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## Disability Awareness Education and Implications for Genetic Counselor Training

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Disability Awareness Education and Implications for Genetic Counselor Training

by

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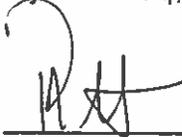
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Disability Awareness Education and Implications for Genetic Counselor Training

A

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Houston, Texas

May, 2021

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## Disability Awareness Education and Implications for Genetic Counselor Training

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The genetic counseling (GC) community has faced criticism concerning the duality of promoting patient autonomy while advocating for individuals with disabilities. Research suggests that focusing on the education of GC students could ensure GCs feel prepared to have conversations about disability, as well as strengthen the relationship with the disability community. This study aimed to evaluate the landscape of GC disability awareness education to identify gaps and strengths. The study also aimed to assess attitudes and perspectives of GCs and the disability community to identify content that should be included in GC student's disability awareness curriculum. GCs and members of the disability community completed an electronic survey with questions unique to each cohort. A total of 76 responses from the GC community and 596 responses from the disability community were analyzed. Most of the GC cohort reported receiving disability awareness training as a student (86%), however, variation was seen in the types of experiences offered by GC graduate programs. Most GC participants (71%) felt they received adequate knowledge of disability topics. However, a discrepancy was revealed when 89% of GC participants reported feeling comfortable discussing medical aspects of disability while only 65% reported feeling comfortable discussing social and lifestyle aspects of disability. Members of the disability community reported consistent perceptions which highlights a gap in GC training and indicates the need for additional guidance in creating disability awareness curriculum. For curriculum content recommendations, both GCs and the disability community agree on the importance of emphasizing four key aspects of disability

including medical, social and lifestyle, lived experience, and the disability rights movement. Participants of both cohorts stressed the inclusion of exposure to persons with disabilities, understanding of the lived experience of persons with disabilities, and familiarity with support and resources. The disability community identified additional content that they felt was important to be included such as empathy training, family hardships, and mental health. While many of these factors are already included in GC training, it emphasizes the need to address these factors in disability awareness curriculum. Results from this study highlight the importance of providing a comprehensive curriculum structure for GC programs and the need for the creation of an accessible disability awareness education toolkit to minimize potential challenges with standardization.

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## INTRODUCTION

Commentaries on the tenuous relationship between the genetic counseling community and the disability community are not novel. Genetic counselors (GCs) must often strike a balance between advocating for persons with disabilities and promoting reproductive freedom of their patients. Critics and past research have questioned whether GCs can accomplish both goals. Advancements of genetic technologies, particularly prenatal screening and diagnosis for genetic conditions, have intensified concerns throughout the disability community about the role of GC in these discussions (Dent et al., 2011; Hodgson & Weil, 2012; Madeo et al., 2011; Parens & Asch, 2003; Peterson, 2012).

Sanborn and Patterson summarized recurring themes to these critiques. First, GCs have a responsibility to develop a balanced concept of disability, in respects to both the challenges and rewards. Secondly, interactions between persons with disabilities and GCs would enhance such understanding, allowing GCs to develop an accurate concept of disability. Finally, in addition to practicing GCs, the governing bodies have a responsibility to address disability issues in an all-inclusive manner, specifically regarding disability awareness education of genetic counseling training programs (Sanborn & Patterson, 2014).

The Accreditation Council for Genetic Counseling (ACGC) is the governing body that establishes curriculum and practice based competencies (PBC) requirements for GC graduate programs. Currently, ACGC includes disability awareness, however, the language surrounding expectations of disability training is vague with only mentioned once (“disability awareness”) under the psychosocial instructional content section (Accreditation Council for Genetic Counseling, 2019b). This is in contrast to medical aspects of genetic conditions, which is emphasized in its own instructional content section titled Principles of Human Genetics/Genomics. Additionally, ACGC does reference disability in the PBC by including

GCs' ability to "recognize the importance of understanding the lived experiences of people with various genetic/genomic conditions" and "present balanced descriptions of lived experiences of people with various conditions" (Accreditation Council for Genetic Counseling, 2019a).

Given the role of GCs in a healthcare setting providing anticipatory guidance to families about diagnosis, prognosis, and manifestations of genetic conditions, the ACGC standards and PBC's place an appropriate level of emphasis on the medical aspects of disability. However, further guidance in aspects of disability beyond medical information and the necessary skills required to address these additional aspects of disability are lacking. In order to facilitate individual program autonomy in the interpretation and implementation of these standards, the language can be intentionally vague resulting in varied levels of emphasis, time, and training experiences in each program.

A 2014 study by Sanborn and Paterson described this variability in training approaches amongst GC graduate programs with respect to the type and depth of such training offered. Cumulative disability training/exposure during the course of a program ranged from as little as 10 hours up to 600 hours (Sanborn & Patterson, 2014). A majority (at least 60%) included attending support groups for persons with disabilities and their family members, attending a workshop with parents of a child with a disability, attending workshops on the nature and history of disability, and attending workshops on appropriate language surrounding disability (Sanborn & Patterson, 2014).

With demonstrated variability of disability awareness education, it is unsurprising that some graduates report dissatisfaction with the disability training they received in graduate school. In 1998, Teicher et al. revealed 30% of recent GC graduates believed the disability training they received was inadequate. Brown et al. in 2009, found similar results with 28% of recent GC graduates commenting on disability topics not being "adequately addressed." GC's

dissatisfaction with the depth of disability awareness training may result in some GC's feeling uncomfortable with persons with disabilities and feeling unprepared to have conversations about disability topics. Those who felt disability topics were not adequately addressed in their graduate training were noted to be significantly less comfortable interacting with persons with disabilities (Brown, 2009). Kline et.al found that only 26.2% of participants felt the training they received in their graduate program was "highly adequate" in preparation to counsel about disability immediately after graduation, indicating areas for improvement. Exercises

The GC community recognizes the need for increased disability education across GC graduate programs. A majority of GCs agree students don't receive an adequate level of disability awareness training and suggest standardizing curriculum to be the first step in increasing disability awareness within the GC community (Kline, 2012). Most GC program directors agree on the importance of disability training. Ninety four percent of program directors believed these skills are important for GCs to have (Sanborn & Patterson, 2014). Eighty five percent agree that skills to address disability should be added to ACGC core competencies (Sanborn & Patterson, 2014).

