FAMILY PALS: AN EXPLORATION OF PARENTS’ EXPERIENCES

Master’s Thesis
Presented to
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Brandeis University

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By
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**Abstract**

Family Pals: An Exploration of Parents’ Experience

A thesis presented to the Biology Department and Genetic Counseling Program

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Family Pals was created by the Brandeis University Genetic Counseling Program to provide students the opportunity to meet with families who have a child with a disability. First-year genetic counseling students are placed with a family during their spring semester in order to more fully appreciate the life experiences of families who have a child with a disability. The students meet with their assigned families in their homes or at mutually agreed upon family/child-centered activities. Since the Family Pals Program inception 11 years ago, the Genetic Counseling Program has actively sought feedback from students, but the perspective of the participating families has never been examined. The purpose of this study was to explore the experiences of parents who have participated in the Brandeis University Family Pals Program. Any parent who had participated in Family Pals at least once was eligible to participate. A total of 10 Family Pals parents took part in the study, which included a qualitative, semi-structured phone interview lasting approximately 15-30 minutes. Participants discussed their motivation in being a part of the Family Pals Program, and provided a program evaluation. Our
findings show that parents are motivated to participate in Family Pals in order to “give back” to other similar families. This motivation is facilitated by 1) providing a first-hand experience for genetic counseling students 2) educating students about their child’s specific condition and about disability in general and 3) demonstrating the possibility of normalcy even with a disabled child. Suggestions for improvement of Family Pals included allowing the parents to provide feedback about the students, and enabling the students in turn to provide feedback to the parents. Our findings may be of interest to other genetic counseling program directors interested in incorporating similar experiences into student curriculum.

**Keywords:** Genetic counseling training, disability awareness, first-hand experience with disability, family pals program
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**Introduction**

Disability is defined by the Americans of Disabilities Act as a “physical or mental impairment that substantially limits one or more major life activities” (1990). According to the United States Census Bureau, in 2005 one in five Americans reported a physical or mental disability (US Census, 2008). This means that the majority of Americans do not have a disability and those with a disability “are forced daily to combat misperceptions and unhelpful attitudes about disability both from the general public and from their health care professional” (Saketkoo et al., 2004). As a result, the disabled population does not feel well integrated with the members of society who do not have a disability because interactions are usually both limited and negative. Limited interactions may cause people without a disability to feel uncomfortable serving those with a disability. Therefore, medical schools across the country are working to alleviate this discomfort for students by providing the opportunity for them to meet with families of children with special needs (Sharma et al., 2005).

Several of these schools acknowledge that students find these types of programs very useful, because it allows them to understand the challenges parents who have children with disabilities face. Students report enjoying the opportunity to understand the many different family dynamics observed in the visits. This includes the strengths of family relationships and the feelings of normalcy amongst the families. (Johnson et al., 2006).
Medical schools believe this aspect of training helps teach their students the concept of empathy, which can be a very challenging task. Medical schools realize that the best individuals to teach empathy are those who have personal experience with disability, or families who care for a child with a disability (Blasco et al., 1999). Since the hospital’s stressful setting may not be the best environment to understand empathy, “the more conducive site to promote empathy and understanding [is] the home, work, and/or play” environments (Blasco et al., 1999).

Genetic counselors are trained differently than physicians. Genetic counseling is a relatively new medical profession which requires a master’s degree with specialized education and training over the course of the two-year period. Within the two-year training period, genetic counselors learn “to provide expertise in clinical genetics, to counsel and communicate with patients on matters of clinical genetics, and to provide genetic counseling services in accordance with professional ethics and values” (NSGC, 2008).

The graduate coursework for the programs, as stated by the American Board of Genetic Counseling (ABGC), include the following: human, medical and clinical genetics, psychosocial theory and techniques, social, ethical and legal issues, health-care delivery systems and public health principles, teaching techniques, research methods and clinical training (2007). Each program teaches these basic concepts in their own desired methods. However, “each of the programs has taken on its own flavor- some focus on psychosocial issues, whereas others focus on clinical features of syndromes, or on laboratory or clinical research” (Begleiter, 2002). The ABGC which certifies the genetic counselors and accredits the programs does not require disability sensitivities training for
all genetic counseling programs. This means that not all genetic counseling students have the opportunity to meet with families one-on-one in a non-medical setting, but some genetic counseling programs do train their students with hands-on experiences similar to medical schools.

**Brandeis University**

At the Brandeis University Genetic Counseling Program, genetic counseling students are able to focus their studies on psychosocial issues. This is because the program “puts an emphasis on exploring all perspectives, including those of individuals and families living with disability and chronic illness” (Brandeis Genetic Counseling Website). One way the program has helped to facilitate students in understanding these issues is through the focus of disability awareness. Students are able to learn directly from children and adults with a disability as they complete volunteer placements in the community. They also form relationships with families of children with disabilities through the Family Pals Program.

The Brandeis University Genetic Counseling Program’s “Family Pals” is exclusive to the Brandeis curriculum. The purpose of the program is for students to interact with the family at least two times during their first year in order to understand family dynamics in a special needs environment. It also allows the families to share their personal stories. Students keep a reflective, experiential journal of their time spent with the families. This is helpful to ensure that they gain optimal experience which can be applied to their counseling. Families who participate in the program are also compensated for their participation through a book of their choosing. Family Pals is important because the students are able to interact with families in a non-medical setting.
For a complete list of student expectations, see Family Pals Program Guidelines and Requirements (Appendix E).

There are between 20 - 25 families who have participated in Family Pals over the past 11 years. All live in or near the Boston area. Many of the children have Down syndrome or autism. However, other children who have participated have Canavan disease, Prader-Willi, velocardiofacial syndrome, isodicentric chromosome 15, achondroplasia, Sanfilippo, fragile X syndrome, Conradi Hunermann syndrome and osteogenesis imperfecta. Most families have participated in the program for several years. However, a handful of families have only participated once.

Although some evidence in the medical literature exists supporting the value for medical students to interact with families one-on-one in the home environment, this literature does not exist on the importance of this type of interaction for genetic counseling students (Blasco et al.; Saketkoo et al.; Sharma et al.). There is also no literature about the parents’ experiences with these types of programs. This study therefore addresses two objectives. The first is to understand parents’ experiences with the Family pals program through an exploration of their goals and motivations to participate. The second is to allow the parents the opportunity to review the Brandeis Family Pals program, to see if any changes can be made to make the program a better experience for either the students or the families involved.
Methods

This qualitative study used semi-structured phone interviews to assess parents’ goals and motivations to participate in the Brandeis University Family Pals Program. During the interview, parents were also asked to give a review of the program. Approval for this study was obtained by the Brandeis University Institutional Review Board.

Study Sample

Participants were recruited by the Brandeis Genetic Counseling Program’s Co-Director of Research and Professional Development. This faculty member is responsible for matching students with families participating in the Family Pals program. The criteria for participating in the study included being involved for at least one year in the Brandeis Family Pals program. A total of 25 families were contacted to participate in this study through two different modes of recruitment. The 13 families currently participating in the program were contacted via email. Twelve families who were not currently participating, but had in the past, were contacted through the United States postal service. Interested participants were asked to contact the project’s Principal Investigator via email.

A total of 12 participants, 11 women and one man, contacted us to participate in the study. However, two of those participants were excluded from the study because they never fully participated with the Family Pals program. In total, ten participants, all mothers, consented to enroll in the study.
Interview Guide

The interview guide consisted of a total of nine open-ended questions focused on the participants’ experiences and participation while interacting with students within Family Pals. A current participant in the Family Pals program was consulted to help create a rough interview guide. The interview guide was finalized through an iterative process involving the whole thesis committee. The questions included the following: How long have you been participating in the program, what motivates you to participate in the Family Pals Program, what does participating in Family Pals mean to your family, what do you hope the genetic counseling students get out of the program, what did you know about genetic counseling prior to participating, do you ever feel burdened by the program, is there anything you think Brandeis should change about the program, and is there anything else about Family Pals that you would like to discuss?

