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Xueying Qiao

Sarah Lawrence College, xqiao@gm.sl.c.edu

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Evaluation of a Disability Immersion Experience

**Evaluation of the Impact Program, a Disability Immersion Experience, in
Genetic Counseling Education**

Student: Xueying Qiao

Joan H. Marks Graduate Program in Human Genetics

Sarah Lawrence College

Bronxville, New York

Advisor: Anne Greb

45 Wrexham Road

Bronxville, NY 10708

Phone: (914) 395-2605

Fax: (914) 395-2608

e-mail: agreb@sarahlawrence.edu

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Abstract: Genetic counseling programs do not have models or standards to guide effective training on disabilities. The disability training can help students understand the psychosocial issues and acquire balanced knowledge pertaining to disabilities. However, there is no research on the effectiveness of disability training in the genetic counseling profession. We have evaluated a disability training course, the Impact Program, in the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College, which includes interactions between genetic counseling students and families that have a member with disability outside of a clinical setting. The results have demonstrated the program helps students enhance their ability to identify psychosocial issues, increase their comfort levels, and expand their knowledge in providing service to people with disabilities and their families. This study provides valuable information that genetic counseling programs can utilize to prepare their students to deliver quality, balanced services to their clients and the disability community.

Keywords: Down syndrome; Genetic counseling; Imbalanced; Disability; Training;

Introduction:

The definition of “disability” varies among societies. The World Health Organization (WHO) defines disability as any impairments, activity limitations and participation restrictions to a human being. WHO estimates 15% of the world’s population (over a billion people) live with a disability (WHO, 2013). The Centers for Disease Control and Prevention (CDC) of the United States defines disability as the presence of physical or mental impairments that limit a person's ability to perform an important activity and affect the use of or need for support, accommodation, or intervention to improve functioning (CDC, 2013). CDC estimates more than 30% of Americans (over 70 millions of people) live with a

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disability (CDC, 2014). The disability community is large and the demand for healthcare service is high; however, people with disabilities experience significant barriers to having access to quality services (Karl et al., 2013). Barriers are not only material (e.g., inaccessibility or inadequate equipment), but also intangible such as knowledge and attitudes of the healthcare providers (National Research Council, 2007).

The knowledge and attitudes misguided by misperceptions bring barriers and trauma to the disability community. In the 1920s, the eugenics movement once misled American scientific and medical elite, leading to the Supreme Court's decision to uphold forced sterilization; the sterilization law lasted until 1968 (Miller and Levine, 2013). The movement is viewed as an attempt to eliminate the disability population and has resulted in an everlasting anxiety and vigilance within the disability community over a possible return of the eugenics era (Miller and Levine, 2013). Today, many healthcare professionals provide care with good intentions; yet the good-natured desire doesn't necessarily guarantee the understanding of the needs, values and goals of their clients with disabilities (Miller and Levine, 2013). Indeed, most doctors are insensitive, perceive their clients with disability as poor and suffering victims in need of pity, and focus on restriction, isolation, and dysfunction of these patients; some clinicians even assume that patients who experience communication difficulty due to physical disability also have cognitive disability (Karl et al., 2013; Symons et al., 2009). Studies demonstrate physicians' attitudes and stereotypes about people with disabilities remain a significant barrier to quality of care; therefore, to provide quality healthcare, physicians need additional knowledge of disabilities and special training in psychosocial skills to manage attitudinal factors towards the disability community (Karl et al., 2013).

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The relationship between healthcare professionals and the disability community is generally disappointing (Sahin and Akyol, 2009). As one of the healthcare professionals, genetic counselors face the same predicament. Madeo et al. (2011) conclude that genetic counselors: 1) hold a negative perspective on disabilities; 2) are directive in a way that is biased against individuals with disabilities, especially in the context of prenatal genetic counseling and testing, which the disability community perceives as means to decrease their population; and 3) tend to focus on clinical and negative aspects of disability, and reluctantly offer options other than pregnancy termination to pregnant women with a fetus with a disability. The disability community is discontented because the information they receive in genetic counseling is biased or overly negative about disability; positive potentials are often omitted (Kellogg et al., 2014; McCabe and McCabe). The disability community is also frustrated because their voice cannot be heard; their values and beliefs are often ignored (Bauer, 2011; Miller and Levine, 2013). Many genetic counselors likely provide balanced service, leaving clients with disability satisfied with the service they received from genetic counselors (Farwig et al., 2010). However, haunted by the shadow of the historical trauma, it is conceivable that the disability community worries about the potential of another genetic genocide. The relationship between the genetic counseling profession and disability community is fragile (Madeo et al., 2011).