While there is a recognized need to improve disability awareness education throughout the GC community, no previous research has focused on what elements should be included. Sanborn & Patterson lay a foundation for areas to consider for standardization. They list "(i) knowledge, beliefs and attitudes of the disability community towards genetic counseling, (ii) the message patients are receiving from genetic counselors regarding disability (iii) genetic counselors' views on disability, and (iv) the most effective training methods to build awareness, sensitivity, and comfort level with disability" (Sanborn & Patterson, 2014).

Sanborn & Patterson continue by outlining content recommendations that could be applied to GC graduate programs disability awareness curriculum. Such content includes:

addressing misconceptions of disability, resources available to persons with disabilities and their family members/caregivers, laws protecting those with disabilities, social aspects of disability, and understanding the experience of persons with disabilities in order to provide accurate descriptions (Raz, 2005; Farrelly et al., 2012; Sanborn & Patterson, 2014). The authors highlight that interaction between GCs and the disability community should take place outside of a medical setting. This is thought to be “an effective way of building comfort in discussing disability and facilitating informed decision-making” (Sanborn & Patterson, 2014).

Incorporating the ideas presented by Sanborn & Patterson, four key aspects of disability can be identified as: medical aspects, social and lifestyle aspects, lived experience of persons with disabilities, and history of the disability rights movement. While there have been broad suggestions as to elements of disability awareness training, none have been specifically investigated for GCs. Many have commented on how this issue should be addressed, however, there is no agreement on what information is necessary to include in order to increase disability awareness education across GC graduate programs.

Due to reported variability in disability awareness education, some GC graduates feeling unsatisfied and unprepared to discuss disability upon graduation. The goal of this study was to evaluate and compare attitudes and perspectives towards disability education of GCs to members of the disability community. The results of this study have practice implications for the profession and provide a framework for training expectations to ensure future graduates possess the necessary skills to improve the quality of services provided to families and persons with disabilities.

## METHODS

### Study design

A cross-sectional survey evaluating attitudes and perceptions of disability awareness education for GCs was administered to two different cohorts: GCs and members of the disability community including persons with disabilities, their caregivers, and family members. Questions were designed by incorporating ideas from prior research on similar topics (Kline, 2012; Sanborn & Patterson, 2014) and the authors' previous experience. Responses were collected from August 2020 to December 2020. This study was approved by the Institutional Review Board at the University of Texas Health Science Center at Houston (HSC-MS-20-0668).

### Participants

GCs were recruited through electronic listservs of the National Society of Genetic Counselors (NSGC), the American Board of Genetic Counseling (ABGC), and the Texas Society of Genetic Counselors (TSGC). Members of these organizations received email invitations, which included a survey link to participate. GCs were eligible to participate if they graduated from an ACGC accredited GC program.

Members of the disability community were recruited through local and national membership listservs and/or the organization's social media pages. Participants were invited to participate via an electronic link to the survey. Partner organizations included: National Down Syndrome Congress, Muscular Dystrophy Association, Tuberous Sclerosis Alliance, University of Texas-Memorial Hermann Tuberous Sclerosis Center of Excellence, University of Texas Mitochondrial Center of Excellence, Camp PHEver, LoneStar LEND, Fetal Alcohol Spectrum Disorder Listserv, Celebration Company, and The Rise School of Houston. Individuals were eligible to participate if they were over the age of 18 and identified as a

person with a disability, a caregiver for a person with a disability, or a family member of a person with a disability. Individuals did not have to have prior experience with genetic counseling in order to be eligible.

### Instrumentation

An online data collection software and survey tool, Qualtrics, was used to create and administer the surveys to eligible participants in each cohort (Qualtrics, UT Provo). Definitions of genetic counseling, medical aspects of disability, social & lifestyle aspects of disability, and lived experiences of persons with disability were created in collaboration with the National Council on Disability (NCD) and displayed throughout the survey for reference (see Appendix).

The survey distributed to GCs contained several sections with a total of 50 questions. Participants were not required to answer every question. The survey contained questions about their personal experience with persons with disabilities, disability awareness education received while enrolled in a GC graduate program, and comfort level discussing disability topics as well as their perspectives standardizing disability curriculum, and demographics. Survey was piloted to five GCs before being finalized.

The survey distributed to the disability community cohort contained several sections including a screening questionnaire, disability awareness curriculum, and demographics. Participants were first directed to a series of screening questions (Figure 1), which identified individuals who have had a GC appointment provided by a GC where disability was discussed. Individuals who met these criteria were given an additional section that explored participants' GC appointment experience. This section focused on the GC's discussion of medical and social & lifestyle aspects of disability. Questions included: time spent discussing each disability aspect, the timing of these conversations (initial visit, time of diagnosis, follow-up

visit/interactions), and how knowledgeable the GC was about these aspects. Furthermore, questions assessed participants' overall impression of how persons with disabilities were represented and satisfaction with the GC's discussion about disability. This survey was reviewed and piloted by the National Council on Disability (NCD) before being finalized.

All participants in both cohorts were asked what fundamental content that should be included in GC students' disability awareness education. Since ACGC accreditation standards outline the necessary content for GC student curriculum for medical aspects of genetic conditions, this area was excluded from content suggestions. This section evaluated content that genetic counseling students should learn regarding social & lifestyle aspects of disability, methods for understanding the lived experience of persons with disabilities, and content that would familiarize students with historical and ethical narratives of the disability rights movement.

### Data Analysis

Due to the difference in the length of the survey and number of sections for each cohort, GC cohort participants were excluded from data analysis if survey completion was <50%. Participants from the disability community cohort were excluded from data analysis if survey completion was <70%, as the survey included skip logic to display appropriate questions for this cohort (Figure 1).

Data analysis was conducted using STATA statistical software (STATA Corp 13.1) with a Type I error rate set at  $p < 0.05$ . Descriptive statistics were used to report means and frequencies of categorical variables. Chi-square analyses were used to determine associations between variables and to compare responses between the two different cohorts. Free responses from participants were coded by first and last authors latent content analysis until

saturation was reached. Analysis of free responses was completed utilizing latent content analysis, a method which is designed to identify and interpret meaning in free response by isolating individual themes or concepts and organizing them in a way to describe or explain a phenomenon. Each response was independently categorized into one or more identified themes by the primary author LD (Bengtsson, 2016; Down-Wamboldt 1992). Thematic coding of each response was subsequently compared and agreed upon by authors LD and CW.

