The Path to Inclusion:
Parent Perspectives on the Transition of their Children with Down Syndrome
into an Inclusion Classroom

Master’s Thesis

Presented to

The Faculty of the Graduate School of Arts and Sciences
Brandeis University
Graduate Program in Genetic Counseling

Janet Rosenfield, Advisor

In Partial Fulfillment
of the Requirements for the Degree

Master of Science
in
Genetic Counseling

by

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ABSTRACT

The Path to Inclusion:
Parent Perspectives on the Transition of their Children with Down Syndrome into an Inclusion Classroom

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Emily Bryant

Many studies have been done on the benefits of inclusion for children with Down syndrome and their typically functioning classmates. The purpose of this study is to gain a greater understanding of the parent experience as their child transitions from Early Intervention or Special Education classes into an inclusion classroom. Using an online, anonymous survey, we found that parents acted as advocates for their child in finding the people and resources that would best help their child be successful in the inclusion setting. We explored the relationship between birth order and perceived helpfulness of educational staff members and found no statistically significant differences between those who were the youngest or the middle child in their family and those who were the oldest or only child in their family. We also explored the relationship between income level and availability of resources and support and found no statistically significant differences between income levels. Every child with Down syndrome is unique and therefore their experiences with inclusion varied accordingly. However, parents’ hopes for their child are the same as for any other child; they want them to be successful, have friendships, and become integral members of the school community. We found that parents had
to advocate for their child to find them the best resources that would help them succeed. Genetic counselors need to make themselves aware of the issues faced by families who are raising children with Down syndrome. By understanding the challenges faced by families transitioning to an inclusion classroom, genetic counselors can align themselves with their patients and families to provide needed support.

Key Words: Down syndrome, parent perspective, transition, inclusion classroom, genetic counseling
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INTRODUCTION

One of the biggest decisions that will be made regarding a child with Down syndrome’s education is whether or not the child is placed in a special education classroom or an inclusion classroom, where they are incorporated into a classroom with typically functioning children. Understanding the parent perspective on this transition can provide important insights into this process and help determine what it is that makes a transition successful.

Several studies have been done to compare the progress and academic achievement of children and young adults with Down syndrome that were educated in a mainstream classroom to those that were educated in a special education classroom. In 1994 Baker, et al. found that students with disabilities did better academically and socially when placed in an inclusion classroom as compared to those who were placed in non-inclusion settings. Students with disabilities educated in special educational environments scored an average of 30-40% below the performance level of students without disabilities and that the longer these students were kept in those settings, the larger this gap became (Education Week, 2004).

Research done on the parental views on the inclusion of their child in mainstream education is important because the information obtained is from the parent perspective, which can be incredibly insightful. One study compared the viewpoints of parents of children with autism to those of parents of children with Down syndrome (Kasari, 1999). Kasari, et al. attempted to determine a relationship between the diagnosis and age of the child and the parents’ attitudes toward inclusion. They found that 41.5 – 46% of all study participants were not completely satisfied with their child’s current educational placement. The older a child was, the
unhappier their parents were about their placement. Parents of older children were also more open to the idea of mainstreaming their child. Many parents were concerned about the level of functioning their child had and how well they would perform in a classroom setting. They felt that it was important for their child to be in a setting similar to what they would experience in the real world, but also wanted to make sure they got the attention and support they needed (Kasari, 1999).

Palmer, et al. (1998) argued that there are three dimensions from which a parent determines their feelings on the integration of their intellectually disabled child into a general education classroom: the quality of educational services their child will receive, the social and educational benefits to both general education students and their child, and how their child will be treated or accepted by their teachers and peers. Parents of children who were less physically and mentally impaired and had fewer behavioral problems valued their child’s inclusion more than parents who had children with a lower level of functioning. Similarly, when the parents themselves valued socialization, they were more apt to favor the inclusion of their child in mainstream education classrooms (Palmer, 1998).

Several studies have focused on the effects of inclusion of children with special needs on the progress of typically functioning students. One study conducted by Hollowood, et al. (1995) found that students that did not have disabilities were not impaired in any way when students with disabilities were a part of their classroom. In 2004, Peck, et al. surveyed parents of children without disabilities in inclusion classrooms. They concluded that the overwhelming majority of parents did not feel their child’s progress was affected by the presence of students with disabilities in their classrooms, and about 15% of parents thought their child’s progress had actually improved because of these students. They also found that most parents felt that their
child’s understanding and acceptance of those with behavioral differences as well as those who had a different appearance had improved. Overall, 87% of the parents that participated in this study felt that their child’s interaction with children with disabilities was a positive experience for them (Peck, 2004). These are important findings and provide evidence for the positive impact inclusion can have on everyone, not just those with disabilities.

The purpose of this study is to identify the successful elements of a transition of a child with Down syndrome from Early Intervention services or Special Education classrooms into an inclusion classroom. Few studies have focused on the parental perspective, especially involving children with Down syndrome. This is an important part of the child’s transition into an inclusion classroom as their insight is invaluable in gaining a greater understanding of what it takes for the child to be as prepared as possible during this transition time. This study will fill in a gap in the literature on what it takes to make a transition successful. We have gathered information from parents regarding this experience by inquiring about the most important resources, the advice they wanted to share, the challenges they and their child faced, things that worked, and things that created greater challenges. In identifying these common experiences, we as genetic counselors can better understand and appreciate what parents must face at different developmental stages. By informing ourselves we can become a resource to our families who are looking for support and information as they navigate these challenging transitions and decisions about their children.
METHODS

Study Design

We invited parents of children with Down syndrome who had gone through a transition from Early Intervention services or a special education classroom to an inclusion classroom within the last three years to participate in an online anonymous survey. They were asked to answer demographic questions about their child’s educational environment. We also inquired about the emotional experiences of both parents and children going through this transition. We hoped that by gathering this information, it would prove to be a resource for genetic counselors as they educate themselves about what it is truly like to live with a disability. Assembling this information from the parental perspective shows parents that we want to hear about their experiences. Hopefully in doing so, families will consider genetic counselors as another resource, multidimensional and empathic as opposed to limited and negative.

