

**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**



**ROSALIE LYONS
2018 LEND TRAINEE
UCONN UCEDD**

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

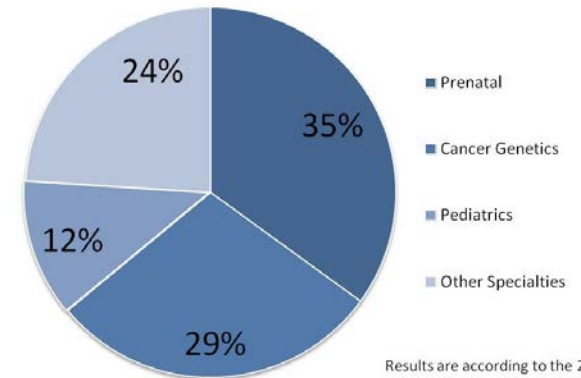
What Do Genetic Counselors Do?



- 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



Results are according to the 2014 NSGC 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 (ie: 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!

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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CT LEND

**LEADERSHIP EDUCATION
IN NEURODEVELOPMENTAL
AND RELATED DISABILITIES**

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