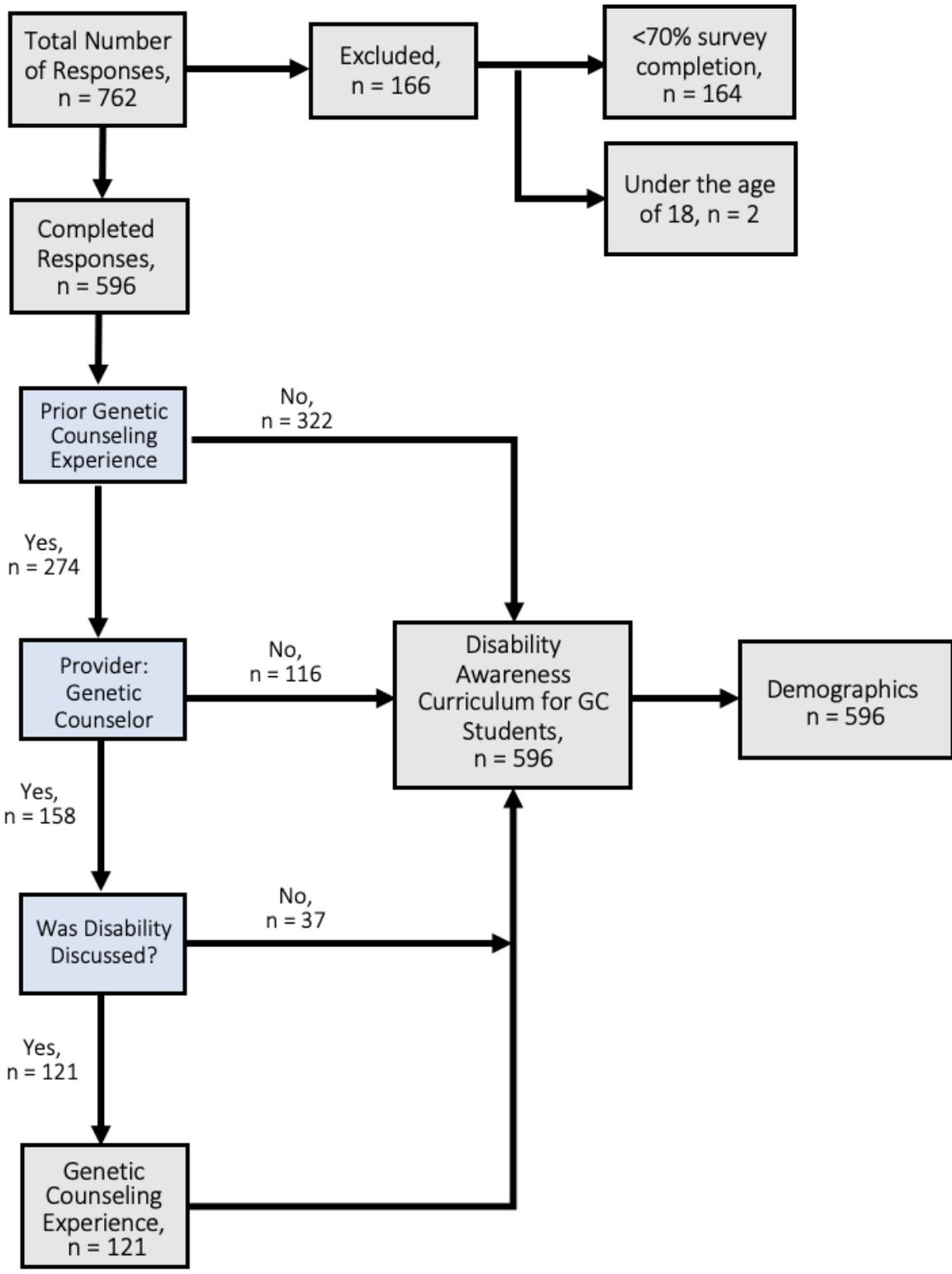


Figure 1: Disability cohort survey schematic

## RESULTS

### Demographics

Based on the number of NSGC, ABGC, and TSGC members, approximately 5,000 GCs received a link to participate in the GC cohort survey. There was a total of 102 responses, which correlates to a 2% response rate. After exclusion criteria was applied, 76 responses were included in data analysis with an estimated overall response rate of 1.5%. However, this response rate is likely underestimated as listserv recipients included individuals outside of the target sample (current GC students) and participants could be members of more than one of the organizations.

A majority of GC participants were female (73/75, 97%), non-Hispanic white (66/75, 88%), and graduated from a GC graduate program between the years of 2014-2020 (56/75, 75%). For “select all that apply” questions, a majority of participants selected their primary role as a patient-facing GC (66/82, 80%) and currently practice in one of the core specialties (general genetics, pediatrics, cancer, or prenatal) (82/121, 68%). There was variability in the region in which participants practice. Of the GC participants, eight identified as having a disability (Table 1). The GC cohort's demographics including gender, ethnicity, region of practice and primary role were compared to the 2020 NSGC Professional Status Survey (National Society of Genetic Counselors, 2020) and was found to be consistent with participant responses.

It is difficult to determine the number of individuals who were notified of the study in our disability cohort due to our recruitment method involving multiple partner organizations. A total of 762 surveys were submitted after exclusion criteria was applied, 596 responses were available for data analysis. A majority of the disability community cohort identified as non-Hispanic white (503/584, 86%), between the ages of 45-74 (386/586, 66%), have a 4-year or

professional degree (355/586, 61%), and identified as having a disability (450/596, 76%) (Table 2).

Table 1: GC participant demographics

	n (%)
<b>Gender (n = 75)</b>	
Female	73 (97%)
Male	2 (3%)
<b>Ethnicity (n = 75)</b>	
Caucasian/White	66 (88%)
Asian	5 (7%)
Hispanic/Latino	3 (4%)
Black/African American	1 (1%)
<b>Personal interactions (non-work related) with persons with disabilities (n = 75)*</b>	
Person with a disability	8
Parent and/or guardian	1
Sibling	8
Other relative	22
Friend	35
Other	9
Not applicable	14

