Disability Awareness Training and Implications for Current Practice:

A Survey of Genetic Counselors

Master’s Thesis

Presented to

The Faculty of the Graduate School of Arts and Sciences
Brandeis University
Department of Biological Sciences – Genetic Counseling
Beth Rosen Sheidley, Advisor

In Partial Fulfillment
Of the Requirements for
Master’s Degree

by
Laura Kline
May 2012
Acknowledgements

I would like to express my gratitude to my committee members, Beth Sheidley, Dr. Brian Skotko, and Christa Haun, for their help in providing insight to my study goals, and using their personal time to edit the numerous drafts of my work. I’d also like to thank Liz Cross for her help in guiding me through the process of SPSS computer data analysis and interpretation of the data. A generous thank you goes out to my friends and family for their continued support, and to the faculty and my classmates for their never-ending support and encouragement.
Abstract
Disability Awareness Training and Implications for Current Practice: A Survey of Genetic Counselors

A thesis presented to the Department of Biological Sciences-Genetic Counseling
Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts
By Laura Anne Kline

Last year Madeo and colleagues challenged the genetic counseling profession by calling attention to tensions between the profession and the disability community. Their commentary inspired renewed debate about whether the genetic counseling profession is committed to understanding the perspective of people with disabilities, to partnering with disability rights organizations, and to educating students regarding disability awareness. Although there have been previous studies that explored genetic counseling training program curricula with respect to disability related issues, there have been no recent studies assessing genetic counselors’ exposure to disability awareness. The aim of this study was to assess the extent to which recently trained genetic counselors have had experiences related to disability awareness issues, including experiences that have occurred before, during and after their genetic counseling training. We also sought to
assess genetic counselors’ perception of the adequacy of their training with respect to
disability awareness and their comfort levels in discussing disability with patients and
families. To this end we recruited genetic counselors who graduated between 2007 and
2011 to complete an anonymous, online survey. Of the 107 respondents, 36% reported
that they had experience working with individuals with disability prior to graduate
school. However, there was considerable variation in the extent to which our participants
had experienced disability awareness training during graduate school. Only 14% of
respondents reported having experiences involving direct interaction with people who
have disabilities during their training, aside from time spent in clinical internships. Only
26% felt highly adequate in their preparation to counsel patients about disability
immediately after graduation, and in their current jobs, 41% of counselors replied that
they sometimes felt conflicted in their discussions about disability. Finally, our study
participants suggested that the genetic counseling profession should consider changing
genetic counseling program requirements and offer more opportunities for CEUs to
promote disability awareness.

Keywords: disability awareness training, disability exposure, genetic counseling,
genetic counseling training programs, comfort level, value of training
<table>
<thead>
<tr>
<th>Section</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1-4</td>
</tr>
<tr>
<td>Methods</td>
<td></td>
</tr>
<tr>
<td>Recruitment</td>
<td>5</td>
</tr>
<tr>
<td>Survey Design</td>
<td>5-7</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>7-8</td>
</tr>
<tr>
<td>Results</td>
<td>9-20</td>
</tr>
<tr>
<td>Discussion</td>
<td>21-26</td>
</tr>
<tr>
<td>Conclusion</td>
<td>27-28</td>
</tr>
<tr>
<td>References</td>
<td>29-30</td>
</tr>
<tr>
<td>Supporting Documents</td>
<td></td>
</tr>
<tr>
<td>Appendix A: Recruitment Notice</td>
<td>31-32</td>
</tr>
<tr>
<td>Appendix B: Survey</td>
<td>33-55</td>
</tr>
<tr>
<td>Appendix C: Introduction to Survey</td>
<td>57</td>
</tr>
</tbody>
</table>
List of Illustrations

Table 1: Topics Addressed in Hypothetical Clinical Scenarios 7

Figure 1: Study Participant Year of Graduation from GC Training Program 10

Figure 2: Respondents as a Subset of Eligible Participants 10

Figure 3: Disability Experiences During Genetic Counseling Training 12

Figure 4: Perceived Value of Disability-Related Experiences during Training 13

Figure 5: Perceived Adequacy of Training 14

Figure 6a: Perception of Knowledge 15

Figure 6b: Perceived Comfort Discussing Disability in the Clinic Setting 16

Figure 6c: Perceived Conflict Discussing Disability in the Clinic Setting 16

Figure 7: Respondents’ Comfort Levels with Hypothetic Clinical Scenarios 17

Table 2: Statistically Significant Relationships between Perception of Training Value and Comfort Level with Scenarios (Correlation Coefficients) 18
Introduction

Recently, several members of the genetic counseling community have highlighted tensions between the medical community and the disability community, regarding the commitment and training of genetic counselors with respect to disability awareness issues (Madeo et al., 2011). A debate has ensued that has focused on the relationship between the genetic counseling and disability communities, and the ways in which this issue should be further addressed (Dent et al., 2011; Bauer, 2011; Resta, 2011). In an official NSGC response to Madeo et al., Dent et al. commented that “the National Society of Genetic Counselors (NSGC) contends that genetic counselors have the unique ability to address all sides of the complex issues” (2011). However, in an invited commentary in the American Journal of Medical Genetics, Bauer (2011) suggested that perhaps genetic counselors feel conflicted regarding their role, in particular in prenatal counseling sessions:

“I’ve heard genetic counselors say they hesitate to tell patients that many people with Down syndrome are beloved by their families because such information wouldn’t be supportive of their patient. It might make the patient feel bad if they decide to terminate.”

The controversy over the relationship between genetic counseling and disability advocacy is not a new one. Since the emergence of prenatal diagnostic testing for genetic disorders such as Down syndrome in the 1970s, there has been disagreement regarding how to talk with families about disability in counseling sessions without the counselors being perceived as biased toward or against disability (Hodgson JM, Gillam LH, Sahhar
MA, & Metcalfe SA, 2010; Chen EA & Schiffman JF, 2000; Parens & Asch, 2000).

Historically, the field of genetic counseling has embraced non-directiveness; however, the field has begun to question its “non-directive” status (Weil et al., 2006; Weil; 2003; Williams et al 2002; Michie et al., 1997) suggesting that it is difficult to reflect upon a patient’s own words without sensing there is some sort of direction the patient is moving in their thought process. Counselors are trained to not let their personal biases show, as these could influence patient decision-making. However, as argued by Parens and Asch (2000), the actual offering of genetic screening and/or testing in the prenatal period is not neutral. In 2006, Weil and colleagues stated that based on discussions at the 2003 NSGC Annual Education Conference, non-directiveness may not have efficacy and appropriateness in all clinical cases. Instead, they suggested support for a flexible approach to counseling that is based on client needs and values, clinical circumstances, and desired outcomes instead of non-directiveness.

Challenges exist for professionals to maintain a balance when giving medical information, including describing the positive and negative aspects of disability, while still providing neutral counseling (Ormond et al, 2003). Driscoll, Morgan & Schulkin (2009) surveyed obstetricians regarding their perception of the impact on their training both before and one year after the American Congress of Obstetricians and Gynecologists (ACOG) practice bulletin No. 77 on screening for fetal chromosome abnormalities was published (ACOG, 2007). Driscoll et al. found that fewer than half of the respondents (47%) believed that they were well qualified in their ability to counsel patients about Down syndrome screening and its implications even after the guidelines were established (2009). Driscoll confirmed previous findings which demonstrated that greater than 40%
of respondents rated their residency training regarding screening and diagnosis for Down syndrome as barely adequate to nonexistent (Driscoll et al., 2009; Cleary-Goldman et al., 2006).

