td>25.0</td>
</tr>
<tr>
<td>3-4</td>
<td>4</td>
<td>33.3</td>
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</tbody>
</table>

<table>
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<th><strong>Number of other children adopted without SN</strong></th>
<th>Number</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>0</td>
<td>8</td>
<td>66.7</td>
</tr>
<tr>
<td>1-2</td>
<td>4</td>
<td>33.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Length of adoption process once match is made</strong></th>
<th>Number</th>
<th>Percentage</th>
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<td>0-5</td>
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<td>25.0</td>
</tr>
<tr>
<td>5-10</td>
<td>7</td>
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</tr>
<tr>
<td>10-15</td>
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<td>8.3</td>
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<td>15-20</td>
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Table 2. Adoption information
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<th>03</th>
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<th>05</th>
<th>06</th>
<th>07</th>
<th>08</th>
<th>09</th>
<th>10</th>
<th>11</th>
<th>12</th>
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</thead>
<tbody>
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<td>Adoption of &gt;1 children with SN</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One child with SN only</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Adoption of a child with physical SN</td>
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<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Adoption of child with intellectual and physical SN</td>
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<td>X</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adoption of child with Down syndrome</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>International</td>
<td>X</td>
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<td></td>
<td></td>
<td>X</td>
<td>X</td>
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</table>

Table 3. Transcript groupings. SN, Special need
RESULTS

The interview discussions focused on three main areas: (1) Motivation for adopting a child with special needs, (2) Acceptance and non-acceptance of the adoption among others, and (3) Messages to others about special needs adoptions. Using codes to categorize the participants’ remarks under those areas of discussion, we identified recurring themes. Figure 1 represents the areas of discussion, themes expressed by the adoptive mothers, number of mothers that expressed each theme, and the code frequency.

1. Motivation for adopting a child with special needs

Four major themes emerged when discussing the underlying motivation for adopting a child with special needs.

All children need a home

The majority of the participants wanted to adopt a child with special needs because they felt that all children need a home. Having a special need did not devalue their child’s need for a family. Adoptive mother 08 stated,

“We just decided that there are kids, lots of kids who need families, wanted kids, and so it just made sense to give those kids [with special needs] a family...”

Adoptive mother 10 added,

“We can close the page on that book or we can turn off the computer or we can do whatever and take the child off the screen, but it doesn't make that child cease to exist. They're going to have a life or a death no matter where they go ... I think a lot of people think that, like, well, they don't belong in my family, so the end. And it's not the end for them. There's something that continues for them, they still need a home.”
Exposure to special needs

All of the participants had some type of exposure to individuals with special needs before the adoption, either through a family member, a friend, their career, or volunteer work. Adoptive mother 03, who already had a child with special needs by birth, stated,

“We kind of felt as if he [child with Fragile X] made us think outside of the box in terms of our parenting and really made us grow in terms of our parenting, really challenged us. So we felt capable of dealing with a lot more than we kind of felt capable of dealing with before we had him.”

Adoptive mother 09 said,

“We had talked for years about adopting a little girl with Down syndrome. And my husband has a cousin who has Down syndrome... we watched him grow up, and we always knew that we enjoyed being around him and his friends.”

Seven of the participants had worked with children with special needs as physical therapists, aids, and camp counselors. Adoptive mother 06 mentioned,

“Both my husband and I have worked with a lot of kids with special needs and to us it was not a big deal if they had some medical needs.”

Religious beliefs

Religious belief was another theme that emerged when discussing reasons for choosing to adopt a child with special needs. Eight out of twelve participants mentioned God as a motivating factor in the decision to adopt a child with special needs. Adoptive mother 02 stated,

“But then we had just decided if God chose us to be this child's parents, regardless of what the child has, he's ours, and we can't say no to that.”

Adoptive mother 08 added,

“We have what they need. And we felt just like God had just put this love in our heart for whoever he brought to us.”
Innate ability

Seven of the participants felt an innate ability to parent a child with special needs, as evident by Adoptive mother 08’s statement,

“They put you up on a pedestal and you feel... well, you must be some kind of wonderful and that's why you did it, and therefore, because they're not so wonderful, they couldn't ever do it. And that's not how it is. It's just that I decided to do and therefore I'm able to do it.”