<b>Year of graduation (n = 75)</b>	
1990-1997	4 (5%)
1998-2005	3 (4%)
2006-2013	12 (16%)
2014-2020	56 (75%)
<b>Region of Practice (n = 74)</b>	
Region 1: CT,MA,ME,NH,RI,VT,CN Maritime Provinces	5 (7%)
Region 2: DC,DE,MD,NJ,NY,PA,VA,WV, PR,VI,Quebec	9 (12%)
Region 3: AL,FL,GA,KY,LA,MS,NC,SC,TN	11 (15%)
Region 4: AR,IA,IL,IN,KS,MI,MN,MO,ND,NE,OH,OK,SD,WI, Ontario	17 (23%)
Region 5: AZ,CO,MT,NM,TX,UT,WY,Alberta, Manitoba, Sask	27 (36%)
Region 6: AK,CA,HI,ID,NV,OR,WA,British Columbia, Yukon	5 (7%)
<b>Primary role (n = 75)*</b>	
Patient facing GC	66
Laboratory GC/coordinator/support	5
Professor/instructor	5
GC training program director/ assistant director	2
Other	4
<b>Current area of specialization (n = 75)*</b>	
Cancer	23
Prenatal	17
Pediatrics	24
General Genetics	18

Preconception/Reproductive screening	5
Cardiology	6
Neurogenetics	10
Education; Public or Professional	1
Metabolic Diseases	4
Newborn Screen	4
Infertility, ART/IVF	1
Research	4
Genomic Profiling/Personal Genomics	1
Other	3

\* indicates question where multiple answers could be selected

Table 2: Disability community cohort demographics

	n (%)
<b>Ethnicity (n = 584)</b>	
Caucasian/White	503 (86%)
Black/African American	13 (2%)
Hispanic/Latino	35 (6%)
Asian	12 (2%)
Other	21 (4%)
<b>Age (n = 586)</b>	
18-24	33 (6%)
25-34	57 (10%)

35-44	85 (14%)
45-54	129 (22%)
55-64	145 (25%)
65-74	112 (19%)
75-84	24 (4%)
85+	1 (<1%)
<b>Level of education (n = 586)</b>	
Some high school	9 (2%)
High school graduate	100 (17%)
2-year degree	91 (15%)
4-year degree	192 (33%)
Professional degree	163 (28%)
Doctorate	31 (5%)
<b>Identification (n = 587)*</b>	
Person with a disability	450
Parent and/or guardian of a person with a disability	185
Sibling of a person with a disability	70
Relative of a person with a disability	63
Caregiver of a person with a disability	56
Other	25

\* indicates question where multiple answers could be selected

Landscape of GC Disability Awareness Education

A majority (65/76, 86%) of participants reported receiving disability awareness training as a GC student. Of these, nearly half (31/65, 48%) felt their GC graduate program placed a moderate level of emphasis on disability awareness education (Figure 2).

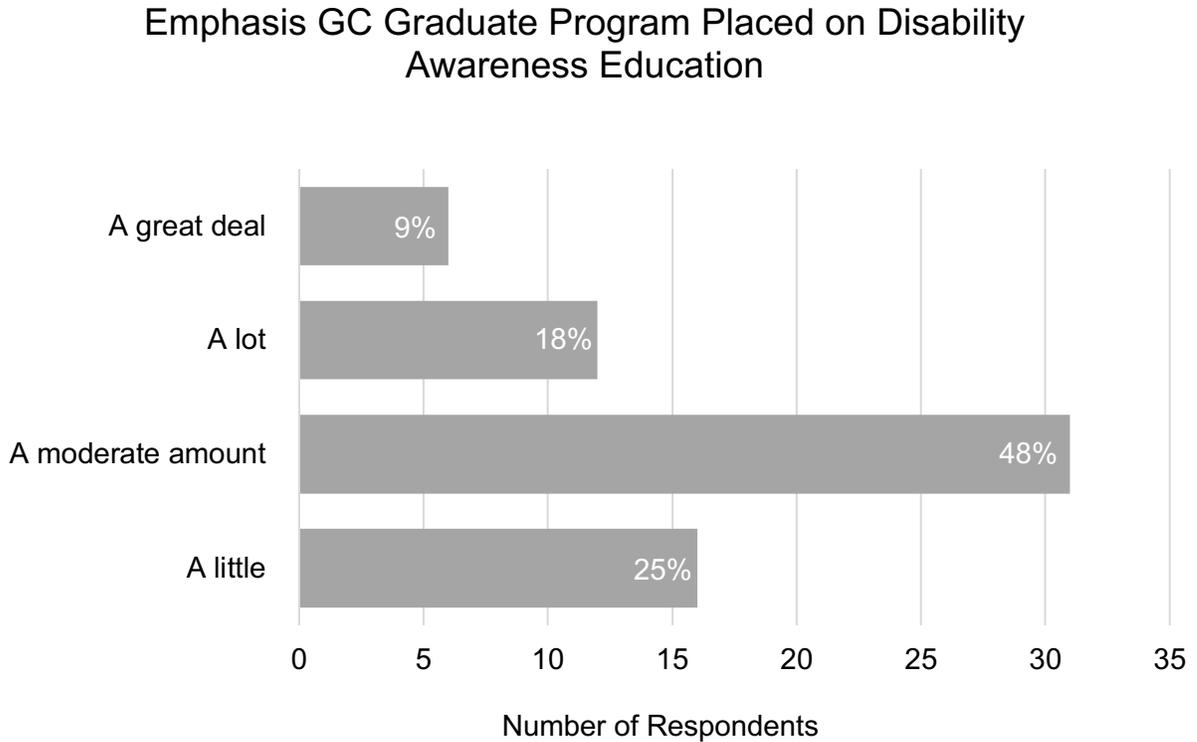


Figure 2: Emphasis GC Graduate Programs Placed on Disability Awareness Education

The most frequently reported disability awareness training experiences offered by GC graduate programs are summarized in Table 3. The two experiences participants felt most prepared them to discuss disability topics with patients were rotations or visits (with a person with a disability, a family member of a person with a disability, or a caregiver of a person with a disability) and exposure to a group home, specialized education facility, or community center for persons with disabilities. Furthermore, participants ranked class lectures focused on disability issues and assigned books as the two least valuable experiences.