Interview Process

Each subject participated in a semi-structured phone interview conducted by the Principal Investigator. The average interview ranged from 15-30 minutes and all interviews were audiotaped. All participants were compensated with a $25 gift certificate.

Data Analysis

After completion of each interview, audiotapes were transcribed verbatim by an outside source and coded by the Principal Investigator for emergent themes, using the qualitative research software ATLAS. The themes were derived by analyzing all of the participants’ answers, line by line. Any common words used in the answers to the interview questions were coded as one theme. At the beginning of the coding process,
large numbers of codes were assigned based on the identification of themes that appeared to be relevant to the parents’ motivations and goals for the program. However, since most of these codes were similar to one another, they were subsequently merged in order to provide one major goal of participation supported by three different means to achieve that goal.
Results

Participant Characteristics

A total of ten mothers, six of whom were currently participating in the Family Pals program, were interviewed.

Represented disabilities. Six different conditions were represented in the sample. Those conditions include Down syndrome, autism, deafness, velo-cardio-facial syndrome (VCFS), fragile X syndrome, and isodicentric chromosome 15. Participants reported being involved with the Family Pals program between one and six years. Current ages of their children were reported to be between 5-years-old to 14-years-old, but ages of the children at the time of the families’ participation were not discussed.

Table 1: Characteristics of families involved with Family Pals (n=10)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down syndrome</td>
<td>4</td>
</tr>
<tr>
<td>Autism</td>
<td>2</td>
</tr>
<tr>
<td>Deafness</td>
<td>1</td>
</tr>
<tr>
<td>Velo-cardio-facial syndrome (VCFS)</td>
<td>1</td>
</tr>
<tr>
<td>Isodicentric chromosome 15</td>
<td>1</td>
</tr>
<tr>
<td>Fragile X syndrome</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of years participating</th>
<th>Number of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 years</td>
<td>3</td>
</tr>
<tr>
<td>3-4 years</td>
<td>5</td>
</tr>
<tr>
<td>5+ years</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ages of children participating*</th>
<th>Number of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5 years</td>
<td>0</td>
</tr>
<tr>
<td>6-10 years</td>
<td>4</td>
</tr>
<tr>
<td>11-15 years</td>
<td>7</td>
</tr>
</tbody>
</table>

*n is 11 for this category because 1 family has 2 children with the same condition

Participant Background. When asked how the participants heard about the Family Pals program, five families reported hearing about the program through a word-
of-mouth referral, and five families reported finding out about Family Pals through organizations such as the Family Voices listserv, Federation for Children with Special Needs, Autism Support Center newsletter, the Down syndrome clinic, and fragile X networks. Respondents who received a word-of-mouth referral reported hearing about the program from either a friend who was participating, or from one of the faculty members of the Brandeis Genetic Counseling program. One participant stated:

My friend explained to me what she did and how she was involved and what the students did, and I thought it sounded really interesting, and I was very up for having some genetic counseling students get some in-home visits.

Parents were asked if they had any prior experience with genetic counseling before participating with the Family Pals program. Most parents heard of genetic counseling before, but were unsure of the genetic counselor’s role. One parent, with no prior experience with genetic counseling reported:

No I didn’t. I didn’t really know prior, I don’t think I knew the difference between a genetic counselor and any other, like a genetic doctor, or a geneticist, MD, or something.

Even parents with prior experience with genetic counseling reported being unsure of knowing what the role of a genetic counselor is.

All but one participant reported interest in referring the Family Pals program to friends who have children with special needs. In fact, most families reported already having referred several people because they had a positive experience with the program, that they want other people to experience it as well.

Table 2: Parents’ responses to different aspects of the Family Pals program (n=10)
<table>
<thead>
<tr>
<th>Compensation important to participation</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>9</td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How did family hear about the program</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Word-of-mouth referral</td>
<td>5</td>
</tr>
<tr>
<td>Another organization</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Any prior experience with genetic counseling</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Would parents refer program to a friend</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
</tbody>
</table>

**Activities That Took Place During A Typical Family Pals Session**

Respondents were asked about activities in which their families participated with the genetic counseling student as part of Family Pals. All families reported participating in activities both inside and outside the home. Activities inside the home included: dinner or lunches, playing games with the children, and talking with the parents. Many parents believed that the activities inside the home allow for more free-flowing conversation with the students. This gives students the opportunity to ask questions about the child’s disability and interact with the children in a place where they are most comfortable. One participant said:

*The first visit I usually just have it at home so that the kids are in their comfortable place and that gives me a chance to talk to the student.*

Most parents enjoyed participating in activities outside the home. Not only because it is fun for their children, but it allowed the student to see how a child with a disability is perceived by the public, or how the child with a disability compared to children without a disability. Some of the activities done outside of the home included: bowling, trips to the museum or zoo, going out to dinner, horseback riding lessons and swim lessons. These activities allowed for more interaction between the student and the
child. Parents felt participating in an active environment outside the home gave the students the most perspective on what living with a child who has a disability is like.

One parent with two children with fragile X syndrome stated:

*I tend to bring in a situation like a museum which is sort of loud and crazy. The kids like it, but it brings out a little bit of the over-activity, and it’s not stressful, because they enjoy it, but it heightens their symptoms a little bit more. So I do that a little on purpose. But also the comparison to the other kids I think is really important. Because if you don’t have children or nieces and nephews or somebody to know what a typical seven-year-old looks like, you wouldn’t know how different this is. So I tend to pick activities, at least one, like we’re going swimming to go swimming, because the kids love it, but it also gets them really excited, and it brings out very typical characteristics of Fragile X like hand-flapping, and they call it approach and avoidance. Want to jump in, but won’t go do it...It’s something the kids do anyway, so it’s a nice way of sitting in the background, just watching it. I think it’s educational.*

One mother who has a son with Down syndrome recalled a time when she took a student grocery shopping:

*I’m single. It’s me and him. If I go to food shop, what am I supposed to do with him? So she came with me just to see what it was like. How do you put bundles in the car when the kid’s too big for a carriage? What do you do? Just to get a feel of ‘Hey, come hang out with me. This is what I gotta do.’ You see what it’s like to, you know how we have to adapt things. I can only shop so much. Then I have to put it in the car then I have to go get more. Because I can’t handle all those things and him in a baby stroller, because I can’t put him in a, he’s too big to put in a grocery carriage and too unsafe to walk by himself. So what do you do with him?*

**Information Discussed in Sessions**

The participants talked about the topics of conversation during typical Family Pals sessions. Most parents said that the topics discussed are dependent upon the questions asked by the students. However, other parents felt it is important to discuss certain aspects of their child’s life, even if the student does not ask the specific question. Four families said it is very important to discuss their child’s schooling during the sessions either because their child had been to several different educational environments, or because they are generally pleased with the education their child is getting. Two
families talked about their struggles with the education system and how they solved them.