Adoptive mother 11’s quote also portrays an innate ability to parent a child with special needs,

“I know we can handle it, so let's just do it.”

Adoptive mother 11 felt it was a personality trait that allowed her family to adopt a child with special needs.

"We can do this. And my husband and I are both really, I don't say this in a bragging way, I promise, we're both pretty strong people. I mean we're in the military."

2. Acceptance of adoption by others

All of the participants mentioned that they felt their other children, family and community eventually accepted the child they adopted. At the same time, they did experience some initial negativity with regard to their adoption of a child with special needs.

By siblings

All participants who had other children expressed that the siblings of the adopted child were very accepting of the adoption as evident by Adoptive mother 11 quote,

“She was so excited. They have been best friends since the very first day.”

In addition, Adoptive mother 03 stated,

“He loved her and he fell in love with her and she ... she changed his thinking, she changed his ways he does things... he feels more compassionate because of her, he feels more patient, he feels like a better person for having her in his life.”
By family, friends, and community

All the participants felt supported by their friends as expressed by Adoptive mother 04,

“Friends [were] also extremely supportive. We had a number of friends who actually donated some money to help make this financially happen for us.”

In addition, all twelve participants mentioned acceptance among their family, Adoptive mother 10 said,

“And as far as my siblings and my husband's siblings, they just love them to death.”

The majority of participants felt that their child was a strong part of the community, Adoptive mother 09 stated,

“He is so part of the community. He's raised by everybody, not only by us. And it's pretty amazing to see that.”

Non-acceptance

Although there was an overall feeling of acceptance with regards to the adoption, eight out of the twelve participants experienced some negative reactions from other individuals. For example, Adoptive mother 02 said,

“We were in a moms' group at church, and the one lady said, when I was talking about adopting a deaf/blind child, she goes, I wouldn't touch that with a ten-foot pole.”

In addition, Adoptive mother 09 stated,

“Oh, very negative at the beginning. We had extreme negative reactions from families and from a few friends...why would we adopt a child with special needs, and even pay money? That was one of the arguments, why would you want to pay money to get crap.”

Even though some experienced negativity or non-acceptance at first, all participants reported that eventually most people came around to accept their child with special needs.
3. Message to others

We asked the participants what they would like to say to birth mothers, other potential adoptive parents, and the general population, and the following themes emerged.

*Many families want to adopt children with special needs*

All twelve participants not only mentioned the large number of families that want to adopt children with special needs but also emphasized it. For example, Adoptive mother 10 said,

“I would say not to assume that no one's going to want that child. Because there are so many people out there that are equipped and willing and have so much to offer. These children are treasured.”

And Adoptive mother 07 mentioned,

“There’s waiting lists for special needs children.”

Lastly, Adoptive mother 11 stated,

“I know beyond a shadow of a doubt that for every child, especially every disabled child born ... I feel [there] is a home for that child. And that it may not necessarily be with the birth parent.”

*Know your limits*

Many of the adoptive mothers felt it was important to stress that they could not handle every special need out there. For example, Adoptive mother 11 said,

“Definitely seriously consider what your family can handle and not handle, and that it doesn’t make you less of a person to say-- and I suspect this is the biggest thing-- to say a cognitive disability is not for you. It doesn't make you less of an adoptive parent or less of a person to say that you can't handle that.”

This was also evident by Adoptive mother 12’s comment,

“There's no condemnation in adoptive families that adopt special needs kids, because we all know our limits. I mean, I cannot adopt a child that has severe total care. That's beyond my capacity to do. I can't do that.”
Grateful to the birth mother

Seven of the participants wanted to thank their child’s birth mother for choosing life. As well, most of them wanted the birth mothers to know that they did not judge them for their decision to make an adoption plan; rather, they respected them for it. Adoptive mother 03 stated,

“It's always important to me that our girls' birth parents know how grateful we are for their courage and for the decisions they've made.”

Adoptive mother 09 understood that the decision to make an adoption plan is not an easy one,

“And we met with her, and we both fell in love with her, just as much as with him. ... She was highly intelligent, a very smart, very sweet woman... I think for birth parents with special needs children, it is—they're harder to deal with the adoption process, because they are having a child that the public is saying, ‘Oh, you gave him up for adoption because he was special needs?’ Hardly any of the public realizes that this child has been given up adoption before anybody knew that it was going to be special needs.”