Table 3: Types of experiences GC graduate programs offered

Type of Experience	n n = 75 (%)
Class lectures on disability issues	51 (68%)
Assigned books	49 (65%)
Rotation/visit	45 (60%)
Lecture from caregivers/family members	44 (59%)
Exposure to group home, specialized education facility, or community center	37 (49%)
Lecture from persons with disabilities	37 (49%)
Volunteering for community activities	34 (45%)
Outside training opportunities	23 (31%)
Assigned movies	22 (29%)
Presentations from national advocacy organizations	20 (27%)
Attending a support group for persons with disabilities	16 (21%)
Attending a support group for family members and/or caregivers	10 (13%)

Most participants (52/65, 80%) felt either extremely satisfied or somewhat satisfied with the disability awareness education they received as a GC student. A small portion (5/65, 8%) were neutral. In comparison, 12% (8/65) felt extremely dissatisfied or somewhat dissatisfied. Below is a quote from a participant explaining their dissatisfaction:

*“We had one or two lectures total on the topic of disability awareness and competency in counseling. A lot of what I know has been gleaned from direct access to individuals with disabilities and advocates on twitter. This shouldn't be the case.”*

Nearly 80% (58/75) agreed that disability awareness education should be standardized across GC graduate programs. There were differing opinions on who would be the best organization to provide these standards with 55% (41/75) of participants indicating ACGC would be the appropriate organization to define such standards. Below represent quotes from participants who agreed and disagreed with the standardization of GC disability awareness education:

*“Because all genetic counselors should be trained to interact and counsel patients/families with disabilities. I think we need to make sure that each program is getting adequate training and exposure to the lived experience of those we are training. I believe it should be very extensive and not just minimal deemed necessary.”*

*“While I believe all programs should have disability awareness and sensitivity training be part of the curriculum, HOW that training takes place would be difficult to standardize. If it were to be standardized, the standards would need to be quite general to allow the programs a lot of*

*flexibility in how they attain that standard. Opportunities are going to be different from program to program depending on the size of the program, location, etc.”*

Additional responses echoed the need for additional guidance in creating these standards to ensure well-rounded graduates prepared to discuss all aspects of disability with patients but highlighted the difficulty of standardizing this across all programs given the variability in the emphasis, location, and access to resources each program may have.

#### Disability Community Thoughts on GC Disability Awareness Education

This section of the survey focused on the four key aspects of disability: medical aspects, social and lifestyle aspects, lived experience of persons with disabilities, and history of the disability rights movement. Most of the disability community (96%) agreed that each of the key aspects of disability is important for GC students to learn. When asked to rank these aspects in the level of importance, the highest-rated area was medical aspects of disability, followed by social and lifestyle aspects, lived experience of persons with disabilities, and the history of the disability rights movement.

Out of a list of eleven social and lifestyle aspects, the disability community ranked support and resources, work, relationships, family planning, financial considerations, and school as the most important social and lifestyle aspects GC students should learn (Table 4). For GC students to understand the lived experience of persons with disabilities, participants ranked exposure to everyday life as the most meaningful method (Table 5). The disability community cohort agreed that The Genetic Information Nondiscrimination Act (GINA) (433/596, 73%), the Americans with Disabilities Act (ADA) (544/596, 91%), and Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCAA) (374/596, 63%) was important legislation for GC students to learn. Furthermore, participants mentioned the importance of the

Affordable Care Act (ACA) and the Individuals with Disabilities Education Act (IDEA). Free-response answers about the historical and ethical narratives of the disability rights movement were categorized into content themes which included: historical timeline and overview of disability, legislative history, and current advocacy efforts.

Table 4: Disability community cohort opinions on the importance of social and lifestyle aspects

	n
Social & Lifestyle Aspects	<i>n</i> = 4,424 (%)
Support and resources	511 (12%)
Work	490 (11%)
Relationships	475 (11%)
Family planning	462 (10%)
Financial considerations	458 (10%)
School	451 (10%)
Transportation	387 (9%)
Impact of stereotypes on healthcare/healthcare disparity	387 (9%)
Community activities	373 (8%)
Housing	371 (8%)
Stigmatization	364 (8%)
Other	82 (2%)

Table 5: Most to least meaningful method for GC students to understand the lived experience of persons with disabilities

Rank Order	Disability Community Cohort	GC Cohort
1	Exposure to everyday life	Exposure to everyday life
2	Lecture from persons with disabilities	Exposure to group home, specialized education facility, or community center for persons with disabilities
3	Lecture from caregivers/family members	Lecture from persons with disabilities
4	Exposure to group home, specialized education facility, or community center for persons with disabilities	Lecture from caregivers/family members
5	Presentations from national advocacy organizations or disability organizations	Presentations from national advocacy organizations or disability organizations

Data from free-response answers were utilized to create overarching themes pertaining to additional curriculum content that participants proposed be added to GC student’s disability awareness training. The most common themes included empathy training, exposure to persons with disabilities, exposure to the lived experience of persons with disabilities, family hardships, mental health, sexual health, and resources (Table 6). Below are quotes from participants for each of the additional curriculum content themes.

Table 6: Excerpts and thematic analysis of free responses. Two hundred twenty-four participants provided comments that were often classified within multiple themes. The number of comments are represented by “n.”

Themes	Participant responses (n = 224)
Empathy (n = 31)	“Training in compassion. I found they were interested more in biology than the human experience of someone living with the disability. Helping with resources might show the patient how to cope.”
	“How to be compassionate when dealing with disabled individuals and their family members.”
Exposure to Persons with Disabilities (n = 30)	“As mentioned before, I think giving them exposure to people who live with disabilities can help reduce stigmatization and ensure that students will ultimately treat their disabled patients just like anyone else.”
	“Adding more interaction from people with disabilities into curriculum. Textbooks and lessons do not do justice what people with disabilities face, their stories and what they experience gives a far better understanding. It’s important to teach able-bodied students that pity or condescension towards people with disabilities CANNOT be tolerated anywhere in the world. People with disabilities need to be humanized more in your curriculum.”
Exposure to the Lived Experience of Persons with Disabilities (n = 25)	“Partnering with a disabled person to fully understand obstacles to daily living and tasks.”
	“Not only is a thorough knowledge and understanding of genetics essential, but also a thorough knowledge and understanding of what it’s like to live with a disability.”
Family Hardships (n = 7)	“A disability doesn't only effect the person diagnosed; it is something the entire family will live with on a daily basis. Counselors should learn about the impacts of disability on the family, and about resources and strategies for dealing with disability as a family unit.”
	“Strain on parental relationships. How siblings deal with having a brother/sister with a disability. For example, many siblings go into fields associated with the disability of their sibling, they learn empathy, they live more independent lives.”
Mental Health (n = 30)	“How challenging medically and emotionally it can be while in search of a diagnosis. Sometimes I pray my condition shows up in genetic testing but

	then another part of does not want it to show up, so my dad or mom does not feel responsible for passing it on to me.”
	“Long term psychological effects of the disability itself and the loss of community due to lack of accessibility and empathy from the physically able.”
Sexual Health (n = 7)	“Understanding sexuality and persons with disabilities, reproduction.”
Resources (n = 32)	“Resources, as many community and medical resources as possible. Any information on advocacy groups. Navigating a brand-new disability is daunting, heartbreaking and overwhelming. Families with no history or knowledge of genetic disorders within their families are often left after a genetics appointment to figure it all out alone.”
	“Referral to community resources, hospital social workers, etc. that can help patients solve the problems they face. In particular, how to identify the best resources and time to offer those resources based on the individual patient/family needs. Don’t hand someone a list of 50+ agencies that might be of help. Discuss the 2 that are likely to be of help. Our family has never had a genetics counselor offer any information beyond the exact test details....”