A key factor to soothing the relationship is the imbalanced genetic counseling practice (Madeo et al., 2011). But why do some genetic counselors possess biased attitudes and hesitate to offer balanced counseling? There are three concerns contributing to the answer: they may not have 1) enough understanding of psychosocial issues of individuals with disability; 2) enough knowledge about positive potentials of a disability; and 3) enough

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confidence to provide service to individuals with disability (Madeo et al. 2011; Sanborn and Patterson, 2014). These deficiencies can be attributed to insufficient disability training in genetic counseling education (Dent et al., 2011).

The training genetic counseling students to enhance their understanding of psychosocial issues of individuals with disability is inadequate (Madeo et al. 2011). The psychosocial issues can elicit strong emotions and stress that can interfere with clients' ability to retain information and therefore affect their ability to make informed, autonomous decisions (Boarders, et al., 2006). Upon the requirements of the Practice-Based Competencies for Genetic Counselors (ACGC, 2013), all genetic counseling programs provide training to support the development of the psychosocial skills in general; however, it is unclear how much psychosocial training is specific to disability, (Sanborn and Patterson, 2014).

In addition, training genetic counseling students in increasing their confidence and acquiring knowledge of disability is perhaps inconsistent as well. Upon entering a genetic counseling program, students likely share the same knowledge of disability as the general public. In general, people have biased knowledge against disabilities; often these attitudes are shaped early in their life by the family, society and culture within which they grow up (Madeo et al., 2011). Unlike other areas of genetic counseling where research supports content covered in the classroom, the positive aspects of disabilities are mostly anecdotal and endorsed by very few studies to present in the classroom. Students need to acquire experience and confidence to convey these potentials to their clients and this can be accomplished if the students have a chance to observe the positive aspects with their own eyes of the lived experiences of individuals with disability outside a clinical setting (Bauer,

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2011). It is therefore important for genetic counseling programs to give students opportunities to gain insights into day-to-day life of, and develop genuine friendship with, individuals with disabilities and their family members.

Evidence shows early encounters with people with disabilities can improve medical students' knowledge and attitudes about disability, further increasing their confidence and understanding of psychosocial issues in providing service to clients with disabilities. Karl et al. (2013) report the interaction between students and individuals with disabilities can help students gain more knowledge about positive aspects of a disability, improve their comfort levels and increase their awareness of attitudinal factors regarding disabilities. The authors conclude medical schools should consider introducing curricula with student-patient contact to improve their students' understanding of psychosocial issues, confidence, and knowledge of disabilities. The same conclusion is also supported by other studies (Ryan and Scior, 2014; Symons et al., 2009).

Another program, "Operation House Call (OHC)," is offered to medical students and operated by The Arc Massachusetts. The course includes spending time with children with a disability and their family members (The Arc Massachusetts, 2014). Students gained better knowledge about disabilities, increased their comfort level to perform psychosocial skills and changed their attitude about children with disabilities after home visits (Hanson et al. 2011).

Genetic counseling students can obtain the same benefits from the interaction with individuals with disabilities. Some studies suggest the interaction should occur outside a clinical setting in genetic counseling training (Madeo et al., 2011; McCabe and McCabe, 2012; Wertz and Gregg, 2000). The phrase "outside a clinical setting" is vital to this training because it is likely the only way for genetic counseling students to gain insight into day-to-

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day life of individuals with disabilities. Students can discover positive potentials of individuals with disabilities and become confident in their knowledge about disabilities (Madeo et al., 2011; McCabe and McCabe, 2012; Wertz and Gregg, 2000). The interaction can enhance the knowledge, confidence and the understanding of psychosocial issues pertinent to disabilities in genetic counseling education, further helping to prepare students to provide quality and balanced genetic counseling service.

The importance and need for disability training are recognized by the genetic counseling profession. The Accreditation Council for Genetic Counseling (ACGC) requires all counselors to be able to “recognize the importance of understanding the lived experiences of people with various genetic/genomic conditions (ACGC, 2013).” The majority of the directors of genetic counseling programs agree that the disability training is imperative and all the programs have such training activities though they vary vastly (Sanborn and Patterson, 2014). While program such as the OHC is an exemplary model of the disability training for medical education; there is no data on similar programs in genetic counseling education (Sanborn and Patterson, 2014). It is important to evaluate and report on the effectiveness of any disability training in genetic counseling, so genetic counseling programs can benefit from each other’s experiences (Peterson, 2011).