The topic of termination arose in the majority of the interviews. The participants wanted to send the message that pregnancy termination is not always the only option. For example, Adoptive mother 12 stated,

“I want them [the birth parents] to know how thankful I am that they gave life to their child and did not abort her.”
Figure 1. Summary of main areas of discussion, themes, and frequencies
DISCUSSION

The twelve qualitative interviews with adoptive mothers performed as part of this study provided an in-depth view of the experiences and issues surrounding adopting a child with special needs.

Motivation for adopting a child with special needs

The four major themes seen in the mother’s discussions of their motivations for adopting a child with special needs were similar to findings in previous studies of families adopting individuals with Down syndrome. Lindh, Steele, Page-Steiner, & Donnenfeld (2007) investigated the characteristics and perspectives of families waiting to adopt a child with Down syndrome. The most common reason stated by these families for choosing to adopt was that they felt equipped with the resources to raise a child with Down syndrome. Although it was not a major theme with all of the participants in the current study, a few mentioned they had physical resources to parent a child with special needs (e.g., good health insurance). The second most common reason found by Lindh et al., was “a positive experience” with an individual with Down syndrome. The current study showed consistency, as evident by the recurring theme of ‘exposure to special needs’. All of the participants in the current study had had some type of positive experience with individuals with special needs. Exposure to special needs appears to both demystify and clear up misconceptions of individuals with special needs. Lindh et al., (2007) also found that some of the parents had religious motivations or a “calling” for adopting a child with special needs, which is consistent with the ‘religious belief’ theme found in the current study.
There is often a specific focus on Down syndrome because of the abundance of information about the condition and the many support and advocacy groups dedicated to Down syndrome (Glidden & Cahill, 1998). The current study looked at adoption of children with a variety of special needs and found that many of the motivations were similar across all types of special needs. It is important for health care professionals, including genetic counselors, to understand that families who are willing to adopt children with different types of special needs share common motivations.

A few novel findings emerged in the themes uncovered during the interviews of the adoptive mothers. The first was the theme of ‘all children need a home’. The mothers felt that having a special need should not make a child less deserving of a home and family. A subtheme of ‘all children need a home’ is the notion that these children were “just like normal kids” and that their special need should not define them. Another finding in this study not reported in the aforementioned study by Lindh, et al. (2007) was the theme of an “innate ability to parent a child with special needs” as a motivating factor. The participants mentioned that they could not explain why they chose to adopt a child with special needs, but rather it was just something they felt they were able to do. These unique perspectives not previously described in past studies may help birth parents and health care professionals understand why certain families would be interested in adopting a child with special needs.

Acceptance of adoption by others

Many of the participants stated that their families and communities were surprised and concerned when they first learned about the adoption. Nevertheless, participants reported that after completing the adoption, the majority of individuals came to accept their family’s decision to adopt a child with special needs. An initial concern of a few of the adoptive parents and their
families was that a child with special needs would take attention away from his/her siblings. However, not only did all of the parents with birth children mention that their birth children accepted their adoptive sibling, but according to these mothers, they felt their children were 'better people' because of the experience of having a sibling with special needs. This is consistent with previous research that shows overall satisfaction with the adoption of children with special needs (Barth, 1991; Glidden & Cahill, 1998). Although the participants in the current study often reported a period of strain in the family immediately after the adoption, all of the families felt that they had adjusted to having a child with special needs.

The theme of acceptance by others is valuable for birth parents trying to understand how an adoptive family would receive their child. They are also important for helping health care professionals involved in the care of these children to recognize that they and their families often have good support from others. This study reveals that extended family and community members often accept adopted children who have special needs. Although many of the families did experience initial negativity from others, the non-acceptance was often short lived. The judgment appeared to have stemmed from the uncertain variables that come with raising a child with special needs. However, as their family and friends gained more exposure to the child with special needs, acceptance and support followed.

Message to others

A major part of the interviews was a focused discussion of the messages that adoptive mothers wanted to share with expectant and birth parents struggling with the decision to make an adoption plan, potential adoptive parents considering adopting a child with special needs, and the general population. All mothers emphasized that no matter what a child’s special need is, there is a family who is not only able to, but also willing to parent that child. In addition, the participants
hoped that their interviews would make the general population and health care providers more aware of the numerous families that adopt, or hope to adopt, children with special needs. By providing the results of this study to health care providers, they will be more knowledgeable about special needs adoption and may be able to both discuss, and perhaps aid in special needs adoptions.