Graduates of genetic counseling programs in the past felt the level of disability awareness training left them unprepared to discuss disability as they entered the field (Teicher et al., 1998, Brasington, 2007). Results of a study of genetic counselors, other medical professionals, and mothers of children with Down syndrome indicated that genetic counselors and medical professionals are perceived by mothers of children with Down syndrome as more biased against disability than the mothers themselves were (Cooley et al., 1990).

In the early years of the genetic counseling profession, clinicians did not have the types of testing available to diagnose the types of disorders they can now. With the evolution of medical technology, they can now test for an increasing number of disorders. Along with these advances have come criticisms of genetic counselors’ role and relationships with the disability community. Prenatal screening and diagnostic testing has been a controversial topic since expectant parents can choose to terminate a pregnancy based on the results. With the recent addition of non-invasive cell-free fetal DNA testing for the most common aneuploidies, there has been increasing concern among those within the disability community that certain genetic disorders might become much less common. Some parents who do have children with these disorders worry that they might also feel more judgment about their personal decisions to not undergo prenatal testing or to not terminate a pregnancy in which a diagnosis of a genetic condition has been made (Bauer, 2005).
Although there have been previous studies that explored genetic counseling training program curricula with respect to disability related issues (Teicher et al., 1998, Brasington, 2007, Brown et al. 2009), there have been no recent studies that have assessed genetic counselors’ exposure to disability awareness, nor their comfort level in discussing disability with clients. In this current study we sought to assess the extent to which recently trained genetic counselors have had experiences which would enhance their awareness of disability related issues, including experiences that have occurred before, during and after their genetic counseling training. Specifically we aimed to:

1. Assess the extent of disability awareness and sensitivity training experience by graduates of genetic counseling graduate programs
2. Determine the relative value of specific disability training experiences to practicing genetic counselors
3. Evaluate the comfort level of recent genetic counseling graduates in discussing the topic of disability with patients and their families
4. Elicit suggestions from practicing genetic counselors regarding disability awareness education
Methods

Recruitment

We recruited genetic counselors who graduated from an accredited genetic counseling training program during the past five years (2007-2011). We sent a recruitment notice (see Appendix A) to NSGC members via the NSGC listserv. The recruitment notice included a link to an introduction to the research (see Appendix C) and an online, anonymous survey (see Appendix B).

Survey Design

As there are no previously validated survey instruments addressing this specific topic, we created a survey based on input from experts in the field of medical genetics and genetic counseling, as well as individuals with personal or family experiences with disability, and tested the survey in a small focus group setting composed of genetic counseling students prior to distribution. We created and disseminated the survey instrument using HIPAA and IRB compliant survey design software (Qualtrics). Our research protocol was submitted to the Brandeis IRB for review, and it was granted exemption status as IRB Protocol #12096.

The survey instrument was composed of six sections (see Appendix B) focusing on:

1. Demographic information
2. Personal experience with the topic of disability before entering genetic counseling graduate training programs

3. General comfort level with discussing disability in current job setting

4. Experiences with disability during genetic counseling training programs

5. Hypothetical clinical genetic counseling scenarios with disability focused themes

6. Ratings of overall experiences with disability training adequacy.

The survey included a series of multiple choice and free response questions with regard to these topics. Respondents also had the opportunity to give suggestions regarding the incorporation of disability awareness and sensitivity education into training program curricula and NSGC sponsored programming.

Likert scales were used in sections 3, 5 and 6. We designed hypothetical clinical scenarios (section 5) to give respondents the opportunity to think critically about their own perceived comfort levels in discussing different types of disability: chronic disease (cystic fibrosis), physical disability (achondroplasia, deafness), and intellectual disability (Down syndrome). There were seven scenarios in total; four prenatal scenarios and three pediatric scenarios.

- Scenario 1: Prenatal diagnosis of cystic fibrosis: parents conflicted about continuing or terminating the pregnancy
- Scenario 2: Prenatal diagnosis of Down syndrome: parents conflicted about continuing or terminating the pregnancy
- Scenario 3: Prenatal diagnosis of Down syndrome: parents have already decided to pursue termination
- Scenario 4: Prenatal diagnosis of achondroplasia: parents conflicted about continuing or terminating the pregnancy
- Scenario 5: Pediatric (postnatal) diagnosis of cystic fibrosis: parents distraught
- Scenario 6: Pediatric (postnatal) diagnosis of Down syndrome: parents distraught
## Scenario 7: Pediatric (postnatal) diagnosis of deafness: parents distraught

In the scenarios, genetic counselors were asked about their comfort levels when discussing different topics with regard to diagnosis of each diagnosis. Table 1 below shows the topics addressed for each subset of scenarios.

<table>
<thead>
<tr>
<th>Prenatal scenario topics</th>
<th>Pediatric/Postnatal scenario topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Termination of pregnancy</td>
<td>Medical facts and statistics associated with the condition</td>
</tr>
<tr>
<td>Continuation of pregnancy</td>
<td>Financial/social/quality of life implications for an individual with the condition</td>
</tr>
<tr>
<td>Adoption</td>
<td>Possibility of a child born with disabilities given this condition</td>
</tr>
<tr>
<td>Medical facts and statistics associated with the condition</td>
<td>Addressing psychosocial issues</td>
</tr>
<tr>
<td>Financial/social/quality of life implications for an individual with the condition</td>
<td>Accessing/offering resources and information</td>
</tr>
<tr>
<td>Possibility of a child born with disabilities given this condition</td>
<td></td>
</tr>
<tr>
<td>Addressing psychosocial issues</td>
<td></td>
</tr>
<tr>
<td>Accessing/offering resources and information</td>
<td></td>
</tr>
</tbody>
</table>

### Data Analysis

We used SPSS 19 for data analysis. After determining the sample to be analyzed, we conducted a scale reliability analysis for each scenario to determine the extent to which the scenario-based questions formed cohesive scales in each scenario, and whether a higher reliability would be seen if questions were discarded from each scale. The Cronbach’s alpha statistic (α) for each scenario ranged from 0.79 to 0.87, indicating each scenario response set was reliable as a whole. Discarding individual questions did not
increase reliability. Therefore, we created composite scores based on the number of items from each scenario. We used the scenario composite scores to analyze differences in comfort levels per scenario in response to different experiences with disability.

In order to determine if background experiences impacted clinical genetic counselors perceptions of disability in the clinical setting, we compared the means of the comfort level composite scores against the three major demographic categories (clinical subspecialties, year of graduation, and undergraduate major) by conducting one-way analyses of variance (ANOVAs). We further conducted independent sample t-tests to compare means for dichotomous background variables, including whether or not respondents had specific experiences with disability before, during and after graduation from their genetic counseling training programs.