The Impact Program, implemented in 2012, offers an opportunity for genetic counseling students of the Joan H. Marks Graduate Program in Human Genetics (JHMGPHG) to visit a family who has a member with Down syndrome. The students spend a day with the family and gain insight into the daily life of individuals with Down syndrome and their families. Students may join families to visit zoos, play in parks, and stay in their houses. Through various activities, students are able to interact with the individuals with disability

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and see how they function, how they interact with their siblings or other family members.

Students are also required to complete an essay, in which they reflect upon their experiences (Su, et al., 2012). The purpose of this study is to evaluate this disability training program, the Impact Program, at Sarah Lawrence College, which occurs outside of the clinical setting.

Methods:

Participants

Students who participated in the Impact Program from 2012-2014 were recruited through an email invitation in February of 2015. An informed consent form and a link to an online survey were sent in the email invitation. The survey was closed in March of 2015, three weeks after the initial invitation was sent.

Measures

A survey questionnaire was designed using an online tool at Survey Monkey and administered by the same website. The questionnaire was developed to assess the effectiveness of the Impact Program in the areas elicited from both the requirements of the Practice-Based Competencies for Genetic Counselors (ACGC) and the needs of quality, balanced service for disability community based upon literature review. The scope of the survey included: 1) students' understanding of psychosocial issues facing families with a genetic diagnosis; 2) students' confidence level while providing genetic counseling services to individuals with a Down syndrome diagnosis and their families; and 3) students' knowledge of disability. The questionnaire had 29 questions and also collected demographic information. Question types included open and closed ended as well as 5-point Likert questions.

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Data Analysis

Descriptive statistics tools from Survey Monkey were used for quantitative data analysis. Charts used to display data distribution were constructed using Microsoft Excel. The Likert questions are scaled for 5 levels with a score of 1 for strongly disagree, 2 for disagree, 3 for neither agree nor disagree, 4 for agree and 5 for strongly agree. Responses collected from open-ended responses were qualitatively analyzed using principles of thematic analysis.

Results:

The survey invitation was sent to 86 students who participated in the Impact Program from 2012-2014. There were 42 responses, yielding a response rate of 49%. Among 42 respondents, 95% (N=40) were females; 98% (N=41) were younger than 30; 26% (N=11) had graduated and worked as genetic counselors; 71% (N=30) were still students; and 2% (N=1) had graduated but didn't work as a genetic counselor. Of the 11 genetic counselors, 73% (N=8) worked in a prenatal practice and 45% (N=5) worked in a pediatric practice. Additionally, 41 respondents reported the year they participated in the program; of them, 20% (N=8), 41% (N=17), and 39% (N=16) participated in the Impact Program in 2012, 2013 and 2014, respectively.

Effectiveness of the Impact Program in enhancing awareness of psychosocial issues, comfort level and knowledge pertaining to disability

Set A statements (Table 1) were designed to evaluate the effectiveness of the Impact Program in enhancing understanding of psychosocial issues, increasing confidence and expanding knowledge in providing service to individuals with disability and their families. Respondents of Set A statements were 42 and the data is organized in Table 1 and Chart 1.

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Skill assessment of the participants in counseling individuals with a prenatal Down syndrome diagnosis

Set B statements (Table 2) were designed to evaluate the influence of the Impact Program in counseling individuals with a prenatal diagnosis of Down syndrome. The respondents of Set B statements were 16 and the data is organized in Table 2 and Chart 2.

Skill assessment of the participants in counseling individuals with a postnatal Down syndrome diagnosis

Set C statements (Table 3) were designed to evaluate the influence of the Impact Program in counseling individuals with a postnatal diagnosis of Down syndrome. The respondents of Set C statements were 14 and the data were organized in Table 3 and Chart 3.

Influence of the Impact Program in the professional activities outside of the clinical setting

Nearly all participants (N=41) answered the question about their professional activities with disability community and/or patient advocacy organization outside of the clinical setting. Of these, 22% (N=9) had an involvement with either the community or the organization, and 78% (32) did not.

The most memorable experience the Impact Program brought to students

Question A was designed to elicit the most memorable experience of the program. The response rate of the question was 71% (N=30). Themes were identified and sorted to two categories; they were designated as Theme 1A and Theme 2A. Themes were described and proportions of the responses were reported in Table 4.