Sample and Recruitment

Brandeis University Committee for Protection of Human Subjects approved this study. The recruitment notice and survey link were posted by the Massachusetts General Hospital Down Syndrome Program and the Boston Children’s Hospital Down Syndrome Program to their respective Facebook pages. Committee members, Tomi Toler, MS CGC and Angela Lombardo graciously helped with the distribution of the survey. The recruitment notice was directed towards parents of children with Down syndrome who had recently undergone the transition to an elementary school inclusion classroom. Only parents over the age of 18, who had a child with
a diagnosis of Down syndrome that had transitioned to an inclusion classroom within the last three years were eligible to participate in the survey. See appendix A for the recruitment notice.

**Data Collection**

We created and distributed an online, anonymous survey using Qualtrics®. It was available from January 20, 2015 through February 6, 2015. The survey contained multiple choice questions, Likert scale questions, and open-response questions divided into categories. The categories included the child’s educational environment, resources they may have had access to, the emotional experiences of parents, and a demographics section. The survey began with four questions used to make sure we identified participants who could give us the most accurate and recent information. However, after several responses came in, the last of the four questions, that asked whether or not the parent was an active participant in their child’s daily educational needs, was eliminated from the survey due to the apparent confusion it caused participants. See appendix B for the survey tool.

**Data Analysis**

At the close of the survey there were a total of 164 respondents. Only 68 were eligible to complete the survey based on their responses to the first three questions. The data were uploaded to IBM SPSS Statistics Version 22 and analyzed. Microsoft Excel was used to analyze open-ended responses. Predictor variables and outcome variables were used as defined in the table below. The relationships between these variables were explored using Chi-square tests.

**Table 1 – Predictor variables and outcome variables**

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>Outcome Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Order</td>
<td>Helpfulness of Educational Staff Members</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td>Availability of Resources</td>
</tr>
</tbody>
</table>
RESULTS

Demographics

The overwhelming majority of respondents identified as female (91.53%). Respondents were between 30 and 59 years of age and reported their children were between the ages of 3 and 18 years old. All but two respondents identified as being Caucasian when asked about their race using US Census categories. The other two respondents identified as being of mixed race, one Caucasian and African American and the other as Caucasian and Native Hawaiian/Pacific Islander. When asked about ethnicity, 100% of respondents identified as non-Hispanic/non-Latino.

The overwhelming majority of respondents reported upper levels of education. More than 75% had a bachelor’s or a post-graduate degree. Similarly, respondents tended to have a high level of income. The highest number of respondents reported their annual household income to be between $100,000 and $149,999.

Table 2 – Age & Gender

<table>
<thead>
<tr>
<th>Participant Demographics</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (n=59)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8.47%</td>
</tr>
<tr>
<td>Female</td>
<td>91.53%</td>
</tr>
<tr>
<td>Age of Respondent (n=79)</td>
<td>30-59 years</td>
</tr>
<tr>
<td>Age of Child (n=79)</td>
<td>3-18 years</td>
</tr>
</tbody>
</table>

Table 3 – Race & Ethnicity

<table>
<thead>
<tr>
<th>Race (n=59)</th>
<th>Participants</th>
<th>US Census Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>96.61%</td>
<td>77%</td>
</tr>
<tr>
<td>African American</td>
<td>0%</td>
<td>13.20%</td>
</tr>
<tr>
<td>Native Hawaiian/Pacific Islander</td>
<td>0%</td>
<td>0.20%</td>
</tr>
<tr>
<td>Asian</td>
<td>0%</td>
<td>5.30%</td>
</tr>
<tr>
<td>American Indian/Alaskan Native</td>
<td>0%</td>
<td>1.20%</td>
</tr>
<tr>
<td>2 or more races</td>
<td>3.39%</td>
<td>2.40%</td>
</tr>
<tr>
<td>Ethnicity (n=57)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>0%</td>
<td>17.10%</td>
</tr>
<tr>
<td>Non-Hispanic/Non-Latino</td>
<td>100%</td>
<td>62.60%</td>
</tr>
</tbody>
</table>

Table 4 – Education & Income

<table>
<thead>
<tr>
<th>Education Level (n=59)</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school diploma</td>
<td>3.39%</td>
</tr>
<tr>
<td>Some college</td>
<td>11.86%</td>
</tr>
<tr>
<td>Associate's or 2-year degree</td>
<td>8.47%</td>
</tr>
<tr>
<td>Bachelor's or 4-year degree</td>
<td>37.29%</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>38.98%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Annual Household Income (n=56)</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>$23,100 - 32,499</td>
<td>5.36%</td>
</tr>
<tr>
<td>$32,500 - 59,999</td>
<td>10.71%</td>
</tr>
<tr>
<td>$60,000 - 99,999</td>
<td>17.86%</td>
</tr>
<tr>
<td>$100,000 - 149,999</td>
<td>30.36%</td>
</tr>
<tr>
<td>$150,000 - 249,999</td>
<td>19.64%</td>
</tr>
<tr>
<td>$250,000 or above</td>
<td>16.07%</td>
</tr>
</tbody>
</table>
The second highest income bracket reported was $150,000 - $249,999 annually.

Respondents were also asked about the state in which they lived. This information was then used to divide participants into regional groups as defined by the US Census. The majority of respondents were from the Northeast.

Most children were in preschool (58.23%) when they first entered an inclusion classroom. The majority were being educated in a public school setting. Most were included full-time. The majority of the children were receiving multiple therapies including speech therapy, occupational therapy, and physical therapy. Some were getting those three services plus other therapies that included music, hippotherapy (horse therapy), social skills or others. Children whose parents completed the survey were often the youngest child in their family.

Table 5 – US Regions

<table>
<thead>
<tr>
<th>Region</th>
<th>Respondents</th>
<th>US Census Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeast</td>
<td>50.85%</td>
<td>17.92%</td>
</tr>
<tr>
<td>Midwest</td>
<td>16.95%</td>
<td>21.68%</td>
</tr>
<tr>
<td>South</td>
<td>16.95%</td>
<td>37.10%</td>
</tr>
<tr>
<td>West</td>
<td>13.55%</td>
<td>23.30%</td>
</tr>
<tr>
<td>Outside the US</td>
<td>1.69%</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Figure 1 – Partial vs. Full-Time Inclusion
Figure 2 – Child’s Educational Demographics

A. Where does your child with Down syndrome fall in your family order?

B. Grade when first entering inclusion

C. Therapies

D. Educational environment at the time of inclusion
FINDINGS

The findings were organized into categories to include: Preparation for Inclusion, Resources, Experience, Relationships, and Support.