Free-response questions were analyzed based on direct responses from respondents, and categorized into overarching themes for each question.
Results

Demographics and Experiences Before Graduate Training in Genetic Counseling

During the years 2007 through 2011, there were an estimated 970 graduates from genetic counseling training programs in North America. We received a total of 142 completed surveys, yielding a 14.6% response rate. In our sample, there appeared to be two main subsets of respondents: clinical genetic counselors (n=107) and non-clinical genetic counselors (n=35). The cohort of non-clinical genetic counselors consisted of research counselors, laboratory counselors, public health counselors, and individuals involved in volunteer programs unrelated to genetic counseling. We tested differences between clinical and non-clinical genetic counselors with regard to scenario responses, to see if the sample should be treated as a whole, given that the research questions were related to clinical practice. We learned that clinical genetic counselors reported significantly higher levels of comfort discussing the topic of disability. Because this study focused on issues more salient to clinical practice, we elected to focus our analysis solely on clinical genetic counselors (n=107, 75% of respondents).

Respondents were predominantly Caucasian (95%) and female (96.3%). This is consistent with what has been previously reported in the NSGC 2010 Professional Status Survey (PSS). There were respondents from graduate programs in all six geographical regions as outlined by the NSGC’s PSS. More recent graduates made up the largest percentage of our respondents, as shown in Figure 1.
Based on information regarding the number of students in each graduating class from 2007 through 2011, it appears that more recent graduates were more likely to participate in the survey.

The size of graduating classes ranged from 180 in 2007 to 220 in 2011, yet the number of participants from the class of 2011 was over 4 times the number that participated from the class of 2007 (see Figure 2). Therefore, response rates based on year of graduation ranged from 5% in 2007 to over 18% in 2011.

According to year of graduation, response rate percentages were as follows: 2007 (5%); 2008 (7.2%); 2009 (10.5%); 2010 (12.5%); 2011 (18.2%).
Of the 107 respondents who reported working in clinical practice, 32% specified prenatal, 28% specified pediatrics, and 25% specified cancer. The remaining respondents reported working in specialized areas of clinical genetic counseling, including: adult genetics, metabolism, general genetics, neurogenetics, and psychiatric genetics. A total of 64% of respondents reported that their current position is their first genetic counseling related job they’ve held since graduation.

A majority of respondents reported their undergraduate majors as one of the biological sciences (79.4%), psychology (6.5%), or a dual major of biological science and psychology (10.3%). Only four clinical genetic counselors (3.7%) identified as having a disability themselves. This was too small of a sample to separate out for analysis, and we therefore included these individuals with the rest of the respondents for purposes of data analysis. Regarding respondents’ experiences with individuals who have disabilities before entering genetic counseling training programs, 88% of respondents stated they had at least observed individuals who have disabilities. A total of 36% reported having had the direct experience of being in a school setting, providing academic support, or having a direct caregiver role for someone with a disability.
Disability Focused Education During Genetic Counseling Training

We found considerable variability among disability related experiences that respondents reported were part of their graduate training. Figure 3 illustrates the different types of experiences that respondents reported, and it is evident that a majority had class lectures about disability, guest lectures by individuals with disabilities and books about disability related issues. A minority of respondents reported that attending a support/advocacy group (48.6%), attending a seminar or conference (41.1%), community field placements (36.4%), or time spent with families or individuals living with disability (27.1%), were requirements of their graduate training. In total, only 14% of respondents stated they had direct interaction with people with disabilities during their graduate training aside from clinical rotations.

![Figure 3: Disability Experiences during Genetic Counseling Training](image)

Respondents were instructed to choose as many experiences as they had, and therefore totals do not add up to 100%.
Perceived Value of Disability-Focused Education and Perceived Adequacy of Training

We asked respondents to choose the most and least valuable experiences during graduate training with respect to learning about disability. (Figure 4).

There was considerable variation in what respondents perceived as most and least valuable experiences in their respective training programs. It was somewhat difficult to interpret this data as respondents were only able to rate the value of experiences they themselves had during their training programs. For example, if a respondent did not have a community field placement as part of his or her training, he or she would not have had the opportunity, as part of the survey, to rate the value of such an experience. A majority of respondents reported that having a guest lecturer with a disability was the most valuable experience. Other experiences most frequently regarded as most valuable were
class lectures about disability, community field placements at organizations that provide services to individuals with disability, placement with a family or individual living with a disability, and attending a support/advocacy group. Experiences that respondents reported as least valuable were books/articles about disability, movies about disability, seminars/conferences, and class lectures.

We asked respondents to rate the adequacy of disability focused training experienced during graduate school. Overall, less than 40% rated their exposure to disability related issues as “Highly Adequate” (see Figure 5). A large percentage of respondents rated their experiences “Somewhat Adequate” in all variables (34-50.5%). The area which the most respondents rated highly adequate levels from training experiences was “Awareness and Sensitivity to Psychosocial Issues (59.2%). Only 26.2% of respondents perceived their “Preparation to Counsel about Disability Immediately after Graduation” as “Highly Adequate”.

**Figure 5: Perceived Adequacy of Training**

<table>
<thead>
<tr>
<th>Training Experience</th>
<th>Highly Adequate (%)</th>
<th>Somewhat Adequate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Exposure to Disabilities</td>
<td>37.9</td>
<td>48.5</td>
</tr>
<tr>
<td>Adequate Access to Resources</td>
<td>39.4</td>
<td>39.4</td>
</tr>
<tr>
<td>Awareness and Sensitivity to Psychosocial Issues</td>
<td>59.2</td>
<td>39</td>
</tr>
<tr>
<td>Knowledge Gained Regarding Range of Disabilities</td>
<td>51.5</td>
<td>34</td>
</tr>
<tr>
<td>Preparation to Counsel Patients about Disability</td>
<td>50.5</td>
<td>26.2</td>
</tr>
</tbody>
</table>

A 5-point Likert scale was used to assess perceived adequacy respondents felt from five training experiences involving disability, from “1-Highly Adequate” to “5-Highly Inadequate”. Figure 5 shows the percentage of respondents who answered “Highly Adequate” and “Somewhat Adequate”.

14
**Comfort Level in Disability-Related Counseling**

A total of 86.8% of our respondents “Agreed” or “Strongly Agreed” to having acquired sufficient knowledge to discuss disability in the clinic setting (Figure 6a). However, only 68.9% of respondents perceived themselves to feel comfortable discussing disability “Quite Often” or “Very Often”, and 29.1% of respondents stated that they “Sometimes” felt comfortable discussing disability in the clinical setting (Figure 6b). While a small percentage of the cohort (5.8%) felt conflicted in their discussion of disability “Quite Often” or “Very Often”, a much larger number of respondents stated they “Sometimes” felt conflicted discussing disability (40.8%) (Figure 6c).

**Figure 6a: Perception of Knowledge**

Respondents were asked to rate whether they had acquired sufficient knowledge to discuss disability in the clinic setting. This question used a five-point Likert scale ranging from “Strongly Agree” to “Strongly Disagree”.

![Figure 6a: Perception of Knowledge](image-url)
Respondents were asked to perceive how often they felt comfortable in discussing the topic of disability in their current job. This question used a five-point Likert scale ranging from “Very Often” to “Never”.

Respondents were asked to perceive how often they felt conflicted in discussing the topic of disability in their current job. This question used a five-point Likert scale ranging from “Very Often” to “Never”.