One mother who has a daughter with Down syndrome reported:

*I’ll go in and talk about schooling and what it’s been like to have the supports of the staff. We’ve been really fortunate to live in a community where they started an integrated pre-school program, full-day. They have made so many accommodations for speech…I have parents requesting now that their children be in [my daughter’s] class because they love getting the extra help for their own children, getting the children exposed to diversity. It’s just been a really wonderful experience.*

Seven out of the ten parents discussed either the disability itself and/or explained how their child came to receive a diagnosis. Five families included their child’s medical history in that discussion. Two parents reported that the child knows the story of his or her diagnosis and Family Pals is a way for them to share their story with others. One parent, whose daughter has isodicentric chromosome 15 reported:

*I love to talk about what my daughter has because it’s a chromosomal abnormality and it’s kind of rare. So I love to talk about that and explain that and give them information.*

Another mother discussed her struggle of finally getting a diagnosis for her son:

*I talk a little about how we went through the diagnostic process because I think ours was pretty typical in that it was, we have basically, my son wasn’t diagnosed until he was four and a half, so that was four and half years searching for an answer of what it was.*

Two of the ten participants discussed the behaviors of their child in the sessions either because the behaviors are typical of the syndrome or because the child’s behavior is something the family struggles with. A mother who has two children with fragile X syndrome discusses the typical behavior patterns of children with fragile X. She uses the opportunity to prepare the students for these behaviors. She reported:

*I explain a little bit about how the kids behave in different situations…We talk about that and then I give them a run-down of some of the symptoms we see, and then I can point them out when the kids are doing them…When my son gets really excited he will flap his hands…and then when he does it I can go ‘check out the hands’ and then I’m not saying this is typical of fragile X syndrome in front of him.*
Six of the ten families discussed the impacts of having a child with a disability on their family. Specifically, they discussed their supports and resources, and in general what it is like to have a child with special needs. Families also discussed what it is like for the siblings without disabilities. One mother reported:

_Sometimes [we] talk about some of the family, sibling issues that go on because those are things that you can’t really learn from a textbook I don’t think._

<table>
<thead>
<tr>
<th>Topics discussed during a session</th>
<th>Number of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schooling or education</td>
<td>4</td>
</tr>
<tr>
<td>Information on the disability</td>
<td>5</td>
</tr>
<tr>
<td>The story of the diagnosis</td>
<td>5</td>
</tr>
<tr>
<td>Medical history of child</td>
<td>5</td>
</tr>
<tr>
<td>Behavior of the child</td>
<td>2</td>
</tr>
<tr>
<td>Impact diagnosis has on the family</td>
<td>6</td>
</tr>
</tbody>
</table>

**Review of Program**

**Number of meetings.** Parents were asked to review the program and discuss if there were specific aspects of the program that either work or do not work for their family. Five parents discussed the length of the program. Three of the five parents discussed how they enjoy the two to three sessions for a few hours each. The parents felt that this set-up allows for the students to become familiar with the children and the family and allows for different interactions, especially depending on the activities and the child’s mood that day. One parent responded that it would be easier to only have to commit to one longer session, due to scheduling concerns. This parent felt that most of the questions are answered in one visit, and the second visit did not make much of a difference. One parent responded that she does not think the time spent with the family is enough and would like to see the student interact for the duration of the master’s program.
**Compensation expectation.** When asked whether or not the book Brandeis offers as compensation for participation is important to their involvement with the program, nine parents responded “no” and one parent responded “yes.” Although most of the parents would participate without compensation, many parents felt it was a nice gesture. One mother enjoys having the opportunity to purchase a book on her child’s condition. She reported:

*I’d probably participate without it. What I’ve always done is I end up using it to purchase a book on something that I either donate to his school for the teachers, or something that I use myself in my own practice.*

**Suggested improvements.** When asked for suggestions on how to improve the Family Pals program, the common themes included families providing feedback to Brandeis about the students, a list of goals for the program, and giving students the opportunity to provide feedback to the parents. One parent suggested the families fill out an evaluation of the Family Pals program:

*[Something that] gives not a lot of space, but just some place to put, so if there’s anything that didn’t go well, or if you were sort of mildly offended by something. Not that I felt like that’s ever really happened, but…I think it’s a nice opportunity for parents to feel like they’re part of the program. And from their perspective, the people that run the program, the person who gets the evaluations and stuff, they actually [can] use it to evaluate their program….to tell the whole class about some of the things that the parents comment on.*

Three of the ten parents commented on a desire to have some guidelines for the program so they can fully understand the goals of Family Pals for the students. These same parents reported frustration in not knowing if they are giving the student what he or she needs. One mother reported it would be helpful to have:

*Some requirements that the student [needs] to get when they [come] for a visit, because sometimes a student will come and have lots of questions and lots of things to ask and say and do, and sometimes they just come and listen. So sometimes I don’t feel like I can determine whether I’m giving them what they need. I don’t know what Brandeis expects*
from the student to be getting when they come for a visit. So I never know if I’m doing a good job…I don’t know if I’m helping them. ‘Is that what you want to hear? Do you want to hear about school?’ I tell her about the things that I think are interesting, but maybe she’s supposed to be getting some other aspect out of this, I don’t know.

Two parents discussed the desire to have the students provide some feedback to the parents about what they learned through their experience with the Family Pals program and whether or not their perspective had changed. One mother reported:

*If they were honest enough, or were able to say ‘Wow, I really had no idea, this is what I thought before,’ because I went through that experience too, before I met my child. My perspective of someone with a disability, we really didn’t know anyone with a disability before our child so you try to draw on your past experiences…*

Another mother reported the desire to know what the students learned for their experience:

*But you know how you wonder what people are saying about you? Like not personally, but did they get it, what I was trying to give them? I wonder if they got the lesson. What lesson did they get? Did they change their professions? What do they get from this?*

**Goals and Motivation for the Family Pals Program – Giving Back**

We wanted to know why parents decided to participate in the Family Pals program, what motivated them to participate, and their goals for participating. One evident theme about the parent’s motivation and goals for participating in the program emerged. The major goal of parents’ who participate within the Family Pals program is giving back in order to help other families in the future. Parents try to meet this goal through three different strategies: providing first-hand experience for the students, educating the students about the importance of giving accurate information on a disability, and showing the students how normal a family who has a child with a disability can be.
Parents discussed their desire to participate in the program because they want to help future families who receive the same diagnosis. Seven out of the ten families felt that teaching the students now will help other families receive better care in the future. One parent talked about being able to relate a diagnosis to a face, a person, and an experience:

*If I can put a face or a memory to the diagnosis, then that will be huge. Do you know what I mean? Rather than just talking from generalizations, you have a story, or his scenario or example.*

Another mother discussed her experience ten years ago, when there was little information about her daughter’s diagnosis. She talked about her hope that participating with Family Pals will help future genetic counselors realize the importance of good resources for families:

*...Thinking that some parent who’s in the shoes that I was in ten years ago is going to have a lot more information at their fingertips with a well-trained genetic counselor giving it to them than I might have…I’ve built a hope, I can see a path where things will be better let’s say than ten years ago when my daughter was diagnosed. So I see that now, I don’t know how long there have been genetic counseling schools or students or anything, but I do know that there, when my daughter was diagnosed, there was a genetic counselor, but the level of information I got was hardly any, so I see the potential that now a parent could get a new diagnosis and a genetic counselor could actually have tons of good, valuable input, and that’s what I hope happens. Evolution, let’s call it.*

Parents discussed three different strategies to achieve the goal of giving back through providing first-hand experience, education, and showing how normal life with a disability can be.