Preparation for Inclusion

Most of our survey respondents (61.43%) reported they were not advised to prepare their child for the inclusion in any way. They described factors that would have been helpful to know prior to transitioning to an inclusion classroom. The major themes expressed included the following: that it was important to learn the routine and how inclusion works (12/48), to know the options and legal rights available to them (9/48) and to understand up front that it is a difficult process that takes time and effort.

Some parents (8/48) reported that they felt as though they had anticipated most of what would happen. One participant stated, “I think I knew how difficult it would be. I had a lot of hope and confidence that my child was in the right place. The cost was overwhelming. Important to find the right aide who can modify, work with general ed teacher, work on behavior, and can teach my [sic] child…” Another parent felt that while they, “[were] pretty prepared, my advice is that it is very different and you can see the gap between your child and the others which is always harder on the parents because you feel for your child!”

Some parents (7/48) commented on the difficulties of getting inclusion. One parent felt that, “What would be helpful is if inclusion were the "norm" and if the teachers and staff on the ground were truly trained in how to address the needs of kids with disabilities in their community schools. It is a constant test of the parent and school staff... nd [sic] many parents simply give up,
or if the [sic] have the money send their kids to private school and then sue the DOE. Or, if they are in their community schools their kids are full time in the 12-1-1 classroom with few opportunities for mainstream. We have fought [sic] last year and this year, and with the support of this one very special teacher, [my child] has benefitted TREMENDOUSLY from mainstreaming, especially for social and behavior but also for academics. The challenge is monitoring his progress and attention within [sic] the mainstream, because there can be "dead time" where he can't connect and needs additional supports.” Some parents commented about their positive experience and looking back, wished they would have known, “how much he would love it.”

When asked about the advice participants would give to another family about to go through the transition to an inclusion classroom several major themes arose. One common theme that was mentioned by many parents (25/52) was that they felt that it was important to stay strong and keep a positive attitude. One participant said, “Stay positive!!!! If you feel doubt and worry your child is going to feel that as well!” Another parent felt it was important to, “Trust your instincts about your child. I felt that we would always have the option to request a more restrictive environment. Whereas, once you start with more support, it's often difficult to transition to a less supportive environment.” Having frequent and open communication was another major theme among participants (15/52). One parent advised other families to, “Keep in touch with all your child's educators, gen Ed teacher, special Ed, aides, etc via email. They need to know what your concerns & priorities are.” They also advised people to seek help from an advocate and educate themselves about the laws surrounding inclusion (10/52). Some parents would advise other parents to visit the school with their child before they begin, and to visit their child’s classroom after they have been in an inclusion setting for awhile (4/52). Seeking out support from people and organizations available to parents was also advisable according to our
survey respondents (7/52). It was also recommended that parents start the inclusion process early in order to best prepare their child (6/52).

**Resources**

Participants had mixed responses about the helpfulness of the healthcare team. The people they ranked as the most helpful were people who are typically more involved in the child’s educational experience. These resources include speech therapists, occupational therapists, physical therapists, early intervention providers, and developmental pediatricians. They also scored pediatricians, social workers, and psychologists as neutral resources. The people they described as unhelpful were nurses, genetic counselors, and nurse practitioners.

Parents who responded to the survey ranked educational resources, including teachers and aides, as helpful, giving them together an average rating of 4.75 on a scale from 1 to 6, 6 being “very helpful.” One participant highlighted the importance of her child’s teacher. She said, “In our experience, it
has been one teacher (our son's Gen Ed teacher, who used to be the special ed teacher [sic] and is very respected in the school) who has lead [sic] our son's opportunities for mainstreaming (the school would not increase his inclusion in Gen Ed based solely on my wishes or information). …” We also analyzed the data to compare the perceived helpfulness of each educational staff member for children who were the oldest or only child in their family to the perceived helpfulness of these individuals if the child with Down syndrome was a middle child or the youngest in their family. This was also analyzed to see if there was a difference in perceived helpfulness levels between income brackets.

All individuals within the group of community members listed in Figure 5 were also ranked by participants as helpful with an average ranking of 4.88 on a scale from 1 to 6. The most helpful member of our participants’ communities was their spouse or partner. People also mentioned the helpfulness of other parents of children with Down syndrome. One parent said, “I found speaking with other parents seem to be most helpful when it comes to the public schools special needs programs. The school [sic] don't come forward with the information that may be [sic] fit your child.”

![Figure 5 – Helpfulness of Community Members](image-url)
When given the opportunity to elaborate on resources found to be helpful, many times parents mentioned other experienced parents of children with special needs, the school staff, their local Down syndrome association, educational advocates, and doing their own research.

**Respondent 53** - “Our local parent support network had educational seminars, explaining the alternatives available; It was also an opportunity to network with other parents and hear their experiences. Also, we have a strong DS support network with private social networking groups so parents can feel comfortable asking questions and sharing their experiences.”

**Respondent 45** - “We had a rough road getting inclusion for my daughter. Her IEP from the pre-school special Ed classroom was for full inclusion starting in kindergarten, but the public elementary school did not want to include her. We had found resources prior to this experience [sic] through our local Down syndrome association and educated ourselves. We knew what kinds of experts we would need and sought them out. Our education advocate and behavior analyst were the most helpful and finally, after hiring an attorney, the district [sic] agreed to fully include her (and to a school change at our request). Now she is fully included in second grade and in a school where they love her and want her to succeed.”

**Respondent 48** - “I did not feel like I got any help except for the research I did online”

**Respondent 75** - “Any/all research studies on methodologies, studies, evidence-based studies that I can bring to the school to demonstrate success/value of inclusion.”