Although there was no specific question about what type of special needs the mothers felt their family could handle, ten participants spontaneously mentioned that they do have their special need 'limit'. Some mothers listed psychiatric disorders, wheelchair use, and cognitive disabilities as a few examples of special needs that would not work within their family. They felt it was important for potential adoptive parents to know their limit. This has important implications for birth parents and health care professionals. First, it seems as though an adoptive family is potentially available for most children with special needs who require one. Second, these families are likely to be aware of what they can handle and, therefore, may have a higher chance of a successful adoption.

All of the adoptive mothers interviewed wanted their children’s birth mothers to know how appreciative they were and a few had the chance to thank the birth mothers themselves. Most of the participants worried that birth parents may feel judged for their decision to make an adoption plan instead of parenting. Finnegan (1993) described stories and experiences of birth parents of babies with special needs and their adoption experiences. In her book, Shattered Dreams - Lonely Choices, she explained how societal expectation of parents with children who have special needs is for them to parent the children. She mentioned that birth parents do, in fact, feel judged for their decision to make an adoption plan. In the current study however, instead of judgment, the adoptive mothers felt immense gratification. There appears to be a disconnect
between how birth mothers feel they are viewed and how adoptive mothers actually perceive them. This has implications for health care professionals, especially genetic counselors, involved in discussing these types of adoptions. When genetic counselors raise the option of adoption after a prenatal or postnatal diagnosis of a special need, they must be sensitive to how the birth parents feel others may perceive them for their decision to choose adoption. Genetic counselors must let the expectant parents who are considering this option know that there are families who are not only willing, but also grateful for the opportunity to parent their child.

Limitations

This was an exploratory qualitative study designed to identify major motivations and characteristics of families who adopted children with special needs. The sample size was small, consisting of only twelve participants. An advantage of the study sample was that the participants were not from one geographic area of the United States. In addition, there was diversity in the types of special needs of the adopted children. However, all of the participants were mothers; no fathers chose to participate. In addition, all participants were Caucasian and had some religious affiliation. Using the NDSAN and a snowball sampling technique to recruit participants may have caused sampling bias. It is possible that only mothers who had positive experiences with special needs adoption may have chosen to participate in this study. Therefore, the results of this study may not represent the views and experiences of all families who adopt children with special needs.

Another limitation was that all twelve interviews occurred via telephone. While this maintained consistency, the anonymity may have affected responses. Moreover, some of the adoptions occurred over ten years ago, which may have affected the participant’s abilities to recall their experiences and emotions. Since many participants adopted more than one child with
special needs, it may have been difficult to answer each question with only their first adoptive child in mind. In addition, as with all self-reports, there is a potential for social desirability bias.

A major confounding factor was that the majority of the adoptions were international. This had an impact on the challenges these families faced. For example, negativity from the general population was often due to the judgment passed on inter-racial adoptions, rather than the adoption of a child with special needs.

Finally, since this study used qualitative methodology, the study’s author subjectively created all coding and emergent themes.

**Future research**

Even with the current study, the area of special needs adoption warrants continued research. While the use of qualitative techniques may have limited the sample size, this approach enabled explorations that may not have been feasible with quantitative methodologies. This study can therefore guide further qualitative research into the various issues identified and discussed to better understand these families and their motivations.

Future studies should include a larger sample size incorporating fathers, non-Caucasians, and individuals without religious affiliations. As well, separation of international and domestic special needs adoptions would avoid confounding variables. A few study participants adopted children who were older and had lived in orphanages for many years outside of the United States. Therefore, future studies should also distinguish between families based on the age of the child at the time of adoption. Since seven of the participants in this study adopted more than one child with special needs, it would be interesting to determine if their motivations changed for subsequent adoptions. In addition, a longitudinal study that begins at the start of the adoption process and continues until completion of the adoption would enable participants to reflect on the
process while it is happening rather than having to recall the experience.