Figure 6b: Perceived Comfort Discussing Disability in the Clinic Setting

Figure 6c: Perceived Conflict Discussing Disability in the Clinic Setting
When presented with hypothetical scenarios involving disability related counseling issues, a majority of respondents reported that they were either “comfortable” or “very comfortable” in each instance (see Figure 7). However, for scenario 3 which involved a prenatal diagnosis of Down syndrome in which the clients had already decided to terminate the pregnancy, there was an increase in the number of respondents who overall felt more uncomfortable in discussing disability issues (31% “Somewhat Uncomfortable” to “Very Uncomfortable”).

**Figure 7: Respondents' Comfort Levels with Hypothetical Clinical Scenarios**

<table>
<thead>
<tr>
<th>Scenario Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 3: Prenatal dx. of Down syndrome—parents want termination</td>
<td>69%</td>
</tr>
<tr>
<td>Scenario 5: Infant dx. of cystic fibrosis</td>
<td>78%</td>
</tr>
<tr>
<td>Scenario 7: Infant dx. of Deafness</td>
<td>81%</td>
</tr>
<tr>
<td>Scenario 1: Prenatal dx. of cystic fibrosis</td>
<td>88%</td>
</tr>
<tr>
<td>Scenario 4: Prenatal dx. of Achondroplasia</td>
<td>91%</td>
</tr>
<tr>
<td>Scenario 6: Infant dx. of Down Syndrome</td>
<td>95%</td>
</tr>
<tr>
<td>Scenario 2: Prenatal dx. Down syndrome—parents conflicted</td>
<td>97%</td>
</tr>
</tbody>
</table>

A 4-point Likert scale was used to measure respondents’ comfort levels for each scenario composite, ranging from “1-Very Comfortable” to “4-Very Uncomfortable”. Here we include the percentages of respondents reporting that they were “2-Comfortable” or “1-Very Comfortable”.

We attempted to assess the relationship between respondents’ perceptions of the value of their graduate training and their comfort level with each of the seven scenarios (see Table 2).
Small but significant correlations were seen in the case of prenatal diagnosis of cystic fibrosis when respondents reported higher perceptions of adequate training in each of the experiences. Interestingly, a significant relationship was only seen in the case of prenatal diagnosis of cystic fibrosis when participants endorsed higher levels of adequacy in overall exposure to disability during graduate training. Higher ratings of adequacy for awareness and sensitivity to psychosocial issues were significantly correlated with all scenarios except in prenatal scenarios involving Down syndrome. Of note, for all training-related preparation variables during school, there was no significant relationship

<table>
<thead>
<tr>
<th>Scenarios</th>
<th>Rating of Training-Related Preparation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall Exposure to Disabilities</td>
</tr>
<tr>
<td>Scenario 1: prenatal cystic fibrosis</td>
<td>0.265*</td>
</tr>
<tr>
<td>Scenario 2: Prenatal Down syndrome</td>
<td>0.108</td>
</tr>
<tr>
<td>Scenario 3: prenatal Down syndrome-parents already decided to terminate</td>
<td>0.204</td>
</tr>
<tr>
<td>Scenario 4: prenatal achondroplasia</td>
<td>0.165</td>
</tr>
<tr>
<td>Scenario 5: pediatric/postnatal cystic fibrosis</td>
<td>0.191</td>
</tr>
<tr>
<td>Scenario 6: pediatric/postnatal Down syndrome</td>
<td>0.164</td>
</tr>
<tr>
<td>Scenario 7: pediatric/postnatal deafness</td>
<td>0.165</td>
</tr>
</tbody>
</table>

* \( p=0.05 \); ** \( p=0.01 \)
seen with any variables when analyzed with Scenario 3, which involved a prenatal
diagnosis of Down syndrome in which the clients had already decided on termination of
pregnancy.

Respondents reporting higher feelings of adequacy to counsel patients about
disability immediately after graduation also reported increased levels of comfort
discussing the topic of disability in all of the hypothetical scenarios. The magnitude of
the significance was highest in the scenario of prenatal diagnosis of achondroplasia
(0.41). Correlations were larger for all scenarios when counselors felt higher levels of
adequacy in on-the-job training while being at their job setting for an extended period of
time. The largest correlations were for prenatal diagnoses of cystic fibrosis (0.48), Down
syndrome (0.47), and achondroplasia (0.47).

Finally, we found that higher levels of perceived comfort were reported by
genetic counselors who reported having had continued interactions with individuals with
disability outside the clinical setting. A total of 54% of the cohort reported ongoing
interactions with individuals with disabilities outside the clinic setting. This set of
respondents felt higher levels of comfort discussing the topic of disability in the
hypothetical clinical scenarios.
Suggestions for Training Program Curricula Regarding Disabilities

Overall, a majority of respondents endorsed the idea that there is not enough exposure to disability awareness during graduate training, and commented that increased awareness among the genetic counseling community, starting with training programs, could be a first step in developing more public awareness. A total of 65 respondents (60.7%) made suggestions for improvements to training programs. Overall, many respondents endorsed:

- More contact in general for students, especially direct contact via caregiver roles or interacting one-to-one with individuals with different types of disabilities
- Increased networking with support groups or advocacy organizations
- Multiple speakers brought into programs to give balanced perspectives on differences and challenges of disability and give perspective on their unique type of disability
- Increased class discussion involving psychosocial issues and different challenges faced by people with different disabilities

With respect to efforts that could be implemented by the ABGC, NSGC or other professional organizations, participants suggested several possibilities, including 1) more opportunities for CEU credits for disability-related activities, 2) More speakers with disabilities speaking at NSGC conferences, 3) Experts in the disability field giving webinars or hosting discussion forums and 4) Creation of a resource database from NSGC, including lists of local/national disability organization, pamphlets about disorders, and links to sites that discuss financial and daily life challenges for different types of disabilities.
Discussion

Issues regarding disability awareness education have caused debates between the disability communities and the medical community for many years without resolution (Hodgson et al., 2010; Shakespeare et al., 2009; Cleary-Goldman et al., 2006; Ormond et al., 2003; Chen & Schiffman, 2000; Parens & Asch, 2000; Cooley et al., 1990; Yuker, 1988). In a recent issue of the American Journal of Medical Genetics, several members of the genetic counseling and disability communities provided commentary highlighting the tensions that still exist, and fostering controversy over next steps (Madeo et al., 2011; Dent et al., 2011; Bauer, 2011; Resta, 2011). In this study we aimed to learn more about what recent graduates of genetic counseling programs have experienced with respect to disability awareness training in an attempt to provide insight into changes in curricula or national efforts that might begin to resolve the perceived conflict.

We specifically asked participants about their exposure to the field of disability before, during and after their genetic counseling graduate programs. Most participants reported that they had some type of experience with people who have disabilities before entering their programs, and about one-third reported interactions specifically in teaching or academic support roles for children with disabilities, or were direct caregivers for someone with a disability. However, during school, only a small percentage of respondents experienced direct interaction with people who have disabilities aside from their clinical internships. These direct interactions could have included community field
placements with agencies that serve individuals with special needs or direct placement with a family or individual with a disability. After graduation, more than half of respondents reported continued interaction with people who have disabilities aside from their current work setting. As long ago as 1988, it was recommended that “To improve attitudes towards persons with disabilities, interactions should, “(1) involve cooperation and reciprocity, (2) be rewarding to both disabled and nondisabled, (3) result in the participants getting to know one another as individuals, and (4) persist over time” (Yuker, 1988). It seems from this data that many respondents acknowledge the importance of interaction with people who have disabilities and have sought out experiences both before and after their training, even when they did not have those interactions during their training programs. When asked about the value of specific experiences in training, guest lecture was the most valuable since that is what most of the graduates experienced. However, that doesn’t mean that it actually was the most valuable considering there were many respondents who did not have access to all training experiences. Respondents may have answered differently regarding what they felt was most valuable to their training if their exposure during training included other activities.