**Experience**

Parents were asked to share a positive experience that came out of this transition for them or their child. Most people chose to focus on the improvement in their child’s skillset (14/41) and the progress they had made socially and in academics. One parent commented that her daughter “was the #2 sight word reader in her kindergarten class in the first week of school.”

**Socially, many parents saw improvements and positive reactions from other children (18/41).**

**Respondent 34** - “Our son was an instant superstar at his new school. He's the littlest man on campus, it's a k-8 school and he had just turned three, but within a week, everyone knew him and everyone wanted to high-five him or get a hug on his way into school. It's amazing. Everyone [sic] has been supportive and caring and he loves it. Being included with kids who are a year older has done wonders for his expressive language and social skills! It is truly the best thing that's ever happened to him.”

**Respondent 57** - “She is making friends. Her speech and social skills are right on track. She is learning at the same rate as her classmates in math reading is behind but she is not the slowest reader in class. The kids love her and she enjoys the kids. She is making relationships [sic] that she can keep for a life time [sic]. She is also changing the way her teachers see people with DS. The funny thing is when she sees others with DS that are her age she corrects them and helps them out.”
Respondent 43 - “He went to our state's special Olympics. They had a send-off party for him with signs, cheers, etc.”

We asked parents about the smoothest part of their child’s transition from special education or early intervention services to an inclusion classroom. Many parents mentioned the positive experiences their child had because of other children (11/49).

Respondent 8 - “My daughter's strengths are all revolved around being social. She loves new experiences and new friends and so far she has transitioned well. She came from a full-inclusion private pre-school where she thrived. The typical child modeling did wonders for [sic] her.”

Respondent 11 - “[The smoothest part of the transition was] Other children accepting our daughter”

Many parents also mentioned how resilient their child was and the large role they played in their own success (7/49). One parent said, “My child was very cooperative & happy.” Another parent said, “His ability to be loved! Makes things so much easier.” It was also important to parents that the school staff was friendly (12/49). One parent commented that the people at her child’s school helped the transition go smoothly, “Every one of his GenEd teachers met him one-on-one before school started. They took time to get to know him & his family.” Some parents felt that there was not a specific aspect of the transition that went well, and responded with sweeping statements (10/49). Half of these parents felt the transition went smoothly (5/10). “ALL OF IT! Thank goodness. It was perfectly smooth, except that one child in his class who has autism cried because our son was ‘too friendly.’” Conversely, some felt there were no smooth aspects of the transition. “There is NO smooth part to the transition. If there is one thing that helps is [sic] our son's love of going to school in general, and his adoration of his classmates in both classroom settings. He loves the kids in his 12-1-1- and in his Gen Ed Classroom. He aores [sic] his Gen Ed teacher, and will do almost anything for her... this has been the single most important aspect of his access to Gen Ed, his teacher.”
When asked about the most challenging aspects of the transition to inclusion, many parents commented on the abilities of their child (16/50), the school (19/50), and changes in communication (8/50). Some parents commented on the appearance of the widening gap between their child and the majority of their classmates. Another mom commented on her daughter’s frustrations, “She gets frustrated when she can't do everything the other kids can do - she certainly participates but is starting to understand she can't do everything they can. Aides and therapists have been great helping her through this.” Others felt the teachers did not have a good understanding of their child’s knowledge and abilities. One mother commented that the most challenging aspect of the transition included, “Uncertainty by staff and parents. Lack of knowledge. Preconceived ideas of my child's abilities. The coat [sic] of the program.” Another parent felt that it was most challenging to “[deal] with the teachers and students in his regular class to let him do the work or expect him to behave the same way the other students were expected too. The teachers seemed to baby him and excuse bad behavior. The other students (mostly girls) would o [sic] his work for him if he said he couldn't or it was to [sic] hard. They didn't encourage him to try.”

When asked about challenging aspects of their transition, several parents mentioned changes in communication. Many parents were not used to less frequent updates and being less involved in their child’s care including, “not being there during his therapies and not knowing exactly what was being worked on.” One parent said the most difficult aspect of this transition for her was, “letting go. Just like with our ‘typical’ child.”

Similar to the responses to the question regarding the smoothest aspect of the transition, parents also responded to the question about challenges with sweeping statements (7/50).

Respondent 75 - “Everything about inclusion is challenging, and requires a heavy amount of support from everyone in the school (from principal to Para professional). It requires a constant ‘checking in’, monitoring, and revision to his schedule and supports. Now, also the teacher/school [sic] has asked us for
a new neuro-psych and we are taking a close look at what his placement will look at next year (he is chronologically a 2nd grader, but his inclusion is with Kindergarten). We have been advised to look at special schools, but there is only one funded DOE 12 month school that would actually meet his needs in speech and language (he is severely delayed in expressive language), and then we have to go to a special board within the DOE (if he is accepted to the school) for them to approve funding. Our options right now for next year are: stay at the school he is in (our local public school) but unclear how to keep him progressing and setting unclear; move him full time to D75 (the special ed district) or move him to a specialized school.

**Relationships**

Most respondents did not feel the transition had a large impact on their child’s relationships, especially when asked about family members including parent-child and sibling relationships. The majority of respondents who felt there was a change reported it as an improvement within that relationship. Over 50% reported a positive change in the relationship between their child and his or her teacher. There was also a positive change reported in their child’s relationship with their friends in over 50% of those who answered this question. Only a handful of respondents reported negative changes in relationships we inquired about.

When asked to elaborate about changes in their child’s relationships, many parents declined to provide an answer. Those who did comment on this topic said changes occurred within the family relationship (4/25), within their student’s relationship with the teachers (10/25), changes in friendships (6/25), and changes within their child themselves (14/25). Many parents commented or alluded to the fact that they themselves had changed. One mother stated, “I changed!!! I no longer felt it was my sole responsibility to teach our son everything he needed to know! I had a team to help me out!!! …” Another participant commented on her daughter’s relationship with the rest of their family, saying the transition, “Strengthened relationships all around. My daughter is very well rounded and is an instrumental member of our family. She has a sister 18 months older and a brother 21 months younger. They are very close.
The biggest improvement has been with my mother-in-law [sic], who now sees firsthand that my daughter is strong and capable in many ways, academics included.”