Ways in which the Impact Program helped to shape the students' current practice

Question B was designed to elicit the ways in which the program helped to shape the students' current practice. The response rate of the question was 52% (N=22). Themes were

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identified and sorted to three categories; they were designated as Theme 1B, Theme 2B and Theme 3B. Themes were described and proportions of the responses were reported in Table 4.

Suggestions from participants

Question C was designed to elicit suggestions to improve the Impact Program. The response rate was 50% (N=21). Themes were identified and sorted to three categories; they were designated as Theme 1C, Theme 2C, and Theme 3C. Themes were described and proportions of the responses were reported in Table 4.

Discussion:

The purpose of this study was to evaluate the effectiveness of the Impact Program by measuring the enhancement of students' knowledge, skills and attitudes in providing service to individuals with disability. The areas to measure include understanding of psychosocial issues, comfort levels and knowledge pertaining to disability. The evaluation also helped us in recognizing the strengths and weakness of the program. The information yielded from the study will be used to improve the program and share with other genetic counseling programs.

Enhancement of the awareness of psychosocial issues, confidence and knowledge in providing service to individuals with disability

Enhancing the awareness of psychosocial issues, comfort levels and knowledge regarding disability is vital for several reasons, including developing counseling skills in caring of with disability and in providing balanced genetic counseling for individuals with disability. The enhancement is important in the long run to reduce the tension between disability community and genetic counseling profession (Madeo et al., 2011). Our data supports that the Impact Program has successfully achieved the goal.

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Students became aware of the psychosocial issues of the disability community through the program. Almost all the respondents (41 out of 42) appreciated the diagnosis of Down syndrome from a perspective of the families; eighty five percent of the respondents acknowledged that the program helped them in understanding the lived experience of people with genetic conditions (Table 1; Chart 1), which is the specific goal of the Practice-Based Competencies (ACGC, 2013). From the family perspective and lived experience, students learned how to identify and address the psychosocial issues of families with disability. Many students indicated they had observed that families treated their affected members just the same as the unaffected ones. One student reported his/her awareness of the existence of poor genetic counseling services after talking to the family. The students also claimed they learned about families' experiences and feelings—grief, joy and hope—from discussion with the families. Most students (90%) reported the program enhanced their understanding of the psychosocial issues of families affected with a genetic condition (Table 1; Chart 1).

Additionally, students expanded their knowledge from observing the lived experience of individuals with disability. In the answers to open-ended questions, a student wrote that the child with Down syndrome in his/her host family was “very limited in their abilities both verbal and in skills;” however, another student wrote that the affected child in his/her host family was “much more high-functioning than I had anticipated.” One student claimed “it [the program] really helped drive home that Down syndrome exists on an incredibly wide spectrum.” Another student stated, “It took learning out of the classroom and made one of the genetic conditions we talk about most, so much more real.” The majority of the students (74%, N=31) found the Impact Program helped them learn how medical professionals can be most helpful to individuals with disabilities and their families (Table 1; Chart 1). Our data

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supports that the program helped students' knowledge grow in ways not possible in the classroom.

Furthermore, students increased their confidence in providing service to individuals with disabilities after participating in the Impact Program. A student reported, "I feel more confident shadowing any case;" another student reported "It [the Impact Program] did give me a foundation for which I feel comfortable speaking with my patients and responding to their needs." In general, the majority of participants (64%; N=27) agreed the Impact Program increased their overall confidence providing genetic counseling services to individuals with disabilities and their families (Table 1; Chart 1).

The program benefited students and helped them enhance their understanding of psychosocial issues, comfort level and knowledge pertaining to disability. The program appears to be effective in reaching its goal of improving the quality of genetic counseling.

Challenges of the Impact Program

While the Impact Program was found to be fruitful in enhancing students' knowledge and confidence in providing service to individuals with disability, the study also disclosed the challenges of the Impact Program.

Almost 43% of the students who gave suggestions (N=9) reported the expectation of both the families and students was not explained prior to the meeting (Theme 1C in Table 4). Some students felt it was not clear about expectations for the family and for students. One student wrote, "they [the family] weren't too sure what to do, and neither was I."

Eight students who gave suggestions (38%) found the diversity of the program was limited (Theme 2C in Table 4). They suggested expanding the conditions from Down syndrome to others, the settings from home to activity centers like GiGi's Playhouse or

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schools, and the family numbers for each student from one to several since each family's experience is different.

