Interdisciplinary Genetics Competencies for LEND Trainees

As recommended by the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Genetics Workgroup

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The purpose of the LEND training program is to improve the health of infants, children, and adolescents with neurodevelopmental disabilities, including autism spectrum disorder. There are 52 LEND programs located in 44 US states, each with its own focus and expertise. They all share the following objectives:

1. Advance the knowledge and skills of all child health professionals to improve health care delivery systems for children with neurodevelopmental disabilities.
2. Provide high-quality interdisciplinary education that emphasizes the integration of services from state and local agencies and organizations, private providers, and communities.
3. Provide health professionals with skills that foster community-based partnerships.
4. Promote innovative practices to enhance cultural competency, family-centered care, and interdisciplinary partnerships.

Neurodevelopmental Disorders is a large umbrella encompassing acquired, genetic, and multi-factorial causes for disability. These genetics competencies were created out of an expressed need for LEND trainees to receive additional training regarding the role that genetics may play in the lives of individuals with neurodevelopmental and related disorders. The purpose of this document is to serve as a resource for those LEND programs desiring to strengthen their genetics content. It is not intended to serve as a mandate or requirement, but rather to provide specific guidance in achieving basic and advanced competencies in genetics. It is the opinion of the LEND Genetics workgroup that all LEND alumni should:

a. Examine their own competence of practice, knowledge of evidence-based guidelines, and awareness of professional resources on a regular basis, identifying areas of strength and areas where professional development related to genetics and genomics would be beneficial.
b. Understand that health-related genetic information can have important social and psychological implications for individuals and families.
c. Know when and how to make a referral to a genetics professional.

Domain 1: Professional Development & Practice

1. Demonstrate an understanding of one's professional role in the referral to or provision of genetics services, and in follow-up for those services.
2. Identify and refer individuals who might benefit from genetic services or from consultation with other professionals for management of issues related to a genetic diagnosis.
3. Utilize information technology to obtain credible, current information about genetics.
4. Ensure policies for your practice that respect the need for privacy and confidentiality of genetic information.

Domain 2: Basic Genetics Concepts & Analysis

1. Demonstrate knowledge of basic human genetics terminology. These include:
    - Allele
    - Expressivity
    - Gene
    - Genotype
    - Locus heterogeneity
    - Mutation
    - Penetrance
    - Phenotype
    - Pleiotropy
    - Polymorphism
    - Variant of unknown significance
2. Demonstrate understanding of basic patterns of biological inheritance and variation, both within families and within populations. These include:
    - Autosomal dominant
    - Autosomal recessive
    - X-linked
    - Mitochondrial
    - Multifactorial
3. Recognize the importance and limitations of family history in assessing predisposition to disease.
4. Describe the interaction of genetic, environmental, and behavioral factors in predisposition to disease, onset of disease, response to treatment, and maintenance of health.
5. Explain the difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation).
6. Generate a family history and critically interpret the significance of relevant family history and family traits in predisposition for disease or disability, distinguishing family patterns of transmission of genetic conditions from shared family traits.

Domain 3: Patient- and Family-Centered Implications of Genetics

1. Describe how identification of disease-associated genetic variations facilitates development of prevention, diagnosis, and treatment options.
2. Recognize the various factors that influence the individual's ability to use genetic information, testing and other clinical and research services, including ethnicity, culture, related health beliefs, ability to pay, and health literacy.
3. Identify the potential physical and/or psychosocial benefits, limitations, and risks of genetic information, testing, and other services for individuals and family members across the life span as well as communities and society.
4. Discuss the pre- and post-test processes (including informed consent), indications for testing, and the risks, benefits, and limitations of genetic information, testing, and other services.
5. Identify the resources available to assist individuals seeking genetic information, testing, and other clinical and research services, including the types of genetics professionals and programs available and their diverse responsibilities.
6. Recognize the ethical, legal, financial, public policy, historical and social issues related to genetic testing and recording of genetic information.