Numerous parents also mentioned the changes they saw in the child themselves. Most observed improvements in their child’s skills and abilities. These included improvements in potty training, taking turns, sharing, imitating speech, and social skills.

Respondent 37 - “Our daughter has become more verbal since being with other children. She feeds off [sic] the verbal abilities of the children in her class.”

However, not all changes reported were positive. One mother noted that, “[her daughter] became more anxious and now has a diagnosis of selective mutism.” Other parents noticed behavior problems that arose during the transition period.

Respondent 8 - “She became very possessive of her things and would always have to have whatever her younger brothers were playing with. She acted out a bit with them when she started school.”

Many parents also commented on their child’s relationship with their friends and classmates. All of the responses mentioned positive experiences involved in being included in activities with typical peers.

Respondent 28 - “The kids in the class really reached [sic] to my son and took him under their wing. It was really heartwarming.”

Respondent 30 - “My daughter has such a wide group of friends. She looks forward to seeing her friends in the typical classroom and they enjoy her. She has had playdates with these children and they ‘get’ her. They help her during the day and include her in everything, ances [sic], lunch, etc”

One relationship we explored in depth is that of families of children with Down syndrome and their genetic counselor. Most of our respondents (69.49%) had worked with a genetic counselor at some point in their child’s life. Some only worked with a genetic
counselor in a prenatal setting, while others met with a genetic counselor in a pediatric setting. Over 17 percent saw genetic counselors in both settings. The overwhelming majority stated that they no longer have a relationship with their counselor. One parent described her relationship with the counselor as a one-time meeting (5/25). Many felt their meeting with the genetic counselor was both helpful and informative.

Respondent 40 - “The counselor himself was great- reminding us that our son was a unique individual, and that we should not put limitations on him or on our expectations of him…”

Respondent 6 - “My best friend from college is a genetic counselor. She is a great resource urge [sic] for us”

Others had a very different experience with their genetic counselor that they described as mainly negative.

Respondent 15 - “Then [sic] only time we saw the genetic counselor was when they gave us the possible prenatal diagnosis. She was cold and did not give us any useful info until I asked specifically for something g [sic] about ds. Thy [sic] really nee d [sic] to partner with ds groups to give ino [sic] properly”

Support

We inquired about how supported parents and children with Down syndrome felt while going through this process. Many felt their child had more support than they did as parents during this time. Over 60% of parents felt that they did not have support in place for themselves. Those that did feel supported felt that the Down syndrome community was helpful to them. One participant
said, “It helped talking to other moms about the process.” Other respondents indicated they had personal support from family members and friends. One mother reported that, “My husband was my biggest support - he had no reservations about the transition, while I was very nervous.” Outside services were helpful to some. “The whole early intervention team was one support. Also DS Parent Support Groups were another.”

Over 77% of parents felt that their child had support available to them at the time of inclusion. Very few felt their child was not supported and this was mainly due to the abilities of the school district to provide for them. One parent experienced this and reported that, “there is [sic] no paras available in our district. We had to advocate for a TA in the classroom to help out. No educated or experienced help.” However, most felt that their child was getting support from a variety of constituencies. These included school provided support, outside support including private tutors and advocates, and family and friends.

Respondent 46 - “The spec. Ed. Teacher worked with the classroom teacher to modify is [sic] work. He also had an aide with him to support him.”

Respondent 20 - “We hired a private tutor.”

Respondent 37 - “The supports were the educational advocate and our teacher friend as stated previously.”

Respondent 40 - “Everyone at his elementary school knows our son, and I feel like I have a lot of people looking out for him.”

We also analyzed the data to see if there was a difference in the feeling of support between income groups. There was no statistically significant difference between any income level and
whether or not parents had support in place for themselves or their child. However, not all income levels were equally represented among participants.
DISCUSSION

Each child with Down syndrome has their own individual abilities and needs, therefore the difficulties or ease parents feel is unique to each child and each school environment as well. This was especially evident to us as we read through responses to each of the open-ended questions. It was very difficult to categorize parents’ answers into themes or groups.

In all places where parents were allowed to elaborate on their experience, it was stressed that they wanted their child treated the same as every other child in the class. Some parents talked about how teachers would baby their child or give them special treatment. Others commented on increasing their own expectations for their child before they started school in their inclusion classroom.

Preparation for Inclusion

Most parents stated they were not advised to prepare their child for inclusion. However, we feel our survey participants may have misunderstood this question, causing those who were “informally” prepared to report receiving no advice on preparation. Inclusion could potentially be more common so parents or other providers may not feel the need to prepare others. Those who reported being advised about the process were given very specific advice. It would be interesting to have asked who advised these parents about the process, whether they were gathering advice mainly from other parents of children with Down syndrome, or educational and medical professionals.

Most parents felt like they did not have support for themselves during the inclusion process. We looked at these results in terms of income level and found no statistically
significant difference between income levels and whether or not parents felt they were supported. This shows us that it is difficult for parents of all income levels to get the support they feel they need during this process; it is not specific to people of a lower socioeconomic group. However, those from lower socioeconomic statuses were not well represented among participants. The results could have changed had more respondents with lower annual household incomes chosen to participate in our study. There is most likely not much support or preparation provided to parents in general.

**Resources**

While many parents listed specific resources they found helpful during the transition period, most of their responses emphasized the need for self-advocacy, as the parents were always the advocate and the driving force behind their child’s inclusion process. They acknowledged the need to always seek out individuals and resources that could best support and facilitate their child’s progress and success. Parents discussed how they sought out resources on their own and educated themselves on potential issues that could arise in the school setting. Just like parents of typical children, the majority of our respondents expressed that they will do “whatever it takes” to get their child the help they need. Many individuals may have felt compelled to respond to this question because they felt the need to help other families in the future that will be going through this transition from early intervention or special education into an inclusion classroom. They are not only advocates for their own child, but are also offering advice and support to others.

It was also not surprising that there were no statistically significant differences between income levels and the perceived helpfulness of educational staff members. People from all income groups found their child’s teachers, providers, and aides to be helpful. This could be
because teachers are directly involved in the inclusion process and are involved in every family’s experience, not only those who are of higher socioeconomic groups. We thought that having experience or a previous relationship with the school system with older children might have been helpful to families, but from our population sample this was not the case. We think this is because every child with Down syndrome has different abilities and needs. However, due to the limited sample size and the sampling technique, we are unable to prove that this is not a factor. We did not directly question participants about this relationship. Each child in the family is different as well, and relationships can change based on the school’s ability to provide for a student with special needs.