Cohort Comparisons- Thoughts on GC Disability Awareness Education

Participants in both cohorts were asked to agree, disagree, or neither agree/disagree with the importance of the four key aspects of disability. There were similarities in the responses between both cohorts with 97% of GCs agreeing with medical aspect, 99% with social & lifestyle aspects, 97% with the lived experience of persons with disabilities, and 97% with the history of the disability rights movement being important. Similarly, 96% of the disability cohort agree medical aspects were important, 96% with social & lifestyle aspects, 98% with the lived experience of persons with disabilities, 94% with the history of the disability rights movement. However, when asked to rank the importance of these key aspects, responses slightly varied between the groups (Table 7). Both cohorts agreed that medical aspects of disability was the most important aspect and history of the disability rights

movement was the least important aspect. The disability community cohort ranked social and lifestyle aspects as second most important, followed by the lived experience of persons with disabilities. Whereas, the GC community ranked the lived experience of persons with disabilities as the second most important aspect followed social and lifestyle aspects.

Table 7: Most to least important key aspect of disability for GC students to learn

Rank Order	Disability Community Cohort (n = 452)	GC Cohort (n = 70)
1	Medical aspects of disability (191)	Medical aspects of disability (32)
2	Social & Lifestyle aspects of disability (178)	Lived experience of persons with disabilities (17)
3	Lived experience of persons with disabilities (136)	Social & Lifestyle aspects of disability (38)
4	History of disability rights movements (366)	History of disability rights movements (54)

When examining different social and lifestyle aspects that are most important for GC students to understand, both groups agreed that support and resources was the most important area for GC students to receive training in. The disability community then listed work, relationships, family planning, financial considerations, and school as the next important social and lifestyle aspects. In contrast, the GC cohort rated impact of stereotypes on

healthcare disparities, school, stigmatization, and family planning as the following most important areas.

Table 8: Five most valuable social and lifestyle aspects GC students should learn

Rank Order	Disability Community Cohort (n = 595)	GC Cohort (n = 76)
1	Support and resources (402)	Support and resources (72)
2	Work (367)	Impact of stereotypes on healthcare/healthcare disparity (53)
3	Relationships (360)	School (45)
4	Family planning (302)	Stigmatization (41)
5	Financial considerations (290)	Family planning (37)

For GC students to understand the lived experience of persons with disabilities, both cohorts ranked exposure to everyday life as the most meaningful method and presentations from national advocacy organizations or disability organizations as the least meaningful method. Differences between the two groups were seen between rankings 2-4 (Table 5).

The final key aspect of disability, history of the disability rights movement, both cohorts reported similar opinions. Both cohorts suggested the following pieces of legislation should be included in curriculum: GINA, ADA, and PPDCAA legislation. Additionally, both cohorts

reported that the ACA and IDEA should be included with the legislation content. Proposed content from both groups for the history of the disability rights movement included a historical timeline and overview of disability, legislative history pertaining to disability rights, and current advocacy efforts.

Within the historical timeline and overview of disability, content ideas included discrimination and social bias, the eugenics movement, sterilization, institutionalization, and the ethics of new genetic technologies. For the legislative history of disability rights, participants reported discussing impacts and limitations focusing on the ADA, case studies, and impacts of universal design on accessibility. The following quotes emphasize the perceived importance of these topics from participants from the GC cohort:

*“I think to not only learn about policies/laws in place that seek to benefit people with disabilities and the history of discrimination that people with disabilities have faced, but also to hear first-hand from people with disabilities and their families about how, historically and currently, policies may not be benefiting them to the fullest potential. It's important to learn about the hurdles that these families have and ways they think things could be improved.”*

*“Discussing the different models/framework of disability (i.e., social model vs. medical model) and the social climate that created these models. Much like the civil rights era, the Disability community had their own civil rights movement and it's important to put that historical framework into context for students.”*

Finally, the cohorts shared similar ideas for additional content that be added to GC student's disability awareness training. The disability community proposed empathy training, exposure to persons with disabilities, exposure to the lived experience of persons with

disabilities, family hardships, mental health, sexual health, and resources. While the GC community reported exposure to persons with disabilities, exposure to the lived experience of persons with disabilities, and resources.

### Genetic Counseling Experience

Based on GC participant's disability awareness training as a GC student, 71% (46/65) felt they acquired sufficient knowledge to counseling patients about disability topics. Whereas 18% (12/65) felt they did not gain enough knowledge as a student. A majority (58/65, 89%) of participants perceived being comfortable discussing medical aspects of disability in a patient setting. In comparison, only 65% (42/65) feel comfortable discussing social aspects of disability. The differences seen in comfort levels between medical and social aspects of disability are exemplified in one participant's response:

*"I just don't feel knowledgeable enough to have informed conversations about the social aspects of disability. I feel much better equipped to discuss medical aspects."*

Only 20% (121/596) of the disability community cohort reported having a genetic counseling appointment provided by a GC where disability was discussed. A majority (85/120, 71%) of participants thought their GC was either extremely knowledgeable or very knowledgeable about medical aspects of disability. For social and lifestyle aspects, nearly half (57/116, 49%) believed their GC was extremely knowledgeable or very knowledgeable.

## DISCUSSION

Conversations regarding variability of disability awareness education for GC students have dated back to 1998, however, little progress has been made in providing clear curriculum guidance to graduate programs. Graduates enter the workforce with a diverse mixture of awareness of disability issues and preparedness to counsel patients about all aspects of disability. This study intentionally included voices of both the GC community and the disability community to create curriculum considerations that would incorporate the viewpoints of both providers and patients. The results from this study will provide a collaborative disability awareness education scaffold for GC graduate programs.