**First-hand experience.** The first strategy used to achieve the goal of giving back focuses on parents’ being able to provide first-hand experience for the students. Nine out of the ten families felt that providing this experience is very important to their participation in the program. Parents want the students to understand that life with a
disability is very different than how it is perceived in a textbook. One mother discussed her training in medical school and what she learned through first-hand experience:

*I think I know from my training in medicine when you actually spend time with people who have these things you just have such a better understanding than reading it in a book. Or seeing people in clinic.*

The following are excerpts from respondents who felt that first-hand experience in order to understand life outside of the textbook is extremely important:

*Well, I think for me I think it’s that not to assume that just because it’s in writing that all of these things are they way they are. That they actually understand it. That that’s the final word, or whatever.*

*That people are not just textbook. It’s real life experience. And I think that when you personalize something it helps give a very, I’m sure an uncomfortable diagnosis just that humanitarian aspect. An emotional tie, perhaps.*

One mother discussed the invaluable opportunity to ask questions outside of the medical setting:

*Because I think the premise is good that you really, you cannot get the perspective without actually meeting people, getting to know people. It’s just, it’s really, that’s really what it is, it’s just invaluable. I mean, I even find it, meeting other families with different disabilities and stuff. You really just have to see it yourself, experience some piece of it for yourself to really get a decent understanding. And just having the opportunity to ask questions that you don’t get to do in a doctor’s setting, doctor’s office or doctor’s appointment or counseling appointment or something.*

One mother discussed that students cannot even begin to understand how a family who has a child with a disability works, without seeing it first-hand. She stated:

*Students can’t get hands-on experience, hands-on family life experience unless the families participate. Because you can’t make it up. You can’t do it in a public setting. Can’t go to a hospital and see how a family works.*

**Education.** The second strategy used to achieve the goal of giving back focuses on education and the importance of giving accurate information to families when giving a new diagnosis. Nine out of the ten families recalled instances when misinformation was
construed to them about their child’s diagnosis. These parents want to make sure that the soon-to-be genetic counselors will never make the mistake of giving wrong information, like some of the professionals they encountered had. The following are parents’ reflections on the importance of providing accurate information to a family:

*And if the information is coming directly from genetic counselors, I guess I sort of have expectations. I have expectations around that they don’t misrepresent like there’s sort of a tendency...Not to assume they know. Not to make bad statements like ‘Your child will never,’ or ‘Most kids don’t.’ Definitive things just aren’t really very helpful to anybody. Not to the family, or, and I think there’s just better ways to get the information across...*

*There’s no crystal ball for any child. No matter what the DNA is. Yes, there are guidelines for our kids. Yes, there are expectations. But you don’t limit it...What if I said ‘He’ll never read, why buy him books?’ That’s just ridiculous. You don’t put a cap on your kid.*

One mother reflected on the time the diagnosis was received:

*It was not so much the misinformation, but about how they gave the information, how matter of fact, and no compassion, no empathy.*

**Normalcy.** The third strategy used to achieve the goal of giving back is by showing the students how normal life with a disability can be. Five out of the ten parents admitted wanting the student to know how normal their family and child really is. The following are parents’ reflections:

*I feel that the more people see how typical, how more alike these kids are than different, that it’s a great thing.*

*So that’s what I’m trying to get people to see that [Down syndrome is] not as abnormal as people might think it is.*

*Just the more people, especially students who are going into this field that can see how normal they are, they just fit right in with the family, it’s nothing. I mean, it is a little different of course. There are challenges. But again, there are challenges with all your kids. So it’s really just, I welcome every opportunity. I’ve never turned them down. I’ve just always been available to participate in this program whenever I can show anybody how Down syndrome is a good thing. We are truly blessed. And how it is not that hard,
or not a bad thing. They're just so much more typical, I think, than people know. And until you meet then and see in a real setting, you don’t know it. So that’s why I do it.

…like I said, just another medium to say ‘here’s a little girl, look what she can do.’...Watching her play in the yard, or watching her in an unmodeled situation. It just allows them to see this is just another little girl.
Discussion

We interviewed ten parents who have participated at least once in the Brandeis University Family Pals program to discuss their motivations and goals for participation in the program, and allow the participants the opportunity to provide an evaluation of Family Pals. We identified one major objective for participating in the program and three primary strategies for meeting that objective. In addition, we found that most parents are very pleased with the program, and only a few suggestions were given to help with improvement.

Many of the mothers spoke about being motivated to participate in the Family Pals program because they want to feel like they are giving back to families who may have the same experiences in the future. A few of the mothers shared with us some of the negative experiences they had with other medical professionals during the struggle of getting a diagnosis for their child. Parents feel the Family Pals program is a great way to share their story with genetic counseling students because their hope is that in the future, the students will remember their story and make sure future families do not have similar negative experiences. This is a very selfless act by the parents participating in the program because their motivation to participate is not for the benefit of their family. Although parents are using Family Pals as an opportunity to share their story with others, it is possible that they benefit psychologically from sharing their story.

Most parents discussed providing first-hand experience to genetic counseling students as one major way to meet their objective. Although most of the parents in this
study did not have prior experience or knowledge about genetic counseling before participating in the program, they discussed the importance for the students to understand what life is like outside of a genetics textbook or at a doctor’s appointment. Parents feel that their children are at their worst at the time of their doctor’s appointment. Many of these children have been in and out of the doctor’s their whole life because of their diagnosis, or because they have serious health concerns. Other children have been back and forth to see specialists because it has taken several years to finally get a diagnosis. Children become especially agitated if blood is drawn at the time of the appointment. Parents say that this is the worst possible time for a student of any kind to be observing their children. If the genetic counseling students see their children at home, in a comfortable atmosphere, parents believe this is the best time to learn about a diagnosis. Only then, in the home environment, can a student truly begin to observe family dynamics in the presence of a child with a disability.

Education is another strategy for parents when participating in the Family Pals program. This stems from many parents actually being misinformed about their child’s diagnosis and the expectations the family should have for their child. Multiple parents became upset when recalling the time a health care provider was giving the diagnosis for the first time. Parents, especially those of children with Down syndrome, vividly remember being told what their child’s limitations would be. Parents felt outraged that a health care provider would set limitations on their children at such young ages. This had such a significant impact on the parents that they were able to recall the limitation the doctor gave their child and the ages at which the child was able to do what the doctor deemed impossible. Many parents stated that this very act alone, of receiving a limitation
for the child that never existed, is one major source of motivation for participating in the Family Pals program. They feel that participating in Family Pals will help dispel myths about their child’s diagnosis. Parents hope that showing genetic counseling students what their children can actually do, despite their disability or diagnosis is a great learning experience for the students. Parents also enjoy teaching the students about their child’s diagnosis because it is a very personal story and journey.

Demonstrating how normal their family is served as another goal for parents to participate. Parents who participate in Family Pals argue that every child is unique and struggles with his or her own issues. Not every child has a diagnosis, but every child has challenges in one way or another. This is why many parents feel that engaging the student and their child in activities that take part in public places such as the park, zoo, or museum, allow for the student to see how their child interacts with children who do not have a disability. Although having a child with a disability has its own set of challenges, parents want to be able to share with the students that one learns to adapt to the disability, and in the end their child is just like any other child.

Parents gave an overwhelming good review of the Family Pals program. Most parents have thoroughly enjoyed their experience with the program. However, some did have further suggestions about helping the families feel part of the program. Suggestions included parent evaluations of the students or providing feedback from the students to the parents. Most of the parents who have been participating for several years are really interested to know what the students learned from their experience. Parents realize that each student comes into the genetic counseling program with varying degrees of hands-on experience. Some students have a family member with a disability, some have
worked with children or adults with disabilities, and others have no prior experience. Many parents struggle to know what the exact goals are for the students participating in the program. Parents realize that their goals may differ from the students, but in order to know if the student really gained any insight from the experience, feedback would be helpful to the parents.

We further discussed ways in which feedback would be helpful. Parents agree that students would be the most honest about their experience if the information shared was anonymous. One option for feedback that was discussed included taking a few quotes from the students’ experiential logs and sharing the quotes anonymously with all the participating families. The quotes would reflect the students’ experience and how it would be useful in practice. The co-director in charge of matching the students with families would then send out a summary report to the parents, including all of the anonymous quotes from the students. This would allow for parents to see what all the students learned from their interaction with all the families. However, parents would most likely not be able to decipher their student. The positive feedback received through these quotes may reassure parents that their time spent with the students is worthwhile and is positively influencing the students.