**Experience**

When parents were asked specific questions about their experience or their child’s experience in inclusive classroom education, it became evident that there is a lot of time and effort that goes into planning and preparation. Several parents responded with sweeping statements about their challenges or successes with the transition. So much thought goes into making inclusion successful that it may have been hard for parents to tease out effective and meaningful experiences. Many participants reported that everything was challenging and that nothing went smoothly. Their responses seem to be about their own experience, rather than their child’s experiences.

Another common theme throughout respondents’ answers was that they wanted their child to be treated the same as any other child. Many parents mentioned getting their child involved with “typically” functioning children from an early age and treating them the same. Others commented that they wanted their child to be challenged in the same way others were.
Relationships

Participants generally did not feel that their child’s relationship with family members changed much due to the transition and those who did report a change categorized it as a positive one. This could be because the child’s family is a constant, steady source of support for them during the transition. The improvements their children were making in school could have been reflected in their home environment as well. More than 50% of parents reported there was a positive change in their child’s relationships with their friends and teachers. In many questions, parents commented on the inclusive nature of other children in the class and how helpful it was to their child. Others commented on the helpfulness of their teachers and how much their students loved their teachers.

Most participants commented on the way their child changed the way people think about individuals with Down syndrome. A few parents stated that their child’s teacher had never taught a child with Down syndrome and did not know what to expect. Others said their child changed the teacher’s way of thinking about people with disabilities.

When questioned about their relationship with genetic counselors, many people indicated it was a very brief meeting and not always helpful. This could be because typically genetic counselors are not as involved with a child’s education as other providers may be, including speech and occupational therapists. Genetic counselors may follow children with Down syndrome throughout their life, but this did not seem to be true for the majority of our respondents, which could explain the low ranking of the helpfulness of genetic counselors. It would have been helpful to ask parents directly what kind of information they would like to have gotten from their genetic counselor or other provider for those who had longer relationships with genetic counselors. Knowing what their relationship is or was with their genetic counselor
would be important information to gather as well. If patients see a pediatric counselor on an annual basis they may have a stronger relationship with that person than someone who only saw a counselor one time in a prenatal setting where they were receiving a diagnosis. Knowing the context of their visit with a genetic counselor can be important as well. If they met with a counselor prenatally, the counselor may be viewed in a more negative light because they often bring up the range of options families have when first receiving this diagnosis. However, if families met with a pediatric counselor this is typically not discussed and the conversation is more focused on helping their child succeed and get good medical care. Therefore it can be reasonably expected that pediatric counselors would be received more positively.

The purpose of this study was not to understand the way a genetic counselor was perceived, but rather to provide genetic counselors with stories and experiences surrounding inclusion from parents of their patients. Families may bring up their worries or concerns about the inclusion process and ask for guidance or support. We would like this information to serve as a resource that genetic counselors can draw upon, allowing them to get closer to their patients.

**Study Limitations**

Limitations of this study include a potential respondent bias. Respondents who took the time to respond to the survey may have more access to resources than other parents of children with Down syndrome who did not respond, therefore skewing the results. Most of our survey participants were Caucasian, females, with a bachelor’s or post-graduate degree, and an income level above the poverty line. There was not much diversity among our respondents and we did not hear from minority groups about their experiences. People in a low socioeconomic group may not have taken our survey because they felt that getting services for any and all of their
children was equally difficult, or they may not have had resources available to them to get their child into an inclusion classroom.

There were also questions it would have been helpful to ask parents to get a better understanding of their journey thus far. Gathering information on whether or not families found out their child had Down syndrome prenatally or after birth could have given us some insight into whether or not this has an impact on families and their attitudes towards the inclusion process.

None of our results were statistically significant. This is likely due to the small sample size, wide spectrum of individual abilities in each child, and the wide spectrum of school experiences. Each child is unique and we did not ask for specific information regarding children’s abilities or what the school is able to provide for each child. For this reason, it is hard to make generalizations about the transition experience. These two factors are difficult to control for, and can shape a family’s experience on their own.

While an online, anonymous survey is a great way to reach a large number of participants, it also does not allow the opportunity for follow-up questions or clarification if necessary. It would have been helpful to press people who responded with one-word answers, to determine why they felt that way and get them to elaborate more. Having additional information from families leads to a greater understanding of their experience and consequently gives counselors information to respond in sensitive and caring ways to the concerns expressed by families.
CONCLUSION

The participants in our survey reported experiences that describe the road to inclusion as a difficult, but rewarding journey. Several repeating themes seemed to emerge throughout parent responses to all questions. Most parents wanted their child to be treated like any other child in their class with the same behavior expectations. It was also apparent in the responses how different each child with Down syndrome is from one another, similar to the wide spectrum observed in typical children. Every experience or piece of advice respondents chose to tell us was different. This reflects the different needs and abilities of their children as well as the differences in educational settings. Therefore, it is difficult to create a ‘one-size-fits-all’ checklist of things to do in preparation for a child with Down syndrome’s transition into an inclusion classroom.

However, respondents indicated that they frequently had to be an advocate for their child. Others indicated a more indirect advocacy role in their child’s education. They sought out resources and people who could best help their child succeed in the inclusion environment. Most parents also reported feeling a lack of support. Those who did feel supported felt that speaking to other parents of children with Down syndrome was the most helpful to them.

Genetic counselors can use this information to better understand this aspect of their patients’ lives. Many pediatric genetic counselors work with families of children with Down syndrome throughout this time period. Knowing this information can help guide the discussion and offer suggestions to families if they are struggling with the transition. As genetic counselors, we need to address our biases, and determine how to dialogue with parents about their
experiences. We need to learn to be empathetic and compassionate without judgment slipping into the dialogue.