One student raised a concern for the safety of the home visit. The student worried about his/her safety when visiting a family that didn't go through back-ground checks of all members of the household. Although the visit was positive, he/she suggested a safety check or some other means to have some assurance of the safety for home visit. This is a real challenge as doing safety checks on participating families may result in a misunderstanding of being not trusted.

Moreover, the participants seemed reluctant to describe their experience with the Impact Program when discussing the Down syndrome diagnosis with clients (Tables 2 and 3). One possible conjecture is students may not want to bring themselves and their experiences into the genetic counseling session because it may be seen directive.

Lastly, 22% (N=9) of the participants expanded their professional activities with the disability community outside of their work setting. Of these, 67% (N=6) spent time with GiGi's Playhouse, a Down syndrome support group with which the Impact Program has established relationship, and from which the Impact Program recruits families. This result suggests optimism that more participants will be interested in expanding their activities within the disability community if the program can help build up more connections with other organizations.

Study Limitations

Despite a good response rate, the sample size of our study was small. In addition, the program was not mandatory before the Class of 2016 and our results may be biased toward students with an interest in disabilities training. In addition, the small number of the

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respondents who work in a pediatric setting may also represent a bias for those with interest in pediatrics.

The study was unable to conduct a survey for the same cohort of the participated students prior to participating in the Impact Program. The analysis may have been strengthened if we could have compared data obtained from students before they attend the program with data obtained from the same group of students after they complete the program. Moreover, the study may have also been strengthened if we could have compared data obtained from students who did not go through the program.

Conclusion:

This study has evaluated the Impact Program, a disability training program for genetic counseling students in the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College. The program offers an opportunity for genetic counseling students to spend a day with a family that has an individual with Down syndrome, and gain insight into the lived experience of the family. The results demonstrate the Impact Program can help genetic counseling students strengthen their understanding of psychosocial issues, increase their comfort levels, and expand their knowledge in providing service to individuals with disability and their families.

Not only does the Impact Program assist students in closing the existing gap between what some genetic counselors think about Down syndrome and what life is really like for these individuals and their families (Bauer 2011), but the program also provides first-hand experience for students to witness the wide spectrum of symptoms associated with Down syndrome. Through the program, students become more confident to deliver balanced

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counseling services with positive aspects of Down syndrome and family values towards the condition, which is desperately welcomed by the disability community (Madeo et al., 2011).

In addition to the discovery of the important achievements of the Impact Program, the study also identified areas needed for improvement. These include: 1) add orientations prior to the start of the program for students and families to let them know the expectations for the program; 2) include opportunities to develop long-term relationship between students and families; 3) address safety concerns by having more than one student visit the family's home at the same time, conducting background check or meeting families in public venues; 4) encourage students and graduates to form connections with more support groups and disease-specific advocacy organizations; and 5) diversify the lived experience by multiple family visits at various settings, visiting more families with different genetic conditions, and adding a post-visit discussion for students at the end of the program to share their unique experiences or reflections.

In general, genetic counselors don't have enough training in enhancing the understanding of psychosocial issues, the confidence, and the knowledge pertaining to disabilities. The insufficient training contributes to imbalanced genetic counseling and leads to a tension between the genetic counseling profession and the disability community (Madeo et al., 2011). The Impact Program in the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College represents one training model that can potentially address this important gap in genetic counseling practice.

Our experience with the Impact Program can benefit other genetic counseling programs that may be considering student exposure to disabilities outside of the clinical setting. This study can help inform the disability education of the genetic counseling

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profession and help genetic counselors provide quality service to disability community in a balanced and client-centered manner. As such, the tension between disability and genetic counseling profession will be reduced.

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Conflict of Interest: Authors Xueying Qiao and Michael Smith declare that they have no conflict of interest. Author Anne Greb is the director of JHMGPHG at Sarah Lawrence College.

Informed Consent: All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all participants for being included in the study. A waiver of written documentation of consent was obtained from the IRB at the Julia Dyckman Andrus Memorial.