### Current Landscape of Genetic Counseling Disability Awareness Training

Most GC participants (65/76, 86%) reported receiving some form of disability awareness training as a GC graduate student. Of those who indicated they did not receive disability awareness training (11/76, 14%), the years in which these participants graduate from their GC graduate program vary immensely (1991-2020). A majority (52/65, 80%) of GC participants felt satisfied with the disability awareness training they received as a GC graduate student. Previous research reported approximately 30% of GC's were dissatisfied with such training (Brown, 2009; Teicher et al., 1998). The current study shows that dissatisfaction rates have fallen dramatically to 12%. This suggests that disability training may have improved in the last decade. However, only 27% of participants reported their GC graduate program had an emphasis on such training (Figure 2). These results indicate that satisfaction of disability awareness training has increased while the depth of such training remains minimal.

A majority of participants agreed that they acquired sufficient knowledge to counsel patients about disability topics. Yet, discrepancies were observed when asked specifically

about comfort levels discussing medical versus social and lifestyles aspects of disability. Based on current ACGC accreditation standardization, there is a focus on students understanding the medical aspects of genetic conditions. This would explain why most participants reported feeling more equipped to discuss medical aspects of disability. However, when assessing comfortability discussing social and lifestyles aspects, we see a decrease in comfort level by 25%.

These results were consistent with perceptions from the disability community. When asked how knowledgeable their GC was about medical aspects of disability, most reported that their GC was knowledgeable about medical aspects. However, GCs were reported to lack the same level of knowledge about social and lifestyle aspects of disability. This may imply that even though GCs perceive receiving adequate knowledge of disability awareness topics, they may feel uncomfortable counseling about all the various aspects of disability in a clinical setting.

The current study revealed variation in the types of disability awareness education methods offered by GC graduate programs and discrepancies in how participants felt about these experiences. A majority of participants (at least 60%) noted that their graduate program offered rotations or visits (with a person with a disability, a family member of a person with a disability, or a caregiver of a person with a disability), class lectures focused on disability issues, and assigned books. Yet, participants ranked class lectures and assigned books as the two least valuable experiences. This suggests that most methods used by GC graduate programs may not be the most effective approach to prepare students to discuss disability topics. It is unknown what the didactic lectures contained in terms of content and who provided these lectures, however, with the wide variation demonstrated by participants responses, it is clear that there are unmet student needs in disability awareness education. Therefore,

graduate programs may need guidance on what content and delivery methods are most effective at preparing students to understand disability topics.

### Suggestions for GC Student Disability Awareness Education Curriculum

This study highlighted four key aspects of disability: medical aspects, social and lifestyle aspects, lived experience of persons with disabilities, and history of the disability rights movement. The GC and disability community both agreed on the importance of all four aspects, suggesting that each should be included in GC student's disability awareness education. Since patients are referred to genetic counseling to discuss a diagnosis, family history, or risks of genetic conditions, it was unsurprising that medical aspects of disability was ranked the most important aspect for GC students to understand. The role of GCs is to educate patients on the medical implications of genetic conditions, thus requiring comprehensive knowledge of this aspect. The importance of medical aspects is reflected the ACGC accreditation standards and is currently applied in all GC graduate program curriculum. The least important aspect reported by both cohorts was the history of the disability rights movement. While it was remarked that GC students should learn about this aspect for perspective, this information is less likely to be discussed with patients in a clinical setting.

A difference in opinion between the two groups lies between the importance of social and lifestyles aspects and the lived experience of persons with disabilities. This dichotomy could be explained by the viewpoint each cohort has about the role of a GC. The disability community ranked social and lifestyle aspect as the second most important aspect for GC students to understand. This patient perspective could indicate that they desire GCs to have thorough knowledge about social and lifestyle factors to be able to discuss with patients. For example, what school and work may look like for someone with a certain genetic condition or what community activities and supports are available to patients and family members. Social

and lifestyle aspects of disability are more tangible concepts, compared to the lived experience of persons with disabilities which may vary immensely even within those with the same condition.

On the other hand, GCs ranked the lived experience of persons with disabilities as the second most important aspect for students to understand and receive training on. GCs may view providing an accurate portrayal of what it will be like to live with a specific genetic condition as a higher priority. In order to discuss the lived experience with patients, GCs feel that having firsthand experience and the opportunity to hear from persons with disabilities about their experience is most beneficial. Overall, these results may be explained by a perceived higher level of importance in a clinical setting, implying a higher level of importance for GC students to understand which varied slightly between a patient versus provider perspective.

Content suggestions and methods of training approaches were compiled from the two cohorts for each of the key aspects of disability. Social and lifestyle aspects was shown to have the least amount of agreeance in priority between the two cohorts (Table 8). Due to the role of a GC, it's unsurprising that the viewpoints of patients and providers ranked support and resources as the most important social and lifestyle factor for GC students to learn. From a provider standpoint, it may not be feasible to talk about all the different social and lifestyle aspects of disability in a single session due to time constraints, logistical considerations, or prioritization of other content in the session. Due to this, GCs should be comfortable finding and providing support and resources for patients available outside the constraints of a session. This could explain why patients ranked this higher than GCs, highlighting the important of training students to be able to locate and disseminate these resources.

Following support and resources, a difference in priority of important social and lifestyle factors were observed between the cohorts. This difference could again be explained by the different perspectives between patients and providers and what each group identify as most important. For example, GCs ranked impacts of stereotypes on healthcare/ healthcare disparities as the second most important social and lifestyle factor. This is logical, given the role of a medical provider and understanding the effects of disability in the field of which they practice. Whereas to patients, this factor may not be as present in daily activities, therefore, patients may find this less important for GC students to learn compared to factors such as work, relationships, family planning, or financial considerations.

Similar trends were observed when evaluating the most meaningful methods for GC students to understand the lived experience of persons with disabilities. These methods included: exposure to everyday life, exposure to group home, specialized education facility, or community center for persons with disabilities, lectures from persons with disabilities, lectures from family members/caregivers, and presentations from national advocacy organizations or disability organizations (Table 5). Both cohorts ranked exposure to everyday life as the most meaningful approach. This suggests the need for rotations or exposure to persons with a disability, family member, or caregivers. For those in the GC cohort, rotations and visits were ranked the highest in terms of being the most valuable experience in their graduate training that prepared them to discuss disability topics. From a patient perspective, ranking exposure to everyday life as the most meaningful method may represent the desire for providers to develop a balanced view of disability to the level of daily living.

Following exposure to everyday life, the GC participants ranked exposure to group home, specialized education facility, or community center for persons with disabilities as the second most valuable method. This could be due to GCs feeling a responsibility to present not

only an accurate description of disability, but also useful community resources. By visiting specialized centers, schools, or facilities, GC students could gain not only an understanding of the lived experience but have a resource to direct patients and family members/caregivers to.

