An Exploration of Disability Training Opportunities in Nationally Accredited Genetic Counseling Programs and the Implications of Disability Training on Reported Student Preparedness in Working With Individuals with Disabilities and Their Families

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Overview

- Who Are Genetic Counselors?
  - What are their roles in health care?
  - What specialties do they work in?
- Components of a Genetic Counseling Program
- The Importance of Disability Training in Genetic Counseling Programs
  - Problems in not receiving disability training
- Disability Training Options
- Future Implications
- Conclusion
What Do Genetic Counselors Do?

- Interprets medical and family histories
- Educates families on health and genetics
- Provides emotional support and counseling to families
- Supports family decision making
- Provides medical, community and social resources
- Creates parent educational materials
- Explains the newborn screening process

Genetic Counselor Specialty Areas

- 35% Prenatal
- 24% Cancer Genetics
- 29% Pediatrics
- 12% Other Specialties

Results are according to the 2014 NSGCE Professional Status Survey
Specialties in Genetic Counseling

- Prenatal and Preconception – for women who are pregnant or thinking about becoming pregnant and want to understand how inherited conditions could affect their family
- Pediatric – for children and their family members to understand genetic or inherited conditions
- Cancer – for patients with cancer or their family members to understand their risk of developing particular cancers (i.e., breast cancer and the BRCA 1 or 2 gene mutation) and to learn about appropriate screening options
- Cardiovascular – for patients with diseases of the heart or circulatory system and their family members
- Neurology – for patients with diseases of the brain and nervous system and their family members
- Research – Research in the advancement of genetic counseling care, applications, and frameworks
- And more!

National Society of Genetic Counselors
Genetic Counseling Training Program Outline

- Acceptance into an accredited genetic counseling program
- Course work
- Clinical rotations
- Internship/fellowship
- Research competency
- Community involvement
- Certification through the American Board of Genetic Counseling
Are Genetic Counseling Students Trained to Work With Individuals with Disabilities?

- Of the current 36 accredited genetic counseling programs, only 18 include disability training in their curriculum.
- 19 host institutions offer LEND.
- 12 of the 19 programs that offer LEND also include disability training in their curriculum.
Why Disability Training is Important for Genetic Counselors

- Prepares genetic counselors with working with individuals with disabilities and their families
- Introduces cultural perspectives, which is critical in working with patients of other cultures
- Identifies strategies on how to implement interdisciplinary care to enhance service delivery for patients and families
- Through LEND, genetic counseling students “feel empowered and prepared in counseling individuals and families with disabilities”
The Problem With Not Providing Disability Training

- Less preparedness in working with families and individuals with disabilities
- Less training on cultural competency
- Less training in family-centered care
- Less training in interdisciplinary practices
Disability Training Options (Curriculum Embedded)

- Disability training opportunities offered through programs include:
  - Volunteering in the community with families of children with disabilities (7/18)
  - Exploring the psychosocial and sociological impact of having a child with disabilities (9/18)
  - Meeting with parent support or advocacy groups (4/18)
  - Pairing students with families of children with disabilities (3/18)
  - Disability awareness courses (8/18)
  - Cultural competency course requirements (3/18)
Disability Training Options (External)

- LEND programs are available in 19 of the 36 host institutions
  - Some schools provide LEND training directly through their UCEDD, others have LEND through university hospitals or health care centers
- The National Society for Genetic Counselors offers a cultural competency course for both genetic counseling students and current genetic counselors
- AUCD webinars and resources
Future Implications

- By creating opportunities for genetic counseling students to have access to disability training, future genetic counselors will:
  - Have increased knowledge of how to effectively work with individuals with disabilities and their families
  - Have increased preparation for their careers
  - Improve the quality of services provided for families
  - Have increased cultural competence
  - Promote the creation of interdisciplinary teams to offer better services for patients and their families
Conclusions

- Disability training should be standardized in genetic counseling curriculums to ensure all students are prepared in working with families and individuals with disabilities.
- Experiences in interacting or working with families of children with disabilities enhances family-centeredness and cultural competence for future practices.
- Interdisciplinary care promotes a better quality of services for families seeking genetic counseling.
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