When clinical genetic counselors reported perceived adequacy of training in discussing the topic of disability, many agreed that they had acquired sufficient knowledge to discuss disability in the clinic setting with clients and students. However, almost half of clinical genetic counselors felt their training experiences in their programs only left them “Somewhat Adequately” prepared in their disability training overall, implying that there are areas where improvements can be made. Only a quarter of participants felt highly adequate in terms of their overall preparation to discuss disability
immediately after graduation, but when respondents rated higher levels of adequacy in this area, it correlated with higher levels of perceived comfort in seven hypothetical prenatal and pediatric scenarios. The variable in which the highest percentage of respondents reported that they felt highly adequate in their training was centered around the topic of awareness and sensitivity to psychosocial issues in speaking with individuals about disability. When respondents reported higher perceptions of adequacy in this area of training, it correlated with higher levels of perceived comfort in many hypothetical prenatal and pediatric scenarios. It could be argued that when programs offer more extensive types of disability-related training experiences, graduates will feel more adequately prepared to counsel about disability, even with less experience before entering their respective programs.

Madeo et al. suggest that genetic counseling programs should recruit individuals with significant experiences with disability prior to schooling. It is true that we found that direct interaction with individuals with disability correlated with respondents feeling more comfortable discussing disability, however, comfort levels did not seem to be dependent on the timeframe in which direct interaction occurred. Those who have had personal interaction with individuals with disability (before, during, and/or after graduation) reported higher levels of comfort in the clinical setting. In fact, we found that the strongest correlation exists between higher levels of perceived adequacy in disability education from training programs and higher levels of perceived comfort in the clinic setting. This supports previous research (Shakespeare et al., 2009) which concluded that the most dramatic learning comes from exposure to peers outside the
clinical setting, and education for professionals should always include experiences outside the clinical setting.

In a hypothetical scenario in which the parents desired termination for prenatal diagnosis of Down syndrome, our data suggests that no matter how much training or exposure one receives in disability, there is a general lower comfort level for counselors in discussing issues related to disability around controversial topics, such as when a couple has already decided to terminate the pregnancy. Counselors may be reluctant to provide detailed information about what life with a child who has a disability would be like when the decision to terminate has already been made. Such situations may occur somewhat frequently in prenatal settings and may be challenging for both new and experienced counselors.

Based on our findings it appears that increased awareness among the genetic counseling community, starting with increased exposure during program training, could be a first step in developing more general public awareness and foster collaboration with training programs, national genetic counseling organizations, and the disability community. Respondents also suggested the creation of an easily searchable resource database from NSGC for students, consumers and counselors to use to search for more literature or specific organizations regarding the topic of genetic conditions and disability. This would allow for easy access that many respondents in this survey mentioned when looking for resources and appropriate referrals to give to their clients who want additional information.

When respondents suggested ideas of what steps the NSGC could take to increase awareness and training, one specific suggestion included CEU credits to support
continued education in disability awareness. Currently genetic counselors can earn professional activity credits (PACs) which can be used in place of CEUs for recertification. One category of PACs is awarded specifically for volunteering at camps for children with special needs. It is unclear whether genetic counselors are aware of this as an option. In addition, volunteering at a camp may not be a feasible option for counselors with full time jobs. Expanding the list of disability related activities that would lead to the ability to earn PACs might enhance the likelihood that genetic counselors would pursue them.

**Limitations**

Between the years of 2007 and 2011 approximately 970 students graduated from genetic counseling programs in North America. The sample for this analysis involved 142 original respondents, only 14.6% of those eligible for participation. Of that number, the sample size was reduced further to 107 participants who identified themselves as clinical genetic counselors, yielding 11% of the total eligible to participate. It is possible that the study participants are not representative of the cohort as a whole, and in particular it is possible that only those counselors with an interest in disability awareness issues chose to participate. If this were the case, respondents may have been more likely to rate their training as less or more adequate, and more likely to express suggestions for improvements in training programs and elsewhere. When comparing counselors who have graduated in the last 5 years compared to 30 years ago, much has changed in the medical field, including the advent of prenatal diagnosis for genetic conditions. With the increasing number of testing options available to parents, as well as services available for
people who have disabilities, it may be the case that counselors are finding it more
difficult to discuss all possible options with clients. Counselors 30 years ago may have
had increased exposure to disability, but without retrospective data analysis on the
subject, it is impossible to understand the differences in exposure during training 30 years
ago compared to the last 5 years. Specifically in regard to prenatal genetic counselors,
the NSGC 2010 PSS reported that 32% of clinical genetic counselors identify as working
in the prenatal setting. This is quite similar to the percentage of prenatal genetic
counselors in this study cohort (31.8%). However, it is unknown what particular biases
these counselors had which may made them more likely to respond to the survey. This
study was not designed to make assumptions about causality, and therefore we cannot
reach definitive conclusions to describe what types of experiences were most beneficial
in preparing genetic counselors to discuss disability in the clinical setting.
Conclusion

Through the reports of 107 recent graduates of genetic counseling training programs, we found that there is considerable variability in exposure to disability awareness issues, and varying levels of comfort with discussing disability related issues with clients. Though 35.5% of our respondents had experience in teaching, caregiving or advocacy roles with individuals with disability before they entered their genetic counseling training program, only 14% reported that activities involving direct personal interaction with individuals with disability was a required element of their graduate training. Not unexpectedly, respondents who felt they had more adequate training also perceived themselves as more comfortable discussing disability in the clinic setting. Respondents who had experienced personal interactions with individuals with disability outside the clinic setting also felt higher levels of comfort in the clinic setting.

The genetic counselors we surveyed proposed that the ABGC consider allowing Professional Activity Credit CEUs for genetic counselors who spend time volunteering with individuals with disabilities. At the moment counselors can earn PACs for volunteering at camps for people with disability, but genetic counselors may not be aware of that as an option and perhaps the PAC definition should be expanded to include volunteering in other capacities with people who have special needs. It was also suggested that professional organizations like the NSGC should play a leadership role in
facilitating and maintaining open discussion and collaboration with disability communities and organizations, much as they do with pro-choice organizations.

The ABGC core competencies could be further defined so as to specifically include the terms disability or disability awareness within its skill sets as defined core competencies for practicing genetic counselors (ABGC, 2010). Currently, the competencies describe four general overarching themes related to: communication skills; critical thinking skills; interpersonal, counseling, and psychosocial assessment skills; and professional ethics and values. They do not specifically address issues related to disability awareness. Also, there are no set training competencies in place from the American Board of Genetic Counseling (2010) for genetic counseling training programs with regard to disability awareness education, making it difficult for the current research to know how which programs offer which types of training in disability awareness. A future direction may include NSGC members collaborating with ABGC in laying the foundation for suggesting guidelines specifically related to disability-awareness issues in addition to the current protocols set in place for programs designated by the ABGC.