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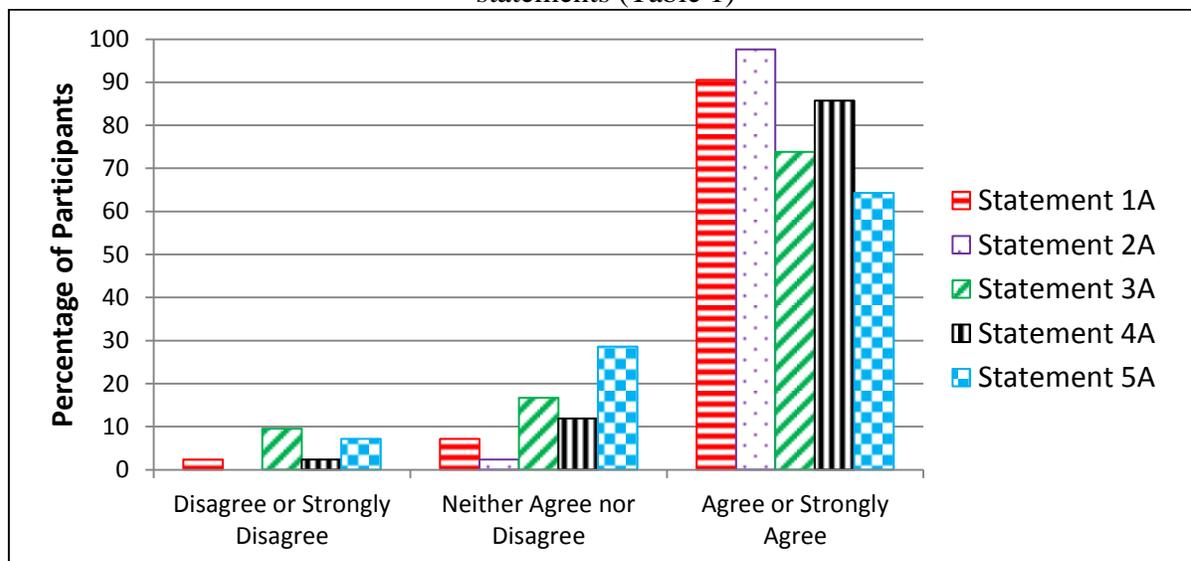
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Tables & Charts

Table 1: Set A statements and their rating rated by all participants (100%; N=42) using the 5-level Likert scale

| | Strongly Disagree (%) | Disagree (%) | Neither Agree Nor Disagree (%) | Agree (%) | Strongly Agree (%) | <i>Mean Score</i> |
|--|-----------------------|--------------|--------------------------------|-----------|--------------------|-------------------|
| Statement 1A: The Impact Program helped me enhance my understanding of the psychosocial issues facing families with a genetic diagnosis | | | | | | |
| Response to 1A | 0 | 2.38 | 7.14 | 61.90 | 28.57 | 4.17 |
| Statement 2A: The Impact Program helped me appreciate the diagnosis of Down syndrome from the perspective of families | | | | | | |
| Response to 2A | 0 | 0 | 2.38 | 45.24 | 52.38 | 4.50 |
| Statement 3A: The Impact Program helped me expand my knowledge about how medical professionals can be most helpful to individuals with Down syndrome and their families | | | | | | |
| Response to 3A | 0 | 9.52 | 16.67 | 54.76 | 19.05 | 3.83 |
| Statement 4A: The Impact Program helped me recognize the importance of understanding the lived experiences of people with various genetic/genomic conditions ("lived experience" is used to describe first-hand accounts and impressions of living as a member of a minority or oppressed group) | | | | | | |
| Response to 4A | 0 | 2.38 | 11.90 | 50.00 | 35.71 | 4.19 |
| Statement 5A: The Impact Program helped me increase my confidence providing genetic counseling services to individuals with Down syndrome and their families | | | | | | |
| Response to 5A | 0 | 7.14 | 28.57 | 42.86 | 21.43 | 3.79 |

Chart 1: Percentage of participants (100%; N=42) and their rating for Set A statements (Table 1)



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Table 2: Set B statements and their rating rated by participants who had provided genetic counseling services to individuals with a prenatal Down syndrome diagnosis (38%; N=16) using the 5-level Likert scale