The information provided from this study gives insight to the parents’ perspectives on first-hand medical training. Many parents involved with the Brandeis University Family Pals program are also involved in similar programs through Harvard and Boston University Medical Schools. However, these programs involve three to four students meeting at a family’s house only once, for no more than one hour. During this time, the students ask generic questions about the child’s diagnosis in order get the
parent’s perspective. However, the information does not allow for further insight and analysis of family dynamics or the child as a unique individual. Parents enjoy participating in Family Pals because it is a great opportunity for their son or daughter to interact with a student in a one-on-one environment. Parents believe it is the act of interaction which helps the student to learn best, not the act of observation or listening.

Research has been done about the usefulness of first-hand medical training and the impact on medical students. However, research about the parents’ attitudes towards first-hand experience for students, particularly genetic counseling students, has not been explored until now. Parents feel that the experiences the students are gaining are extremely important to their training. Although most parents had little or no prior experience with genetic counseling, through participating in Family Pals they now understand the usefulness of genetic counselors and how their training differs from the training of a doctor. Parents hope that the experiences the students gain through the program will be shared with the doctors and nurses so that they may become as compassionate and empathetic as genetic counselors.

Although more research is needed in order to show the effectiveness of first-hand experience and its long-term impact on students’ counseling skills, the anecdotal evidence and the findings in this study support the value of the Family Pals program. As a result, the information from this study can be used to help other genetic counseling programs develop a similar program to Family Pals. The parents in this study believe first-hand experience is the best way for genetic counseling students to learn about what life is like to have a child with a disability. Parents believe that the information students can learn from spending only a few days with a family is invaluable to their training.
Unfortunately, the sample size in this study is extremely small. However, only a small number of families have participated since the inception of the program. The results may also be skewed due to the location of where this study took place. All the participants live in or around the Boston area and as a result have access to some of the best resources for their children. Although questions about socioeconomic status and ethnicity were not asked for the purposes of this study, the families involved are all middle class and not from a minority culture. The results may also be skewed because participants who are highly motivated to participate in Family Pals, and believe that the program is useful in the training of successful genetic counselors are those that are more likely to participate in such a study.
Conclusion

Participants in this study were asked questions about the motivation and goals for participation with the Brandeis University Family Pals program. Participants were also asked to evaluate the program. One theme emerged surrounding participants’ motives and goals for participation which was supported by three different objectives to achieve the goal. Useful information was also provided in order to help improve the program, for the sake of the parents.

The results of this study are useful to other genetic counseling programs interested in implementing a similar program to Family Pals. The findings also provide a need for further research about first-hand medical training for not only genetic counseling students, but medical students as well. These findings are important because parents have given insight to providing important lessons to students which cannot be taught through a textbook or through lectures.

Future research may include surveying parents of a child with a disability to see if they would be interested in participating in a program like Family Pals which would benefit genetic counseling students. Then, the responses of those who respond “yes” and “no” can be compared to certain aspects such as socioeconomic status, income, marital status of parents, education of parents, services the children receive, resources available in the family’s community, and location of the family in the United States. Gaining insight on all these aspects of a family would help to see if it would be possibly to make first-hand experience more available to genetic counseling, or even medical students.
Due to the small sample size we were unable to determine whether the child’s diagnosis influenced the parents’ responses. For example, did the parents of a child with Down syndrome feel strongly one way versus parents of a child with autism? Unfortunately, because the study sample is so small this type of investigation cannot be done.

Since the main motivation for the parents’ participation was to ensure that further families were treated better by the genetic counselors it would be important to ask genetic counseling alumni from the Brandeis University Genetic Counseling program to recall what they learned from the Family Pals program and whether their experience influence their counseling practice. This would provide the opportunity to see if Brandeis’ goals for the program have been met as students go on to work in the field. If Brandeis chooses to make changes to the program as suggested by the parents, a follow-up study to see if the changes have been helpful would provide more information.

Overall, the results from this study support the importance of the Family Pals program for genetic counseling students as perceived by the parents. Genetic counseling program directors should take these results into consideration and possibly implement their own Family Pals program, if not done already. Requiring students to meet with families one-on-one may in the end, may make for more empathic genetic counselors.
References


Appendices

Appendix A – Study Proposal Submitted to the IRB

Family Pals: An Exploration of Parents’ Experiences

STUDY PURPOSE
The purpose of this study is to explore parents’ experiences with the Family Pals Program. In particular, I hope to learn more about what motivates parents to participate in programs like Family Pals and to understand parents’ perspectives on the importance of the Family Pals Program for genetic counseling students. This information will be important for the Brandeis Genetic Counseling Program in order to help improve the program and help students better understand the motivation of the families and the impact that participating has on families. The information may also be helpful for other genetic counseling programs that are thinking about creating a similar type of program for their students.

STUDY SPONSOR
Brandeis University Genetic Counseling Program.

PRINCIPAL INVESTIGATOR'S QUALIFICATIONS TO DO THE RESEARCH
The Principal Investigator is a student in the Brandeis University Genetic Counseling Master’s Program and is conducting this research project as a requirement for the Master’s Thesis.

RESULTS OF PREVIOUS RELATED RESEARCH
As highlighted on the Brandeis Genetic Counseling Program website the Program, “puts an emphasis on exploring all perspectives, including those of individuals and families living with disability and chronic illness.” The focus of disability awareness is an aspect that sets the Brandeis Program apart from any other genetic counseling training program. Students are able to learn directly from children and adults with a disability as they complete volunteer placements in the community. They also form relationships with families of children with disabilities through the Family Pals Program.

Family Pals is unique to the Brandeis University Genetic Counseling Program. The purpose of the program is for students to interact with the family at least two times in order to understand family dynamics in a special needs environment. It also allows the families to share their personal stories. Students also keep a reflective journal of their time spent with the families. This is helpful to ensure that they gain optimal experience which can be applied to their counseling. Family Pals is important because the students are able to interact with families in a non-medical setting. Students are assigned to
families during the spring semester of their first year. For a complete list of student expectations, see Appendix D (Family Pals Program Guidelines and Requirements).

There are between 20 - 25 families who have participated in Family Pals. All live in or near the Boston area. Many of the children have Down syndrome or autism. However, other children who have participated have Canavan disease, Prader-Willi, velocardiofacial syndrome, isodicentric 15, achondroplasia, Sanfilippo, fragile X, Conradi Hunermann syndrome and osteogenesis imperfecta. Most families have participated in the program for several years. However, a handful of families have only participated once.

Since Family Pals is a unique program, there is no prior background or significant literature which supports the purpose of the program for the training of genetic counselors. Since this information does not exist, it is even more important to explore parents’ perspectives of the Family Pals Program. This project will also provide an opportunity to explore what motivates families to participate in programs like Family Pals. Since the families are the key element to the success of the Family Pals Program, understanding their motivation and goals of participation would be useful information to the Brandeis Genetic Counseling Program. The results may also support the incorporation of Family Pals programs into other genetic counseling training programs.

SUBJECT CHARACTERISTICS
The study participants will be parents who have participated in the Brandeis Family Pals Program.

SUBJECT INCLUSION EXCLUSION CRITERIA
Subject Inclusion Criteria
• Participants must be either a mother or father who participated at least once in the Family Pals Program

JUSTIFICATION FOR USE OF ANY SPECIAL VULNERABLE SUBJECT POPULATIONS
No special or vulnerable subject populations will be recruited for this study.

STUDY DESIGN
Participants who consent to enroll in the study will take part in a phone interview conducted by the Principal Investigator. The interview will be semi-structured and qualitative, and will focus on the participants’ experiences while interacting with students as part of the Family Pals program. The Principal Investigator will conduct approximately 10-12 interviews.