**Future Research Suggestions**

Future studies could include repeating the survey, but widening the window of possible participants by asking for those who have transitioned within the last five years. Many people were willing to participate, but were excluded due to the time that had elapsed since their child had first gone through the inclusion process. It would be interesting to hear responses from people who had undergone this transition longer than three years ago. Many attempted to take the survey and therefore may have had important things to say regarding their own path to inclusion.

It also would have been important to hear more about how they intersected with genetic counselors, whether they received a prenatal diagnosis or if their child was diagnosed with Down syndrome after birth. It would have been helpful to know more from this parent group about their early intervention experiences and if there are any perceived differences in the two settings, and specifically, if parents felt there was a great amount of support given in early intervention that was no longer there in the inclusion setting. The literature implied that parents of typical children said their child benefited by inclusion and it would have been interesting to contrast the perceptions of inclusion from parents with typical children in these same settings.
REFERENCES


APPENDIX A: RECRUITMENT NOTICE

Recruitment Notice

My name is Emily Bryant and I am a second year genetic counseling student from Brandeis University. I am writing to invite you to participate in my graduate research.

After working for several years as a classroom assistant in an early intervention special education program, I found that I would like to know more about what families go through after they finish the program and transition to an inclusion classroom in early elementary school. Previous research has shown that many factors go into a successful academic experience of a child with Down syndrome. I would like to investigate what makes a transition successful and builds resilience in families.

I invite parents of children with a diagnosis of Down syndrome to participate in my online survey. I am looking for the most current information, therefore I welcome anyone who has a child that has gone through the transition to kindergarten or an early elementary school inclusion classroom within the last 3 years.

The survey will be completely anonymous and all identifying information will be kept confidential. You will be able to exit the survey at any time. It should only take about 30 minutes to complete the survey. Participants must be at least 18 years of age or older and must have a child with Down syndrome that has transitioned into an inclusion classroom within the last 3 years. This includes part-time inclusion as well.

Upon completion of the survey, there will be a raffle for Amazon gift cards valued at $50. There will be 3 winners.

Please note that this survey is being distributed to several online groups, and there is no need to complete it more than once.

This project has been approved by the Brandeis University Institutional Review Board. If you have questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or 781-736-8133.

We do not anticipate the survey to induce stress upon any individual. However, we are sensitive to the fact that this time in a family’s life can be stressful and recalling memories from that time could be difficult. For this reason, we have made counseling services available. If you feel you need support, please contact Dr. David Rintell, our on-staff clinical psychologist, at rintell@brandeis.edu. Thank you so much for considering participating in my survey. Your input is very valuable and we hope that you will share your experience. We hope that the
information we are gathering will allow genetic counselors and clinicians to support other families transitioning their child to an inclusion classroom.
APPENDIX B: SURVEY INSTRUMENT

Introduction:

Thank you for agreeing to participate in our survey inquiring about the transition to a partial or full-time inclusion classroom for the family of a child with Down syndrome. Inclusion is defined as the integration of students with disabilities or other special needs into regular curricular or noncurricular activities. Partial inclusion means the child will have some of their classes in a regular education level classroom. Full-time inclusion means the child spends the entire day in the regular education classroom.

As the parent of a child with Down syndrome, your experiences and insights into this process are valuable and important. We really appreciate you sharing your experiences with us. We hope that the information gathered in this survey can help genetic counselors and other healthcare professionals better understand what families go through during this time. By providing them this background knowledge, we hope they will be better prepared to help other families in their own transitions to inclusion classrooms.

The survey will be anonymous and confidential. You may stop the survey at any time if you feel uncomfortable proceeding. You may also choose to skip questions. You will still be eligible to receive the Amazon gift card if you skip questions.

We do not anticipate any risk to survey participants, but some respondents may feel discomfort remembering times that may have been stressful. If you feel you need additional support, contact the Brandeis Genetic Counseling program’s on-staff psychologist, Dr. David Rintell at rintell@brandeis.edu.

If you have questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or 781-736-8133.

By clicking next, you are consenting to participate in the survey.

Screeners:

1. Does your child have a diagnosis of Down syndrome?
   a. Yes → Continue to 2
   b. No → Exit survey
2. Are you 18 years or older?
   a. Yes → Continue to 3
   b. No → Exit survey

3. Has your child transitioned from an early intervention program or a special needs classroom into an inclusion classroom (either partial or full-time) within the last 3 years?
   a. Yes → Continue to 4
   b. No → Exit survey

4. Are you an active participant in your child’s daily educational needs?
   a. Yes → Continue to survey
   b. No → Exit survey

Survey Exit:
Thank you for your interest; unfortunately you do not meet the criteria for completing the survey.

Survey:
First we’d like to ask you some information about your child’s educational environment.

1. At what grade did your child join a partial or full inclusion classroom?
   a. Preschool, Pre-K, Head Start
   b. Kindergarten
   c. Grades 1 – 3
   d. Grades 4 – 6
   e. Other: __________

2. What age did your child first join an inclusion classroom?
   a. _________ (Years)

3. In what educational environment was your child with Down syndrome being educated at the time of their first inclusion?
   a. Public school
   b. Private religious school
   c. Private nonsectarian school
d. Home schooled  
ed. Other: Please specify

4. Was your child’s first inclusion partial or full-time?  
   a. Part time  
   b. Full time

5. What therapies (speech, OT, PT, etc) was your family receiving at the time?  
   ___________________________________________________  
   ___________________________________________________  
   ___________________________________________________

6. In what educational environment is your child with Down syndrome currently being educated?  
   a. Public school  
   b. Private religious school  
   c. Private nonsectarian school  
   d. Home schooled  
   e. Other: Please specify

Now we’re going to ask you about the helpfulness of resources that may have been available to you and your family at the time of the inclusion.