It is important to recognize that clinical genetic counselors do have a delicate balance to strike between giving the patient enough information to make informed decisions, and discussing the topic of disability without being perceived by the patient as having a bias in any direction. Continued education in disability awareness is also important for non-clinical genetic counselors, such as those in clinical research or group outreach, or public health positions. It is our hope that our findings will lay the groundwork for continued research and education in this critical area.
REFERENCES

Appendix A

Request for Participation in Research Study: Disability Awareness Training and Implications for Current Practice of Genetic Counselors

Dear NSGC member,

My name is Laura Kline, and I am a 2\textsuperscript{nd} year graduate student in the Brandeis University Genetic Counseling Program. I am conducting this research project in partial fulfillment of the requirements necessary to obtain a master’s degree.

What is the purpose of the study?

I am conducting a survey of how disability awareness and sensitivity training in genetic counseling graduate programs in recent years has impacted genetic counselors’ personal perspectives and practices.

Who is eligible to participate in the study?

If you graduated from a genetic counseling program between 2007 and 2011, you are invited to participate in this research project.

You are eligible if you graduated from your program within the last five years, regardless of your current job or if you do not work as a genetic counselor.

What does participation involve?

Participation will involve completion of an anonymous online survey, which will take approximately 15 minutes of your time. Participation is voluntary, anonymous and confidential.

What are the benefits of participation?

Participation does not cost anything but your time and effort in filling out the survey. If you complete the survey, you have the option to enter your email into a raffle to win one of two $50 gift cards to Amazon.com.

You can access the survey at the URL below.

https://brandeis.qualtrics.com/SE/?SID=SV_02mtwpCZJz3vto8

Who do I contact if I have questions about this research?

If you have any questions about this research project, contact me by email at lkline@brandeis.edu. Thank you in advance for participating in this project. Your time and input are valuable and very much appreciated.

Sincerely,

Laura Kline
Second Year Master’s Level Graduate Student
Brandeis University Genetic Counseling Program
Appendix B

Q1.1 Thank you for agreeing to participate in this study. This is a student research project being conducted under the affiliation of Brandeis University and has been approved by the Brandeis University under IRB study number (____________). By taking this survey, you are formally consenting to participate in this research project and give permission for your answers to be used in analysis. The survey will take approximately 15 minutes to complete. Participation is anonymous, voluntary and confidential. You may choose to opt out of the survey at any time. The aim of this graduate thesis is to assess genetic counselors’ prior training and experiences in disability and how it has shaped their current clinical practice. The student conducting this study is Laura Kline, a master’s degree candidate at Brandeis University’s Genetic Counseling program. If you have comments, questions or concerns, please contact Laura at lkline@brandeis.edu. Thank you for your participation. Proceed to the survey by clicking the ‘NEXT’ button below.

Q2.1 This first set of questions will ask about demographic information as well as pre-graduate school information. Click the 'NEXT' button to continue.

Q2.2 Gender
☑ Male (1)
☑ Female (2)
☑ I prefer not to disclose (3)

Q2.3 Ethnicity
☑ Hispanic (1)
☑ Non-Hispanic (2)
☑ I prefer not to disclose (3)

Q2.4 Ethnicity
☐ White or Caucasian (1)
☐ Asian (2)
☐ Black or African American (3)
☐ Native Hawaiian or other Pacific Islander (4)
☐ American Indian or Alaskan Native (5)
☐ Other (6)
☐ I prefer not to disclose (7)
Q2.5 In what geographical region was your genetic counseling graduate training program?
- Region 1 (MA, ME, NH, RI, VT, Canadian Maritime Provinces) (1)
- Region 2 (DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec) (2)
- Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN) (3)
- Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario) (4)
- Region 5 (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan) (5)
- Region 6 (AK, CA, HI, ID, NV, OR, WA, British Columbia) (6)

Q2.6 What year did you graduate from your genetic counseling training program?
- Prior to 2007 (1)
- 2007 (2)
- 2008 (3)
- 2009 (4)
- 2010 (5)
- 2011 (5)

If Prior to 2007 Is Selected, Then Skip To End of Survey

Q2.7 What was your undergraduate major in college?
- Biology (1)
- Psychology (2)
- Liberal Arts (3)
- Nursing (4)
- Biotechnology (5)
- Other (6) ____________________

Q2.8 What is your current job role? (You may choose more than one or choose the setting you practice in most often)
- Clinical Genetic Counseling (1)
- Clinical Genetics Research (2)
- Diagnostic Laboratory (3)
- Public Health (4)
- Teacher/Education (5)
- Other (6) ____________________
- Not currently working (7)
Q2.9 How long have you been employed at your current position? (If you have more than one job, please answer with the position in which you most identify as your primary position)
- Less than 1 year (1)
- 1-2 years (2)
- 3-5 years (3)
- 5+ years (4)
- Not currently working (5)

Q2.10 What area do you currently specialize in? (You may choose more than one or choose the specialty you practice in most often)
- Prenatal (1)
- Assisted Reproductive Technology (ART) (2)
- Pediatric (3)
- Cancer (4)
- Adult Genetics (5)
- Metabolic (6)
- General Genetics (7)
- Neurogenetics (8)
- Psychiatric Genetics (9)
- Specialty Clinic (10)
- Other (11) ________________
- Not applicable (12)

Q2.11 What other areas of genetic counseling have you worked in prior to your current position, or do you currently work in aside from your primary position? (check all that apply)
- Prenatal (1)
- Assisted Reproductive Technology (ART) (2)
- Pediatric (3)
- Cancer (4)
- Adult Genetics (5)
- Metabolic (6)
- General Genetics (7)
- Neurogenetics (8)
- Psychiatric Genetics (9)
- Specialty Clinic (10)
- Other (11) __________________
- Not applicable (12)
Q3.1 The following questions pertain to your personal experience with disability before entering your genetic counseling training program. Click the 'NEXT' button to continue.

Q3.2 Do you personally have a disability?
- Yes (1)
- No (2)
- I prefer not to disclose (3)

Q3.3 Before entering your genetic counseling training program, what, if any, types of experience did you have with people who have disabilities? (check all that apply)
- Guest lecturer with a disability (Example: Down syndrome, cerebral palsy, blindness, born with a limb abnormality) (1)
- Personal care for someone with a disability (2)
- Friend or family member with a disability (3)
- Hospital or clinic (volunteer work/employment/observation) (4)
- Advocacy work (national or local disability organization, community involvement group, etc) (5)
- Other (please specify) (6) __________________
- None (7)

Answer If Before entering your genetic counseling training program,... Advocacy work (national or local disability organization, community involvement group, etc) Is Selected Or Before entering your genetic counseling training program,... Friend or family member with a disability Is Selected Or Before entering your genetic counseling training program,... Other (please specify) Is Selected Or Before entering your genetic counseling training program,... Hospital or clinic (volunteer work/employment/observation) Is Selected Or Before entering your genetic counseling training program,... Personal care for someone with a disability Is Selected

Q3.4 What types of personal care experience with people who have disabilities did you have before entering your genetic counseling training program? (check all that apply)
- School setting and/or academic support (1)
- Respite care (2)
- Adult day program (3)
- Hospice care (4)
- In-home care (5)
- Physical or occupational therapy sessions (6)
- Other (please specify) (7) __________________