STUDY PROCEDURES
Recruitment: The Brandeis Genetic Counseling Program’s Co-Director of Research and Professional Development, who is responsible for matching students with families participating in the Family Pals program, will e-mail the Recruitment Notice (see Appendix A) to all families who have participated in the Family Pals program. Those
families interested in participating in the study, or who have further questions about the study, may then contact the PI directly via e-mail.

**Data Collection:** The data for this study will be collected through 30 minute, semi-structured, phone interviews. In total, I anticipate that approximately 10-12 phone interviews will take place. The interviews will be audiotaped. The Interview Guide (Appendix C) which will be used for all of the interviews includes 9 open-ended questions focused on participation within the Family Pals program.

**Data Analysis:** Once the interviews are completed the audiotapes will be transcribed, the interviews coded for themes using ATLAS software.

**INFORMED CONSENT**
When a potential study participant contacts the PI regarding the details of study participation, the PI will provide the study participant with a written Informed Consent Form (Appendix B). The PI will review the ICF and the study details with the participant via phone. The participant will then return the ICF via a preaddressed, postage paid envelope provided by the PI. Upon receipt of the ICF, the PI will sign the ICF and return a copy of it to the study participant via mail. The PI will then contact the participant to schedule the study interview.

**ADVERSE EVENTS**
No adverse events are anticipated.

**COMPENSATION**
Each participant who takes part in the study will receive a $25 gift certificate to Amazon.com.

**PRIVACY/CONFIDENTIALITY**
In order to protect privacy and confidentiality, the PI will assign each study participant a unique ID number. The audiotapes and interview notes will be labeled with the study ID numbers rather than personal identifiers, and throughout the interview the participant will be referred to by ID number rather than by name. The PI will keep a password protected database which contains the link between participant identifiers and ID numbers. This database will contain information such as names, phone numbers, e-mail addresses and home addresses. The consent forms, audiotapes and interview notes will be kept in a locked filing cabinet that only the PI has access to. If the participants are quoted or referred to in any oral or written report of the study, only their unique ID numbers will be used. Once the study is completed, all interview guides and transcribed information will be shredded, the database will be deleted from the hard drive of the computer and audiotapes will be destroyed.

**COSTS**
There will be no cost to study participants.
REFERENCE

Appendix B: Recruitment Notice

Dear Family Pals Participants,

My name is Kim Fanelli and I am a second year student in the Brandeis Genetic Counseling Program. I am interested in exploring parents’ experiences as participants in the Family Pals program. To do so, I am conducting a research study for my master’s thesis.

Participation in the study involves a 30-minute phone interview scheduled at your convenience. During the interview, we will discuss your family’s participation in the Family Pals program and some of your experiences.

There is no cost to participate in the study and any parent who has taken part in the Family Pals program is eligible. At the end of the study you will receive a $25 gift certificate to Amazon.com.

I am hoping to conduct all interviews in January of 2009. If you have any questions about the study, or would like to participate, please contact me at Fanellik@brandeis.edu. I look forward to hearing from you.

Sincerely,

Kimberly A. Fanelli
Principal Investigator
Genetic Counseling Student
Dear Parents,

Thank you for your interest in my research study, “Family Pals: An Exploration of Parents’ Experiences.” Through talking with families such as yours, I hope to learn parents’ motivation to participate in programs such as Family Pals and understand parents’ perspectives on the importance of the Family Pals program for genetic counseling students.

Please take a moment to read the enclosed informed consent form. I will call you to discuss the consent form and study details. If you decide to participate in the study, please sign and date the consent form and return it to me in the enclosed pre-addressed, postage paid envelope. Once I receive the signed consent form I will contact you to schedule the phone interview.

Participant Agreement:

I understand that this is a research study involving parents who have participated in the Brandeis Genetic Counseling Program’s Family Pals program. The purpose of this study is to explore parents’ experiences as participants in the Family Pals program.

I understand that this study involves a telephone interview. The interview will last approximately 30 minutes, and will be audiotaped. I will be assigned a study ID number which will be used during the interview rather than my name or other identifiers. The audiotape and any other study notes that the Principal Investigator takes during the interview will be labeled with my ID number rather than my name. I understand that only the Principal Investigator will know my personal information (name, telephone number, home address and e-mail address). My information will be kept in a password protected database that only the Principal Investigator will have access to. I understand that if I am quoted or referred to in any written or oral report of the study, my identification number will be used so that my identity will remain confidential.

I understand that there is no cost to participate, and that I will receive a $25 gift certificate to Amazon.com after the entire interview is completed.

I understand that participation in this study is voluntary. I may refuse to answer any questions during the interview, choose to stop participating at any time or refuse to
participate in this study without any consequence. I am aware that if I want to withdraw from the study I may contact the Principal Investigator.

If I have any questions at any time regarding this research, I may contact Kim Fanelli, the Principal Investigator, at Fanellik@brandeis.edu. If I have any concerns about how this study is being carried out, I may contact the Brandeis Institutional Review Board at 781-736-2123.

Please sign if you agree to participate in this study under these conditions.

______________________________          ________________
Participant’s Signature          Date

______________________________          ________________
Investigator’s Signature          Date
INTRODUCTORY STATEMENT: Hi (name), thanks so much for participating in my research project, is this still a good time to talk? I am hoping to learn about the experiences of families who have participated in the Family Pals program. If it’s okay with you I’d like to audiotape our conversation so that I don’t miss anything in my notes. At the beginning of the audiotape I’m going to refer to you by the study ID number I’ve assigned to you. The interview should take about half an hour. If for any reason you feel uncomfortable answering any of the questions I ask just let me know and I will move on to the next question. Do you have any questions that I can answer before we get started? Are you ready to begin the interview?

1. How long have you been participating in the Family Pals Program?
   a. How did you first hear about the program?
   b. Why did you decide to participate in the program?

2. What motivates you to participate in the Family Pals Program?
   a. Can you elaborate?
   b. Do you participate in any other programs like Family Pals?
   c. If so, what motivates you to participate in those programs?
      i. How long have you been participating in these types of programs?
      ii. When did you become interested in participating in these types of programs?
      iii. How did you become interested?
      iv. Was there a specific turning point, or a specific event, that helped to spark your interest in participating?

3. What does participating in Family Pals mean to your family?
   a. Did you have any prior expectations before participating in the program?
   b. Have your expectations been met?
   c. Did you get anything out of participating that you didn’t originally anticipate?
   d. Tell me about the kind of activities you/your family does with students during a typical visit.
   e. How does each member of the family feel about participating in the program and the activities?
4. What do you hope the genetic counseling students get out of the program?
   a. What do you talk with the students about?
   b. Are there specific issues that you hope the students become aware of as a result of Family Pals?
   c. If so, what are those issues?
   d. When do you speak to the students about these issues?
      i. Do you do it in front of the child or alone?
      ii. Do you make special time to talk with the students?
   e. What activities, within the context of Family Pals, do you feel the students are able to learn the most from?

5. Prior to participating in Family Pals, what did you know about genetic counseling?
   a. Did you have any personal experiences with genetic counseling?
   b. Since participating in Family Pals, has your impression of genetic counseling changed?

6. Do you ever feel burdened by the program in terms of time and energy spent with the students?
   a. Is the compensation that Brandeis offers for participation with the Family Pals program important to you?
   b. Do you feel there is a different compensation you would prefer instead of the traditional book the program gives?
   c. If so, what would that be?

7. Is there anything that you think Brandeis should change about the Family Pals program?
   a. Have you found that certain aspects of the program work or don’t work?
   b. Do you think anything should be added to the Family Pals program to make it a more, well rounded experience for the students?
   c. Is there anything that should be added to the Family Pals program to make it a better experience for your family?