Finally, there is a gap in literature with regard to the birth parents’ perspectives. Future studies should also delve into the perspective of birth parents of children with special needs who chose to make an adoption plan. Having both the birth parents’ and adoptive parent’s perspectives could help those who are involved with discussing this option with their clients.
CONCLUSION

This study explored the motivations of mothers who adopted children with special needs and provided greater insight into these families’ experiences. When genetic counselors encounter a client who learns there is a prenatal diagnosis or suspicion of a physical and/or developmental disability, they should discuss the option of adoption. By sharing the results from this study, genetic counselors can approach the option of adoption with greater ease. Also, greater familiarity with the perspectives of the adoptive families can help genetic counselors be better equipped to answer their client’s questions and refer them to appropriate adoption professionals should the client be interested in pursuing this option.

Since clients facing a pregnancy decision will often question who would seek to adopt a child with a disability, genetic counselors can help clients who are interested in creating an adoption plan better understand adoptive families’ motivations from the themes that have emerged in this study. These motivations include the belief that all children need a home, prior exposure to individuals with special needs, religious beliefs, and an innate ability to parent a child with special needs. The adoptive mothers in this study did not judge their children’s birth mothers for their decision. Rather, they reported feeling extreme gratitude towards the birth mothers and respected them for their ability to recognize that parenting and termination were not their only options.

Overall, the mothers in this study felt that others respected their decision to adopt a child with special needs and that their families, friends and communities accepted the child. It is important that birth parents and health care professionals responsible for discussing pregnancy
options know that these families and children receive adequate support and acceptance as they discuss this option. Adoptive mothers in this study agree that there is a lack of information about special needs adoption and that few people, specifically health care professionals, know of the vast number of families waiting to adopt a child with special needs. Expectant parents and professionals need more exposure as they discuss pregnancy options after a pre- or postnatal diagnosis. The hope is that this study brings a greater awareness to these waiting families and their motivations, in order that professionals may be better prepared to answer the question, “Who would want to adopt a child with special needs?”
REFERENCES:


Appendix A: NDSAN permission to recruit letter

October 16, 2011

To Whom It May Concern:

This letter is to inform you that the National Down Syndrome Adoption Network (NDSAN) is willing to help Bailey Gallinger with her master’s thesis project entitled: Motivations and Characteristics of Families who Adopt Children with Disabilities.

We understand that the purpose of this study is to learn more about why families choose to adopt children with disabilities. The aim is to gain a better understanding of these families, their characteristics, and their reasons for adopting a child with disabilities. The hope is that the experiences shared by participants in this study will be useful in educating genetic counselors and other health professionals about the adoption of children with special needs and the families involved in these unique types of adoption.

We are willing to help with the recruitment of participants for this study after it has been approved by the Brandeis University Institutional Review Board.

Sincerely,

[Signature]
Stephanie Thompson
Assistant Director
National Down Syndrome Adoption Network
Appendix B: Recruitment notice

**Have you adopted a child with special needs?**

I am a graduate student in the Brandeis University Genetic Counseling Program and I am seeking volunteers to participate in a research project. The goal of this study is to explore the motivations and characteristics of families who adopt children with special needs.

**You are eligible to participate in this study if you:**

- Are 18 years of age or older
- Adopted a child with special needs from a private adoption agency

Participation in this study is voluntary. Following a brief phone survey to assess eligibility, participants will be asked to take part in one audiotaped face-to-face or telephone interview that will last approximately one hour. All participants will be compensated with a $25.00 gift certificate.

→ I hope to have all interviews completed by February 29th, 2012.

All identifying information from participants will be kept confidential and will be destroyed after the completion of the study. Identifying details will be changed to protect the privacy of the participants.

If you are interested in participating in this study, please contact Bailey Gallinger at bgalling@brandeis.edu.

I appreciate your willingness to participate in this study and look forward to hearing from you.

Sincerely,
Bailey Gallinger
Genetic Counseling Graduate Student
Brandeis University, Waltham, MA
Appendix C: Eligibility Screening tool

Eligibility Screening tool

Name:

Location:

Phone Number:

1. Are you over 18 years old?

2. How did you hear about this study?

3. Have you adopted a child with special needs from a private adoption agency?
   - If yes, when did you complete the adoption process?

4. What kind of special needs does your child have?

5. Can you tell me a bit about your family
   - Do you currently have a partner?
   - How many children do you have and how old are they?
   - How many children by birth?
     o Who are the birth parents of each child?
   - How many children by adoption?
     o Have you adopted any other children with special needs?