Q4.1 The following questions pertain to your general comfort level with discussing disability in your current job setting. Click the 'NEXT' button to continue.
Q4.2 I feel that I have acquired sufficient knowledge to discuss disability with patients, clients, or students.
 Strongly Agree (1)
 Agree (2)
 Neither Agree nor Disagree (3)
 Disagree (4)
 Strongly Disagree (5)

Q4.3 In your job, how often do you feel comfortable with your discussions of disability with your patients, clients or students?
 Very often (1)
 Quite often (2)
 Sometimes (3)
 Rarely (4)
 Never (5)
 Not applicable (6)

Q4.4 In your job, how often do you feel conflicted about your discussion of disability with your patients, clients, or students?
 Very often (1)
 Quite often (2)
 Sometimes (3)
 Rarely (4)
 Never (5)
 Not applicable (6)

Q5.1 The following set of questions pertains to the experiences you had with disability in your genetic counseling training program. Click the 'NEXT' button to continue.
Q5.2 What types of experience did your genetic counseling training program include in your disability awareness and sensitivity training, aside from clinical rotations? (Check all that apply)

- Class lectures specifically focused on disability issues (1)
- Guest lecturer with a disability (Example: Down syndrome, cerebral palsy, blindness, born with a limb abnormality) (2)
- Assigned books (3)
- Assigned movies (4)
- Assigned/required community field placement (such as a school for the blind or for children with autism) (5)
- Assigned/required placement with a family or individual living with a disability (6)
- Assigned/required to attend a support/advocacy group for individuals with a disability (7)
- Seminar/Conference (8)
- None (9)
- Other (10) ________________

Answer: If What types of experience did your genetic counseling training program include in your disability awareness and sensitivity training, aside from clinical rotations? Assigned/required community field placement (such as a school for the blind or for children with autism) is selected and What types of experience did your genetic counseling training program include in your disability awareness and sensitivity training, aside from clinical rotations? Assigned/required placement with a family or individual living with a disability is selected.

Q5.3 What age groups were the individuals you had that experience with? (check all that apply)

- 0-2 years old (1)
- 3-17 years old (2)
- 18-64 years old (3)
- 65+ years old (4)
Q5.4 What types of assigned/required community field placement, or placement with a family, did you have as part of your genetic counseling training in disabilities, aside from your clinical rotations? (check all that apply)

- School setting and/or academic support (1)
- Respite care (2)
- Hospice care (3)
- Adult day program (4)
- In-home meetings (5)
- Physical or occupational therapy sessions (6)
- Early intervention program (7)
- Comprehensive care clinic for single diagnosis (Down syndrome, neurofibromatosis) (8)
- Other (please specify) (9) ____________________

Q5.5 Which experiences during genetic counseling training did you find the most valuable in helping you feel prepared to discuss disability as a genetic counselor? (pick the 2 experiences that were most valuable to you in your training)

- Class lectures specifically focused on disability issues (1)
- Guest lecturer with a disability (Example: Down syndrome, cerebral palsy, blindness, born with a limb abnormality) (2)
- Assigned books/articles (3)
- Assigned movies (4)
- Assigned/required community field placement (such as a school for the blind or for children with autism) (5)
- Assigned/required placement with a family or individual living with a disability (6)
- Assigned/required to attend a support/advocacy group for individuals with a disability (7)
- Seminar/Conference (8)
- Other (9) ____________________
Q5.6 Which experiences during genetic counseling training did you find the least valuable in helping you feel prepared to discuss disability as a genetic counselor? (pick the 2 experiences that were least valuable to you in your training)

- Class lectures specifically focused on disability issues (1)
- Guest lecturer with a disability (Example: Down syndrome, cerebral palsy, blindness, born with a limb abnormality) (2)
- Assigned books/articles (3)
- Assigned movies (4)
- Assigned/required community field placement (such as a school for the blind or for children with autism) (5)
- Assigned/required placement with a family or individual living with a disability (6)
- Assigned/required to attend a support/advocacy group for individuals with a disability (7)
- Seminar/Conference (8)
- Other (9) ____________________

Q5.7 Since graduation from your genetic counseling training program, have you had any interactions with individuals with physical and/or intellectual disabilities or with their families, apart from your job? (family member, friend, volunteer, support/advocacy groups, other)

- Yes (1)
- No (2)

Answer: If since graduation from your genetic counseling training program, have you had any interactions with individuals with physical and/or intellectual disabilities or with their families, apart from your job? Yes is selected.

Q5.8 In what capacity have you had interactions with people with disabilities? (check all that apply)

- I have a family member with a disability (1)
- I have a friend with a disability (2)
- I have volunteered in a program that provides direct care for people with disabilities (3)
- I am a member of a support and/or advocacy group for people with disabilities (4)
- Other (5) ____________________

Q6.1 The next series of questions involves clinical genetic counseling scenarios. Click the 'NEXT' button to continue.
Q6.2 Scenario 1: A fetus is diagnosed with two cystic fibrosis (CF) mutations via amniocentesis at 15 weeks. Both parents are known carriers of a mild CF mutation. One of the parents has an affected sibling. Before you even sit down with them to start the session, the male partner says to you, "We didn't think this was going to happen, even with the odds they told us before. I mean, medicines are becoming more effective, but we don't know if we could raise a sick child. What do we do?" The clients are conflicted whether to continue or terminate the pregnancy.

<table>
<thead>
<tr>
<th>I would discuss the option of termination with this client (1)</th>
<th>Strongly Agree (1)</th>
<th>Agree (2)</th>
<th>Disagree (3)</th>
<th>Strongly Disagree (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the option of continuation of the pregnancy with this client (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the option of adoption with this client (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the medical facts and statistics associated with this condition (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the financial, social and quality of life implications associated with this condition (5)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I am comfortable discussing the possibility of a child born with disabilities,</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>given this condition (6) I feel comfortable addressing psychosocial issues with the client (7) I feel comfortable accessing and offering resources and information to the client (8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q6.3 Scenario 2: You are seeing a prenatal diagnosis of a female fetus with Down syndrome. There are persistent echogenic cardiac foci and echogenic bowel seen on ultrasounds. Before you even sit down with the client, she starts crying and states, "How could this happen? I don't know what to do. What should I do?" She is very conflicted about whether she wants to continue or terminate the pregnancy.

<p>| I would discuss the option of termination with this client (1) | Strongly Agree (1) | Agree (2) | Disagree (3) | Strongly Disagree (4) |
| I would discuss the option of continuation of the pregnancy with this client (2) | o | o | o | o |
| I would discuss the option of adoption with this client (3) | o | o | o | o |
| I would discuss the medical facts and statistics associated with this condition (4) | o | o | o | o |
| I would discuss the financial, social and quality of life implications associated with this condition (5) | o | o | o | o |
| I am comfortable discussing the possibility of a child born with disabilities, given this condition (6) | o | o | o | o |</p>
<table>
<thead>
<tr>
<th>I feel comfortable addressing psychosocial issues with the client (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel comfortable accessing and offering resources and information to the client (8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
</tr>
</tbody>
</table>
Q6.4 Scenario 3: You are seeing a case of prenatal diagnosis of a female fetus with Down syndrome. There are persistent echogenic cardiac foci and echogenic bowel seen on ultrasounds. Before you even sit down with the client, she looks you in the eye and states, "I don't really know why I'm here to meet with you since I already know I want an abortion. When can we schedule it?"