In contrast, the disability community ranked a class lecture from persons with disabilities as the second most meaningful method. From a patient perspective, this could signify the importance of patients wanting providers to have firsthand interactions with persons with disabilities in order to formulate an accurate understanding of disability. Thus, amplifying the “nothing about us without us” mantra. By incorporating exposure to everyday life of persons with disabilities in GC student curriculum, this will make improvements towards overcoming the recurring critique for GCs to have interactions with persons with disabilities in order to develop an accurate concept of disability (Sanborn & Patterson, 2014).

Both cohorts ranked learning about the history of the disability rights movement as the least important aspect of disability awareness education. However, participants suggested that students should learn about the historical timeline and overview of disability. Learning about the history of the disability rights movement may help GCs connect with patients by understanding how society views disability and provide students with context of the inherent bias that persons with disability face. With the historical significance acknowledged by both groups, the lower rank of importance most likely reflects the lower likelihood of this being discussed in a clinical setting.

Both the GC and disability community participants felt similarly about content that should be included in disability awareness education including exposure to persons with disabilities, exposure to the lived experience of persons with disabilities, and being familiar with available support and resources. The disability community highlighted additional content that they felt should be included in ideal curriculum. Other factors specially mentioned by the

disability community included empathy training, family hardships, mental health, and sexual health. While many of these areas are already included in various aspects of GC training, it highlights the need to emphasize these factors when formulating GC student disability awareness education - especially those that are of importance to persons with disability.

### Standardization

Previous literature suggests that the next step in increasing disability awareness in the GC community is to create standardized GC student curriculum. This corresponds to recurring critiques that the governing bodies have a responsibility to address disability issues in an all-inclusive manner, specifically regarding disability awareness education of genetic counseling training programs (Sanborn & Patterson, 2014). A majority of the GC cohort (77%) agreed that disability awareness education should be standardized across GC graduate programs. However, this result may be misleading. Based on free responses, it can be inferred that most were hesitant on the idea of *standardization* but agreed that general guidance on GC student disability awareness curriculum is necessary.

Hesitation regarding standardization implied from free responses may be explained by barriers cited by the GC cohort. Many note that resources vary between GC graduate programs and access to persons with disabilities may be more difficult to achieve based on location. Thus, it is feared that some programs may not be able to meet detailed standards. Some responses conveyed concern over standardization affecting the uniqueness and flexibility of program disability awareness training. Due to these factors, it is not surprising that many in the GC cohort felt that ACGC may not be the appropriate organization to define disability awareness education standards. While standardization would help ensure that GC

students are receiving training that best prepares them to discuss disability topics in clinic, the unique barriers to individual programs could possibly outweigh such efforts.

Given these findings, we propose general guidelines for disability awareness training to include the four key aspects of disability: medical aspects, social and lifestyle aspects, lived experience of persons with disabilities, and history of the disability rights movement. It is recommended that graduate programs consider exposure to everyday life through rotations or visits with a person with a disability, family member or caregiver of a person with a disability as a way for GC students to obtain practical experience that best prepares them to counsel patients and their families about the various aspects of disability. To further reinforce these concepts, programs should focus on empathy training, family hardships, mental health, and sexual health as recommended by members of the disability community.

#### Study Strengths and Limitations

To our knowledge, the current study has one of the largest disability community samples in examining perspectives of curriculum content for GC student's disability awareness education. As a collective, the disability community cohort represents a narrow spectrum of disability with most participants identify as having a muscular dystrophy condition. Despite this limitation, each participant's experience and perspective is unique which contributes to an overall strength of the study.

The GC cohort had a significantly smaller sample size compared to the disability community cohort. This could indicate a response bias based those GCs who elected to participate. Those who participated could have a higher interest in disability awareness training or disability topics. Furthermore, a response bias could be contributed to GC participants who had higher satisfaction with the disability awareness training they received as

a GC student. Those who declined to participate may not have been satisfied with the training they received or are not comfortable with disability topics. Additionally, a strength of the study is incorporating and comparing the viewpoints of patient versus provider. This allows for comprehensive study results which creates a beneficial and important contribution to this area of research.

### Practice Implications

In general, more tangible training experiences were found to have more perceived value than didactic experiences. For example, patient panels and opportunities to create relationships within the disability community were recommended by members of the disability community. By having persons with disabilities participate in the education of GC students, this would make progress towards alleviating the tensions between the two communities. Recent calls for diversity within the profession should also include members of the disability community and their unique perspectives. Active and intentional recruitment and inclusion of these individuals is critical in amplifying these voices in classrooms, committees, and the profession as a whole. Based on the results of our survey, it was found that some level of guidance on GC student disability awareness curriculum is needed and desired. However, standardization through an organization like ACGC could potentially heighten barriers graduate programs face. Therefore, this study highlights the need for the creation of a toolkit that provides meaningful resources that are accessible to all GC graduate programs.

## APPENDIX

### Definitions

Medical aspects of disability: Discussion focuses on the medical condition and symptoms that resulted from impairments in body functions or structures; often seen as a deficiency or abnormality. Discussions of these topics include symptoms, course of disease, and medical treatments.

Social & Lifestyle aspects of disability: Discussion focuses on social and lifestyle factors such as being a student, worker, friend, community member, patient, spouse, partner, or parent. It may also include a discussion of engaging in social activities like using public transportation, getting a job, receiving adequate health care, having relationships, and enjoying other day-to-day activities.

Lived experience of persons with disabilities: Firsthand experience and the opportunity to hear about what it is like to live with a disability. Knowledge is gained through the familiarity of the lived experience of people with disabilities AND the ability to refer parents to those with familiarity with disabilities for more information.

Genetic Counseling: is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources and research.

- Counseling to promote informed choices and adaptation to the risk or condition

Source: Resta, R., Biesecker, B. B., Bennett, R. L., Blum, S., Hahn, S. E., Strecker, M. N., & Williams, J. L. (2006). A new definition of genetic counseling: National Society of Genetic Counselors' Task Force report. *Journal of Genetic Counseling*, 15(2), 77–83.

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Disability: According to the Americans with Disabilities Act, the term “disability” means, with respect to an individual—

- a physical or mental impairment that substantially limits one or more major life activities of such individual;
- a record of such an impairment; or
- being regarded as having such an impairment

Source: Section 12102 of the Americans with Disabilities Act

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