| | Strongly Disagree (%) | Disagree (%) | Neither Agree Nor Disagree (%) | Agree (%) | Strongly Agree (%) | <i>Mean Score</i> |
|--|-----------------------|--------------|--------------------------------|-----------|--------------------|-------------------|
| Statement 1B: I was comfortable discussing the range of phenotypic expression associated with Down syndrome including the everyday lived experiences of families that have an individual with Down syndrome. (“lived experience” is used to describe first-hand accounts and impressions of living as a member of a minority or oppressed group) | | | | | | |
| Response to 1B | 0.00 | 0.00 | 6.25 | 68.75 | 25.00 | 4.19 |
| Statement 2B: I routinely offered patients the opportunity to speak with another family that has an individual with Down syndrome | | | | | | |
| Response to 2B | 0.00 | 25.00 | 43.75 | 31.25 | 0.00 | 3.06 |
| Statement 3B: I routinely offered patients a referral to a Down syndrome support group or other advocacy Organization | | | | | | |
| Response to 3B | 0.00 | 12.50 | 25.00 | 50.00 | 12.50 | 3.63 |
| Statement 4B: I routinely described my experience with the Impact Program when discussing the prenatal diagnosis of Down syndrome with patients | | | | | | |
| Response to 4B | 25.00 | 37.50 | 25.00 | 12.50 | 0.00 | 2.25 |

Chart 2: Percentage of participants who had provided genetic counseling services to individuals with a prenatal Down syndrome diagnosis (38%; N=16) and their rating for Set B statements (Table 2)

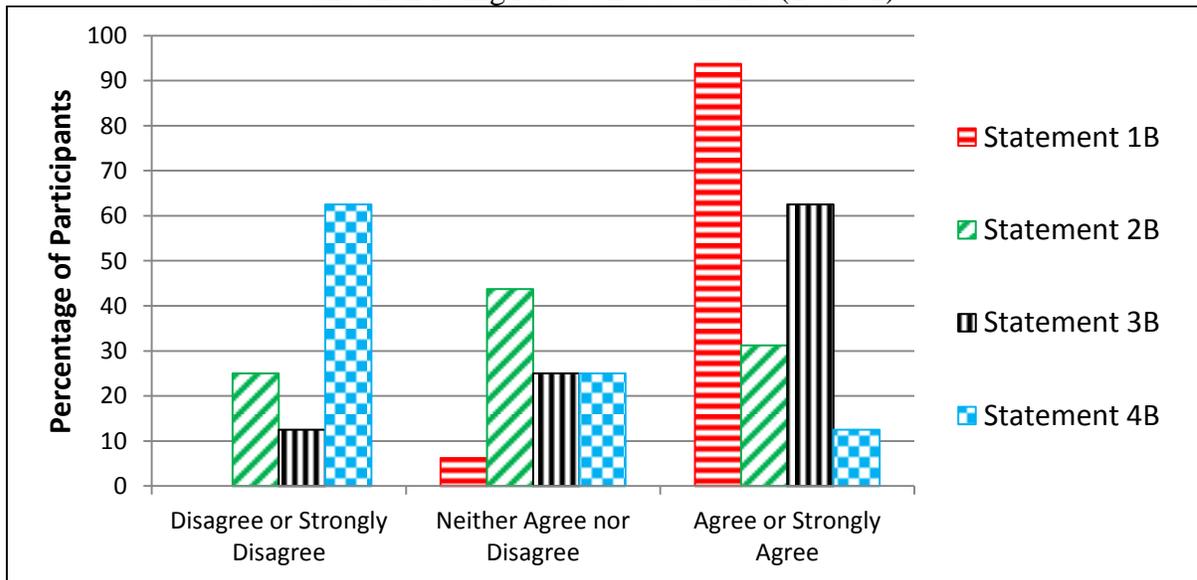


Table 3: Set C statements and their rating rated by participants who had provided genetic counseling services to individuals with a postnatal Down syndrome diagnosis (33%; N=14) using the 5-Level Likert scale

| | Strongly Disagree (%) | Disagree (%) | Neither agree nor disagree (%) | Agree (%) | Strongly Agree (%) | Mean Score |
|--|-----------------------|--------------|--------------------------------|-----------|--------------------|-------------|
| Statement 1C: I was comfortable discussing the range of phenotypic expression associated with Down syndrome | | | | | | |
| Response to 1C | 0.00 | 00.00 | 7.14 | 42.86 | 50.00 | 4.43 |
| Statement 2C: I was comfortable describing the everyday lived experiences of families that have an individual with Down syndrome ("lived experience" is used to describe first-hand accounts and impressions of living as a member of a minority or oppressed group) | | | | | | |
| Response to 2C | 0.00 | 0.00 | 21.43 | 64.29 | 14.29 | 3.93 |
| Statement 3C: I routinely offered patients the opportunity to speak with another family that has an individual with Down syndrome | | | | | | |
| Response to 3C | 7.14 | 28.57 | 35.71 | 28.57 | 0.00 | 2.86 |
| Statement 4C: I routinely offered patients a referral to a Down syndrome support group or other advocacy organization | | | | | | |
| Response to 4C | 0.00 | 0.00 | 21.43 | 50.00 | 28.57 | 4.07 |
| Statement 5C: I routinely described my experience with the Impact Program when discussing the postnatal diagnosis of Down syndrome | | | | | | |
| Response to 5C | 28.57 | 42.86 | 7.14 | 21.43 | 0.00 | 2.21 |