8. Would you recommend the Family Pals program to friends who have children with special needs?
   a. Please explain.

9. Is there anything about the Family Pals program that we did not discuss today that you would like to comment about?

Thank you so much for taking the time to be a part of my research. Within the next few weeks, I will e-mail your $25 amazon.com gift certificate! Please let me know if you don’t receive it by March 15, 2009.
Family Pals Program Guidelines and Requirements
Spring 2008

1. The family should have a child between the ages of 15 months – 20 years with a disability of any kind (it does not have to be genetic).

2. The family may be one you have met during your first semester placement and would like to continue a relationship with, or a family you are aware of through friends. However, the family should not be one you have spent any significant amount of time with already.

3. This program must be explained to the family and they must agree to commit to you for the entire semester. They must understand the Family Pals Program consent form and be willing to sign it.

4. Plan to scheduled 2-3 meeting times during the semester for approximately 2-3 hours each, at the family’s convenience. Not all family members need attend each meeting, but at some point try to schedule something where each family member could attend at least one activity.

5. Meeting locations may be a playground, McDonald’s, museums, the mall, the zoo, or any other appropriate location based on the interest of the family members.

6. Try to schedule one of the visits at the family’s house, for a family lunch or dinner, for instance. You should arrange to bring in dinner for everyone (e.g. pizza) and not arrange to have the family cook.

7. Brandeis will cover the cost of activities (e.g., admission to museum, lunch) up to $50-75 for the semester, so plan your activities carefully. You must submit receipts to get reimbursed. Collect them and give them to Missy.

8. You should not arrange any activities that require you to drive any of the family members anywhere. Brandeis is not in a position to assume the liability and presumably neither are you.
9. You must notify me of any planned meeting times and where the meeting will take place so that we are up to date on the program’s progress.

10. You will be expected to keep a journal of your experiences including what you did with the family, what you learned about them and their lives, what you learned about yourself, and how you can translate what you learned to your counseling experience. (refer to Reflective Journaling Guidelines for details)
Appendix F: Family Pals Literature Review

Literature Review

Family Pals: An Exploration of Parents’ Experiences

Disability is defined by the Americans of Disabilities Act as a “physical or mental impairment that substantially limits one or more major life activities” (1990). According to the United States Census Bureau, in 2005 one in five Americans reported a physical or mental disability (US Census, 2008). This means that the majority of Americans do not have a disability and those with a disability “are forced daily to combat misperceptions and unhelpful attitudes about disability both from the general public and from their health care professional” (Saketkoo et al., 2004). As a result, the disabled population does not feel well integrated with the members of society who do not have a disability because interactions are usually both limited and negative. Limited interactions may cause people without a disability to feel uncomfortable serving those with a disability. Therefore, medical schools across the country are working to prevent this discomfort for students by providing the opportunity for them to meet with families of children with special needs (Sharma et al., 2005).

Several of these medical schools acknowledge that students find these types of programs very useful, because it allows them to understand the challenges parents who have children with disabilities face. Students report enjoying the opportunity to understand the many different family dynamics observed in the visits. This includes the strengths of family relationships and the feelings of normalcy amongst the families (Johnson et al., 2006).
Medical schools believe this aspect of training helps teach their students the concept of empathy, which can be a very challenging task. Medical schools realize that the best individuals to teach empathy are those who have personal experience with disability or families who care for a child with a disability (Blasco et al., 1999). Since the hospital’s stressful setting may not be the best environment to understand empathy, “the more conducive site to promote empathy and understanding [is] the home, work, and/or play” environments (Blasco et al., 1999). Providing students one-on-one interactions with families, who have a child with disability, in order to ease students’ discomfort levels, is not only useful for medical students, but genetic counseling students as well.

Genetic counseling is a recently evolved medical field which requires specialized education and training. Prior to 2006, there were many broad definitions which helped to clarify different aspects of what encompassed the practice of genetic counseling. However none of these definitions accurately defined the field as a whole. It was not until 2003 that the National Society of Genetic Counselors (NSGC) determined that due to the evolution of the field which “expands beyond traditional settings into laboratory genetic medicine, public health, social and behavioral research, and common disease subspecialties” a new definition of genetic counseling needed to be developed (NSGC, 2006). This new definition created by an appointed group of NSGC members defined genetic counseling as “the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease” (NSGC, 2006). This definition includes the act of interpreting families’ medical histories to clarify recurrence risks, educating about diseases and testing offered and counseling families about choices and risks (NSGC, 2006).
What is a Genetic Counselor

The American Board of Genetic Counselors (ABGC) Website defines a genetic counselor as a “health care professional who is academically and clinically prepared to provide genetic counseling services to individuals and families seeking information about the occurrence, or risk of occurrence, of a genetic condition or birth defect” (2007). These unique health care professionals work as part of a medical team, but are a unique and vital source of information for patients. This is because genetic counselors are specially trained to “interpret and provide clear and comprehensive information about the risk of any medical condition that may have a genetic contribution” (ABGC, 2007). They provide information to patients and help facilitate the decision making process in a non-directive approach (ABGC, 2007).

Genetic counselors work in many different settings and interact with both patients and other health care professionals. Genetic counselors may work in clinical or non-clinical settings, including “university-based medical centers, private hospitals, private practice, and industry settings” (NSGC, 2008). According to the Genetic Counselors’ Scope of Practice, there are three main roles of the genetic counselor. The first role is the provide expertise information in clinical genetics. The second role is to counsel the patient about the specific matters of clinical genetics as it specifically pertains to the patient. The third role is to provide genetic counseling services, such as: reviewing family and medical histories, risk assessments of genetic conditions, discussing available options, explaining important medical terminology and assisting the patient by devising some sort of plan (NSGC, 2008).
Training of a Genetic Counselor. The training of a genetic counselor is unique and focused. All genetic counselors bearing the title CGC, or certified genetic counselor, obtain certification through the American Board of Genetic Counselors. To become certified, a counselor must have completed a two-year Master’s degree from an accredited program. The graduate coursework from the programs include the following: human, medical and clinical genetics, psychosocial theory and techniques, social, ethical and legal issues, health-care delivery systems and public health principles, teaching techniques, research methods and clinical training (ABGC, 2007). Each program teaches these basic concepts in their own desired methods. However, “each of the programs has taken on its own flavor- some focus on psychosocial issues, whereas others focus on clinical features of syndromes, or on laboratory or clinical research” (Begleiter, 2002).

Genetic Counseling Training Programs

According to the ABGC Website, there are 25 fully accredited genetic counseling programs in the United States and three fully accredited programs in Canada. Each program teaches their students the core coursework needed for certification, but does so in a unique manner. Each program also has different qualifications for accepting incoming students.

Brandeis University Genetic Counseling Program. At the Brandeis University Genetic Counseling Program, genetic counseling students are able to focus their studies on psychosocial issues. This is because the program “puts an emphasis on exploring all perspectives, including those of individuals and families living with disability and chronic illness” (Brandeis Genetic Counseling Website). One way the program has
helped to facilitate students in understanding these issues is through the focus of
disability awareness. Students are able to learn directly from children and adults with a
disability as they complete volunteer placements in the community. They also form
relationships with families of children with disabilities through the Family Pals Program.

The Brandeis University Genetic Counseling Program’s “Family Pals” is
exclusive to the Brandeis curriculum. The purpose of the program is for students to
interact with the family at least two times during their first year in order to understand
family dynamics in a special needs environment. It also allows the families to share their
personal stories. Students keep a reflective, experiential journal of their time spent with
the families. This is helpful to ensure that they gain optimal experience which can be
applied to their counseling. Family Pals is important because the students are able to
interact with families in a non-medical setting. For a complete list of student
expectations, see Family Pals Program Guidelines and Requirements (Appendix I).