6. Would you be willing to meet for an in-person interview lasting for about an hour?
   - If unable to meet in person, would you be willing to participate in a telephone/video conferencing interview
Appendix D: Informed Consent

BRANDEIS UNIVERSITY
DEPARTMENT OF BIOLOGY
GENETIC COUNSELING GRADUATE PROGRAM

Informed Consent to Participate in Research

Motivations and Characteristics of Families who Adopt Children with Special Needs

Student Researcher: Bailey Gallinger
Principal Investigator: Gretchen Schneider

INTRODUCTION
Bailey Gallinger is a graduate student in the Genetic Counseling Program at Brandeis University. She is conducting a research study to learn more about why families choose to adopt children with special needs. Gretchen Schneider is a Professor of the Practice of Genetic Counseling at Brandeis University and Co-Director of Clinical Training for the Brandeis University Genetic Counseling Graduate Program.

You are being invited to participate in this study because you have adopted a child with special needs.

Taking part in this research study is your choice. You should not feel any pressure to participate. You can decide to stop taking part in this research study at any time for any reason.

Please read all of the following information carefully. Ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form. You should keep your copy for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

PURPOSE OF STUDY
The purpose of this study is to learn more about why families choose to adopt children with special needs. We hope to gain a better understanding of these families, their characteristics, and their reasons for adopting a child with special needs. It is our hope that the experiences shared by participants in this study will be useful in educating genetic counselors and other health care professionals about the adoption of children with special needs and the families involved in these unique types of adoption.

PROCEDURES TO BE FOLLOWED
You will be asked to participate in an audiotaped face-to-face or telephone interview lasting approximately one hour. During this interview, you will be asked questions regarding your adoption experience and your motivations for adopting a child with special needs.
RISKS
Participation in this study presents no more than minimal risk. However, it is possible that by taking part in this interview, you may experience thoughts or feelings that are upsetting to you. Should that occur, Gretchen Schneider is available to talk with you.

BENEFITS
There will be no direct benefit to you for your participation in this study. We hope that in the future, information obtained from this study will help us gain a better understanding of adoption of children with special needs and motivations of families who are involved in these adoption plans.

ALTERNATIVES
An alternative is to not participate in this research study.

PRIVACY AND CONFIDENTIALITY
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.

PAYMENT
You will receive a $25 gift certificate for participation in the research study as a gesture of appreciation for your time and expertise.

COST
There will be no cost to you to participate in the study, other than the time it takes to conduct this interview.

WHOM TO CONTACT
If you encounter any problems related to study participation or have questions about the study, you may contact the Student Researcher, Bailey Gallinger, at bgalling@brandeis.edu or (781) 996-9975.

You may also contact the Principal Investigator for this project, Gretchen Schneider, at gretchen@brandeis.edu or (781) 736-3108.
If you have questions about your rights as a research study subject, contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.
PARTICIPANT’S STATEMENT

I have read this consent form and have discussed with Bailey Gallinger the procedures described above. I have been given the opportunity to ask questions, which have been answered to my satisfaction. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement.

I understand that my participation is voluntary. I understand that I may refuse to participate in this study. I also understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so.

If I have any questions concerning my rights as a research subject in this study, I may contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above.

I understand that as a participant in this study my identity and data relating to this research study will be kept confidential.

Please indicate your willingness to be audiotaped by initialing here: ________

_________________________  ____________________________
Date  Participant’s Signature

_________________________  ____________________________
Date  Student Researcher Signature
Appendix E: Interview Guide

Interview guide

Participant name:
Date:
Time:
Location:

Background Information from Screening

Year of adoption completion:
Type of special need:
Any other information about the family (other children, other adoptions etc...):

I. Introduction and Background
   a. Briefly describe the purpose and research aims of interviews
      i. The purpose of this study is to learn more about why families choose to adopt children with special needs. We hope to gain a better understanding of these families, their characteristics, and their reasons for adopting a child with special needs. It is our hope that the experiences shared by participants in this study will be useful in educating genetic counselors and other health professionals about the adoption of children with special needs and the families involved in these unique types of adoption
   b. Explain the presence and purpose of recording equipment and note-taking
      i. I would like to audiotape our interview so that I don’t miss anything. I may also take a few notes during the interview. Afterward, the interview will be transcribed by a confidential transcription service and your name will not be associated with it. In fact, I will only report my findings in aggregate and use your information as one of several respondents. Does that sound ok?
   c. Review informed consent that has been read and signed by the participant prior to this interview
   d. Let the participant know that he/she can take a break or terminate the interview at any time for any reason