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (1)</th>
<th>Agree (2)</th>
<th>Disagree (3)</th>
<th>Strongly Disagree (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would discuss the option of termination with this client (1)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the option of continuation of the pregnancy with this client (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the option of adoption with this client (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the medical facts and statistics associated with this condition (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I would discuss the financial, social and quality of life implications associated with this condition (5)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I am comfortable discussing the possibility of a child born with disabilities, given this condition (6)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I feel comfortable addressing psychosocial issues with the client (7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable accessing and offering resources and information to the client (8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q6.5 Scenario 4: You are seeing a case of prenatal diagnosis of a male fetus with achondroplasia. There is no previous family history of skeletal dysplasias. The fetus has shortened limbs and slight lordosis of the spine. The client tells you she has been changing her mind every 5 seconds as to whether to continue or terminate the pregnancy, and she has been very stressed since receiving the diagnosis.

| I would discuss the option of termination with this client (1) | Strongly Agree (1) | Agree (2) | Disagree (3) | Strongly Disagree (4) |
| I would discuss the option of continuation of the pregnancy with this client (2) | | | | |
| I would discuss the option of adoption with this client (3) | | | | |
| I would discuss the medical facts and statistics associated with this condition (4) | | | | |
| I would discuss the financial, social and quality of life implications associated with this condition (5) | | | | |
| I am comfortable discussing a typical daily life for this child living with disabilities, given this | | | | |

47
<table>
<thead>
<tr>
<th>condition (6)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel comfortable addressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>psychosocial issues with the clients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable accessing and</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>offering resources and information</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to the clients (8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q6.6 Scenario 5: A newborn girl is diagnosed with cystic fibrosis after newborn screening indicated a need for further testing. She has two different CF mutations. When you start talking about cystic fibrosis with the parents, the father starts raising his voice and questioning, "What do you mean that we can't treat and cure this? There has to be a way to fix this."

<table>
<thead>
<tr>
<th>I would discuss the medical facts and statistics associated with this condition (1)</th>
<th>Strongly Agree (1)</th>
<th>Agree (2)</th>
<th>Disagree (3)</th>
<th>Strongly Disagree (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would discuss the financial, social and quality of life implications associated with this condition (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am comfortable discussing a typical daily life for this child living with disabilities, given this condition (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable addressing psychosocial issues with the clients (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable accessing and offering resources and information to the clients (5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q6.7 Scenario 6: You are seeing a 4-week old baby girl with a diagnosis of Down syndrome. The mother is very quiet and when you ask her if anyone has ever spoken with her about what Down syndrome is, she starts to cry. She states, "They all asked me why I didn't get an amnio. I am not prepared to raise a baby with Down syndrome, I don't even know where to start. They told me she will never be independent."

<table>
<thead>
<tr>
<th>I would discuss the medical facts and statistics associated with this condition (1)</th>
<th>Strongly Agree (1)</th>
<th>Agree (2)</th>
<th>Disagree (3)</th>
<th>Strongly Disagree (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I would discuss the financial, social and quality of life implications associated with this condition (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am comfortable discussing a typical daily life for a person living with disabilities, given this condition (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel comfortable addressing psychosocial issues with the clients (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel comfortable accessing and offering resources and information to the clients (5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
I would share with the family the contact information of the local non-profit organization for Down syndrome. (6)
Q6.8 Scenario 7: You are seeing a 2-month old boy who failed his newborn hearing test and was subsequently tested and found to have two Connexin-26 mutations (associated with deafness). One parent has a sibling with partial hearing loss. The couple was expecting the testing to come back normal. They are very surprised and sad about this diagnosis. The mother states, "How will we even be able to communicate with him? He's going to have such a hard time learning. We want him to be treated the same as everyone else."

| I would discuss the medical facts and statistics associated with this condition (1) | Strongly Agree (1) | Agree (2) | Disagree (3) | Strongly Disagree (4) |
| I would discuss the financial, social and quality of life implications associated with this condition (2) | | | | |
| I am comfortable discussing a typical daily life for a person living with disabilities, given this condition (3) | | | | |
| I feel comfortable addressing psychosocial issues with the client (4) | | | | |
| I feel comfortable accessing and offering resources and information to | | | | |
Q7.1 This final series of questions will allow you to rate your overall experience with disability training. Several free response questions will allow you to reflect on your training, and the opportunity to give suggestions for continuing improvement of training. Click the 'NEXT' button to continue.
Q7.2 Please respond to each of the following statements.

<table>
<thead>
<tr>
<th></th>
<th>Highly Adequate</th>
<th>Somewhat Adequate</th>
<th>Neutral (3)</th>
<th>Somewhat Inadequate</th>
<th>Highly Inadequate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate your exposure to disabilities during your genetic counseling training (1)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Rate the preparation from your program on disability training, as to whether it provided you with adequate access to resources and services that you could discuss with your patients (2)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Rate the level of preparation from your program on disability training, in regards to your awareness and sensitivity to psychosocial issues involved in talking to individuals/families about disability (3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Rate the amount of knowledge you gained from your genetic counseling training, in understanding the range of disabilities for different genetic conditions, and the potentials and limitations for different groups of people with</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q7.3 From your personal perspective, what recommendations, if any, do you have for genetic counseling programs to improve their disability awareness and sensitivity training curriculums?

Q7.4 Do you know of any specific resources (books, videos, Internet webinars, etc) that were helpful for you, and might be valuable for future students?

Q7.5 Aside from genetic counseling programs continually improving their curriculums in disability awareness and sensitivity training, do you have any suggestions as to what resources the NSGC could provide to help promote continuing education in this topic for genetic counselors?

Q7.6 What do you think would be the most useful resource for you in further developing your personal practice to include a more well-rounded understanding and discussion of disabilities?

Q8.1 This is the end of the survey, thank you for your participation. To enter the raffle for one of three $50 gift cards, copy and paste this link into your email, give your contact information on how best to reach you, and send the email. (GCdisabilitysurveyraffle@gmail.com)

To officially finish the survey, click the 'NEXT' button below.
Appendix C

Disability Awareness Training and Implications for Current Practice

Dear NSGC member,

Thank you for agreeing to participate in this study. This is a graduate student research project being conducted by Laura Kline, a master's degree candidate in the Brandeis University Genetic Counseling Program. The aim of this research is to assess genetic counselors' training and experiences in disability and how such training has shaped their current clinical practice.

The survey will take approximately 15 minutes to complete. Participation is anonymous, voluntary and confidential. You may choose to opt out of the survey at any time.

The research protocol has been approved by the Brandeis University IRB. By taking this survey, you are giving consent to participate in this research project and give permission for your responses to be used in analysis.

Upon completion of the survey, you will have the opportunity to enter a raffle for one of two $50 gift cards to Amazon.com. Entry into the raffle will not be linked in any way to your survey responses.

If you have comments, questions or concerns about the survey or the project, please contact Laura at lkline@brandeis.edu. Thank you in advance for your participation.

Proceed to the survey by clicking the ‘NEXT’ button below.