There are between 20 - 25 families who have participated in Family Pals over the
past 11 years. All live in or near the Boston area. Many of the children have Down
syndrome or autism. However, other children who have participated have diagnoses of
Canavan disease, Prader-Willi, velocardiofacial syndrome, isodicentric chromosome 15,
achondroplasia, Sanfilippo, fragile X syndrome, Conradi Hunermann syndrome and
osteogenesis imperfecta. Most families have participated in the program for several
years. However, a handful of families have only participated once.

Although some evidence in the medical literature exists, supporting the value for
medical students to interact with families one-on-one in the home environment, this
literature does not exist on the importance of this type of interaction for genetic
counseling students (Blasco et al.; Saketkoo et al.; Sharma et al.). There is also no literature about the parents’ experiences with these types of programs. This study therefore addresses two objectives. The first is to understand parents’ experiences with the Family Pals Program through an exploration of their motivations to participate. The second is to allow the parents the opportunity to review the Brandeis Family Pals Program, to see if any changes can be made to make the program a better experience for either the students or the families involved.
References:


Appendix I: Family Pals Program Information Sheet for Students

Family Pals Program Guidelines and Requirements
Spring 2008

1. The family should have a child between the ages of 15 months – 20 years with a disability of any kind (it does not have to be genetic).

2. The family may be one you have met during your first semester placement and would like to continue a relationship with, or a family you are aware of through friends. However, the family should not be one you have spent any significant amount of time with already.

3. This program must be explained to the family and they must agree to commit to you for the entire semester. They must understand the Family Pals Program consent form and be willing to sign it.

4. Plan to schedule 2-3 meeting times during the semester for approximately 2-3 hours each, at the family’s convenience. Not all family members need attend each meeting, but at some point try to schedule something where each family member could attend at least one activity.

5. Meeting locations may be a playground, McDonald’s, museums, the mall, the zoo, or any other appropriate location based on the interest of the family members.

6. Try to schedule one of the visits at the family’s house, for a family lunch or dinner, for instance. You should arrange to bring in dinner for everyone (e.g. pizza) and not arrange to have the family cook.

7. Brandeis will cover the cost of activities (e.g., admission to museum, lunch) up to $50-75 for the semester, so plan your activities carefully. You must submit receipts to get reimbursed. Collect them and give them to Missy.

8. You should not arrange any activities that require you to drive any of the family members anywhere. Brandeis is not in a position to assume the liability and presumably neither are you.

9. You must notify me of any planned meeting times and where the meeting will take place so that we are up to date on the program’s progress.

10. You will be expected to keep a journal of your experiences including what you did with the family, what you learned about them and their lives, what you learned about yourself, and how you can translate what you learned to your counseling experience. (refer to Reflective Journaling Guidelines for details)
Appendix II: Family Pals Program Consent Form

Brandeis University Master's Degree Program in Genetic Counseling

Family Pals Program Spring 2008 Consent Form

The Family Pals Program has been designed to give Brandeis University Genetic Counseling students an opportunity to develop a personal relationship with families currently living and dealing with the everyday issues of disability or chronic illness. It is essential that the students learn about the daily ups and downs experienced by the families so that they will be able to provide sensitive, balanced and knowledgeable counseling to the families they will be serving in the future. Your family’s participation in this program is important and most appreciated by both the students and faculty of the program.

The basis of the program is a few informal gatherings between a student and a family in which together they participate in any number of activities. These may include eating dinner together, visiting a park or the mall, taking a trip to the zoo or a museum, or any other activity that is mutually agreed upon. These meetings will allow the genetic counseling student and family to become acquainted and for the student to learn more about the challenges and rewards of daily family life. It is an opportunity for the family to teach a genetic counselor what they believe is important for the counselor to know in order to become a better health care provider.

Outlined below is a description of the 1) student requirements, 2) expectations for participating families, 3) guidelines for family-student activities and, 4) a parental informed consent form.

1) Student requirements
   a. Students are required to arrange two or three 2-3 hour get togethers with your family at your convenience.
   b. Students will be expected to keep a journal of their experience, including what activities they did with you, what they learned about the issues of disability in your daily lives, what they learned about themselves, and how they can translate what they learned to their counseling. This journal will be submitted to the course instructor and excerpts may be shared during class meetings of the genetic counseling students. Only family members’ first names will be used and information will not be shared with others outside the class.
c. The student is not permitted to provide childcare or drive family members anywhere while visiting as part of the Family Pals Program.

2) Expectations for participating families

a. It is essential for the success of the program that the family participates throughout the semester. If the family is unable to complete the program, please notify the student as soon as possible.
b. Although not required, as many family members as possible are encouraged to join the student during the scheduled get-togethers.
c. The student will rely on the parents to approve safe activities for family members to engage in.

3) Guidelines for family-student activities

a. The family and student should agree upon activities that allow all family members to participate as desired, are age appropriate for all family members and encourage interaction between the student and family. For example, a visit to a museum would support communication but attending a movie may not.
b. The student cannot drive any family members during gatherings, due to safety concerns.
c. Students have been given a modest budget to help cover the basic costs of selected activities (e.g. pizza dinner, entrance fees to a park). It is not intended that the family should incur any expenses for participation in this program.

4) Parental informed consent form

As the representative of the family I understand the goals of the program, expectations of the family and the requirements of the student. Should I/we have concerns or questions at any time during the family’s participation in the program, I/we will first address them directly with the student. If concerns persist, I/we agree to discuss them with the course instructor, Beth Rosen-Sheidley at (781) 736-2336.

Signature:
Family Representative:__________________________
Date: __________________

Signature:
Genetic Counseling Representative:__________________________
Date: __________________
Appendix III: Reflective Journaling Guidelines

Reflective Journaling Guidelines (adapted from WebGURU Guide to Research)

Reflective journaling can be an extremely useful tool. If you are not familiar with this technique, you are not alone. Not often used in the science and engineering fields but a standard practice in clinical training and the field of education, reflective journaling is regarded as an extremely useful and powerful technique for affecting self-discovery and personal and professional growth. The act of journaling involves the regular practice of recording activities and/or situations on paper or electronically with the goal of reflecting on those experiences in order to learn from them and grow personally and professionally.

Journaling is useful in providing insight into self-awareness - what you do (behaviors), why you do it (values, assumptions, aspirations) how you feel (emotions), and how you think. Journaling can expose contradictions, misconceptions, and conflict. In short, it helps you turn every incident into a new potential learning experience.

It is important to understand though that journaling isn't merely the act of chronicling one's experiences. Writing about one's experiences can be useful as it helps to make explicit knowledge that one may have learned and practiced implicitly for better or worse. It also helps to provide perspective and structure to daily events that sometimes appear chaotic and random. However, educational research suggests that active reflection is needed if true transformational learning is to be realized.

Depending on your goals and individual nature, your journal can be either more or less structured in format and style. One important thing that is known about journaling is that for it to be effective the journal must be more than merely a written record. A set of guiding questions can be useful in facilitating critical reflection if the questions motivate you to reflect. For this reason the following questions are offered as useful starting points in facilitating meaningful reflection.

- Briefly describe a situation that occurred during your Family Pals Placement that affected you as an individual.
- Why are you describing this incident - did you experience challenges in meeting it? Did you exhibit strengths? Did you learn something?
- Is there an overarching issue or problem here? What is the potential value here?
- What were you feeling at the time of the incident?
- What were you thinking at the time of the incident? Did you have any preconceived ideas? New insights?
- What was good or bad about the situation?
- (How) Has this experience challenged your assumptions, prejudices, or biases?
- What specific possible solutions have you been able to identify to the problem?
- (How) will this experience alter your future behavior, attitudes, or career?