Chart 3: Percentage of participants who had provided genetic counseling services to individuals with a postnatal Down syndrome diagnosis (33%; N=14) and their rating for Set C statements (Table 3)

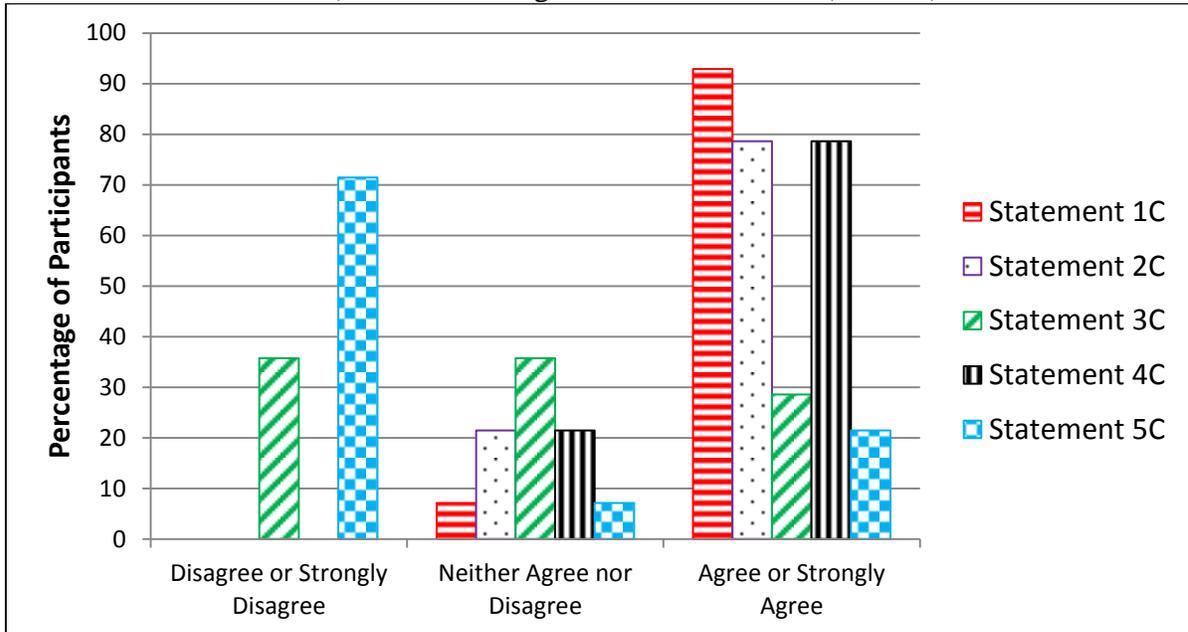


Table 4: Themes of Open-ended Questions A, B, C and their rating

| | |
|-------------|--|
| Question A: | Please describe your most memorable experience from your involvement in the Impact Program (Responses: 71%; N=30) |
| Theme 1A | How families felt about the diagnosis of Down syndrome and how other family members interacted with the child with Down syndrome (73%; N=22) |
| Theme 2A | A range of presentations and various severities of the symptoms associated with Down syndrome (27%; N=8) |
| Question B: | Please describe any other thoughts about how the Impact Program helped you shape your current practice (Responses: 52%; N=22) |
| Theme 1B | The ways through which the knowledge of disability was expanded (55%; N=12) |
| Theme 2B | The ways through which the psychosocial issues were recognized (27%; N=6) |
| Theme 3B | The ways through which the participants' confidence was increased (18%; N=4) |
| Question C: | Please provide any suggestions you have which may be helpful in improving the Impact Program (Responses: 50%; N=21) |
| Theme 1C | Both students and families should know their expectations prior to meeting each other (42%; N=9) |
| Theme 2C | The Impact Program should be more diversified (38%; N=8) |
| Theme 3C | A long term student-family relationship should be developed (10%; N=2) |