II. Questions:

I would like to ask you a few questions about the adoption itself

   a. I know we spoke a little bit about this over the phone but could you briefly describe how your adoption plan came to be?
      i. Why was adoption chosen in general?
         • Prompt - not specifically the adoption of child with special needs. E.g. history of infertility?
      ii. Discussion/planning before the adoption
iii. When it happened?
   1. How old were you?
   2. How old was your child?
   3. How long was the entire process?

iv. Is there any ongoing contact with the birth family? (Closed or open adoption?)
   1. If no, was there ever any contact with the birth family?
   2. Agency involvement?

b. Did you initially want to adopt a child with special needs?
   i. Did the decision evolve after you decided to adopt?
   ii. What were your reasons for considering adopting a child with special needs?

c. What did you know about your child’s special needs before the adoption?
   i. In what format did the information come in?
      1. Doctor’s notes, written information from the birth family, pictures or videos?
   ii. Did you do any research? If so, what?
   iii. Was it an accurate depiction?

d. Had you had any experiences/contact with individuals with special needs before the adoption?
   i. Before thinking about adoption?
   ii. Before the actual adoption took place?
   iii. During the adoption process?

e. What were your feelings:
   i. During the waiting period?
   ii. During the first weeks or months after the adoption was complete?
   iii. Currently about the adoption?

Now I would like to shift gears and ask you about other’s reactions to the adoption

f. If applicable: How did your partner feel about the adoption?
   i. Was he/she supportive of the decision?
   ii. How did the adoption affect your relationship with your partner:
      1. During the waiting period?
      2. Currently?

g. If applicable: How did your other children feel about the adoption?

h. How did your family (parents and siblings) and friends feel about the adoption?

i. What kind of reactions have you received from the general population?
   i. Has it been positive or negative?
      1. Do/did you receive any praise/compliments?
      2. Do/did you receive and negative responses?
      • Prompt - are people surprised when learning about the adoption?

Now I would like to shift again, and ask you a bit about your child

j. Tell me about your child and his/her special needs?
   i. What special needs does she/he have?
      1. What type of medical professionals has he/she seen?
ii. What does he/she excel in?
iii. Is any extra help needed?
iv. What type of school is he/she in?
k. Have you learned from your child? What?

Now I just want to ask some more general questions about this adoption experience

l. Did you encounter challenges with this type of adoption?
   i. What was the biggest challenge facing this type of adoption?
   ii. What were the benefits of this type of adoption?
m. Has your life changed since the adoption? How?
   i. Family dynamics?
n. Briefly, what would you want to tell birth parents about special needs adoption?
   i. What would you tell them when they are wondering who would want to adopt their child?
   ii. Is there anything you would like to say to the birth parents of your child?
o. What would you want to tell other potential adoptive parents who are considering adopting a child with special needs adoption?
   i. Any wisdom to share with them?
   ii. What would you have wanted to know?
p. What would you want to tell the general population about special needs adoption?
q. Do you have any plans to grow your family?
   i. Adoption?

III. Wrap-up
   a. We have reached the end of the tape-recorded portion of the interview. Before I stop recording, do you have anything else you would like to add? Was there anything you thought I was going to ask but didn’t?

IV. Closing comments
   a. Thank the participant
   b. Ask them how the interview experience was for them
   c. Remind them that Gretchen Schneider is available as a resource if they experience any emotional distress following the interview
   d. Reassure participant of confidentiality of responses
   e. Offer to send a copy of the abstract to the participant when the study is complete

V. Demographics
   a. How did you find out about our study?
   b. How old were you when the adoption was completed?
   c. How old are you now?
   d. What is your highest level of education?
   e. Employment?
   f. What racial or ethnic background do you belong to? (You may choose more than one)
i. White 
ii. Black or African American 
iii. Hispanic or Latino 
iv. American Indian/Alaska Native 
v. Asian 
vi. Native Hawaiian or Other Pacific Islander 
vii. Other, specify 
viii. Would rather not disclose