7. The list below includes a number of different healthcare workers who might have been helpful during your child’s first transition into an inclusion classroom.  
   Indicate how helpful each person was using the scale below:
8. The list below includes a number of different **educational staff members** who might have been helpful during your child’s first transition into an inclusion classroom. Indicate how helpful each person was using the scale below:

<table>
<thead>
<tr>
<th></th>
<th>Very helpful</th>
<th>Helpful</th>
<th>Somewhat helpful</th>
<th>Somewhat unhelpful</th>
<th>Not helpful</th>
<th>Very unhelpful</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child’s pediatrician</td>
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<tr>
<td>My child’s developmental pediatrician</td>
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<td></td>
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<tr>
<td>My child’s nurses</td>
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<tr>
<td>My child’s early intervention provider</td>
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<tr>
<td>My child’s nurse practitioner</td>
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<tr>
<td>My child’s psychologist/social worker</td>
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<tr>
<td>My child’s speech pathologist</td>
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<td>My child’s occupational therapist</td>
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<tr>
<td>My child’s physical therapist</td>
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<tr>
<td>A genetic counselor</td>
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<tr>
<td>Other, please specify:</td>
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</tr>
</tbody>
</table>


9. The list below includes a number of different **community members** who might have been helpful during your child’s first transition into an inclusion classroom.

Indicate how helpful each person was using the scale below:

<table>
<thead>
<tr>
<th>Resource</th>
<th>Very helpful</th>
<th>Helpful</th>
<th>Somewhat helpful</th>
<th>Somewhat unhelpful</th>
<th>Not helpful</th>
<th>Very unhelpful</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>My family</td>
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<tr>
<td>My spouse</td>
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<td></td>
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<tr>
<td>My friends</td>
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<td></td>
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<tr>
<td>Other parents of children with Down syndrome</td>
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<tr>
<td>Internet resources</td>
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<tr>
<td>Literature/pamphlets</td>
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<tr>
<td>A special education advocate</td>
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<tr>
<td>Other, please specify:</td>
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</tbody>
</table>

Please describe the kind of resource that was very helpful:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

Now we’re going to ask you about the inclusion process.

10. Were you advised to prepare your child for the inclusion?

   a. Yes

   b. No
11. What were the smoothest parts of the transition?
_________________________________________________________
_________________________________________________________
_________________________________________________________

12. What were the most challenging parts of the transition?
_________________________________________________________
_________________________________________________________
_________________________________________________________

13. What would have been helpful for you to have known before beginning the transition to inclusion process?
_________________________________________________________
_________________________________________________________
_________________________________________________________
Would you advise other families to be aware of this?

a. Yes
b. No

14. What advice would you give another family about to go through this transition?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

15. Did your **child's relationship** change with anyone because of the transition?

Please use the sliding scale to indicate the change experienced.

Teachers:

a. Changed positively
b. Did not change
c. Changed negatively

Friends:

a. Changed positively
b. Did not change
c. Changed negatively

Siblings:

a. Changed positively
b. Did not change
If there were a change in any of these relationships, how would you describe that experience?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

16. Did you have supports in place for yourself when your child first started this transition? Please elaborate.

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
17. Did your child have supports available to them at the time of the first inclusion to help them work through the transition?

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

18. Please share a positive experience of your child’s inclusion process that you think is important for us to be aware of.

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

19. Have you ever worked with genetic counselors?
   a. Yes → Question 20
   b. No → Question 23

20. Before or after the time of your child’s birth?
   a. Before (prenatal counselors)
   b. After (pediatric counselors)
   c. In both settings

21. Do you still have a relationship with genetic counselors?
   a. Yes → Question 22
   b. No → Question 23
Demographic Information:
We are collecting this information to make sure we have captured an accurate representation of the diverse community we are surveying. As always, this section is optional to complete.

23. Which gender do you identify with?
   a. Male
   b. Female

24. How old were you on your last birthday?
   a.  (Number field)

25. How old was your child on their last birthday?
   a.  (Number field)

26. Where does your child with Down syndrome fall in your family order?
   a. Oldest child
   b. Middle child
   c. Youngest child
   d. Only child

27. How would you describe your racial identity? Check all that apply.
   - Black or African American
   - White or Caucasian
   - Asian
   - American Indian or Alaskan native
   - Native Hawaiian or Pacific Islander
   - Other
28. What is your ethnicity?
   a. Hispanic/Latino
   b. Non-Hispanic/Non-Latino

29. How would you describe your child’s racial identity? Check all that apply.
   - [ ] Black or African American
   - [ ] White or Caucasian
   - [ ] Asian
   - [ ] American Indian or Alaskan native
   - [ ] Native Hawaiian or Pacific Islander
   - [ ] Other

30. What is your child’s ethnicity?
   a. Hispanic/Latino
   b. Non-Hispanic/Non-Latino

31. What is the highest level of education you have received?
   a. Elementary/Middle school/Some high school
   b. High school diploma
   c. Some college
   d. Associate’s or other 2 year degree
   e. Bachelor’s or other 4 year degree
   f. Post-graduate degree

32. What is your annual household income?
   a. Less than $23,100
   b. $23,100 – $32,499
   c. $32,500 - $59,999
   d. $60,000 - $99,999
   e. $100,000 - $149,999
   f. $150,000 - $249,999
   g. $250,000 or above

33. What is your marital status?
   - [ ] Single
   - [ ] Married
   - [ ] Divorced
   - [ ] Widow/Widower
   - [ ] Common Law Marriage/Living with Partner
   - [ ] Other

34. Where do you live?
   [ ] Drop-down menu
Thank you very much for your participation in this study. Your experiences are very valuable to us. Please enter your email address in the space provided below in order to be entered in to the raffle for Amazon gift cards valued at $50 each. There will be 3 winners. Your chance of winning depends upon the number of participants that choose to enter their email address below. Your response to this question will not be linked to the rest of your survey responses.

Email address
APPENDIX C: PERMISSION LETTERS

Toler, Tomi L. 10:48 AM (1 hour ago)

to me

Yes, it's ok to distribute through MGH.
It would be sent out a few ways:
1) Facebook post
2) Twitter post
3) Newsletter listserv possibly, but the others are much easier.

Tomi

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Emily Bryant <ebryant@brandeis.edu> 10:05 PM (14 hours ago)  
to Angela  

Hi Angela,  

I am just confirming that it is okay for you to distribute my survey over your Boston Children’s Hospital Down syndrome Program email listserve and to your Facebook group. I need written confirmation for my IRB application.  

Thank you!  

Lombardo, Angela 9:03 AM (3 hours ago)  
to me  

Yes, No problem!  

Sent from my iPhone