Genetic Counselors' Perspectives on Disability Training and Experience

Emily Brown, Kira Apse, Erica Sanborn, Heather Peters, MaryAnn Whalen Campion, Jeff Milunsky

Boston University School of Medicine, Boston, Massachusetts

Genetic counselors often encounter individuals with some degree of physical or mental disability in both clinical and research practices. It is imperative that genetic counselors are appropriately trained in the field of disability awareness and have adequate experience with individuals with disabilities in order to interact with this patient population in a professional, non-biased, yet compassionate and culturally appropriate manner. This study assessed the disability training experiences and comfort levels surrounding disability of recent genetic counseling graduates. This study also determined the extent of disability training within students' genetic counseling graduate programs and whether or not this training was adequate and satisfactory. Participants included 176 recent graduates (2004-2008) from genetic counseling graduate programs who completed an online or paper version of a survey comprised of three main sections: demographics, disability experience, and comfort level with disability issues and situations. Data analysis included descriptive statistics of Likert scale questions, student t-tests, and themes determined from open-ended questions. Results demonstrated that respondents who had interacted with individuals with disabilities outside of a clinical setting and visited an individual with a disability at home or work were significantly more comfortable with individuals with mental disabilities. Respondents who had interacted with individuals with disabilities outside of a clinical setting, attended a support group, and visited an individual with a disability at home or work were significantly more comfortable with individuals with physical disabilities. Additionally, respondents who felt that disability was not adequately addressed in their graduate school training were significantly less comfortable with individuals with physical disabilities. The results demonstrate a strong need for a standardized disability curriculum for genetic counseling training programs.