



10.15.15 Fact Sheet

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Partners in Health Education for People with Disabilities (PHEPD)

A curriculum designed to improve access and achieve positive healthcare outcomes for people with Intellectual and Developmental Disabilities.

Background

The New York State Developmental Disabilities Planning Council developed and launched a multi-year pilot training project to implement the Partners in Health Education for People with Disabilities (PHEPD) curriculum. The PHEPD curriculum has been successfully piloted with residents and medical students; and is currently being piloted in four NYS colleges with Nurse Practitioner (NP) and Physician Assistant (PA) students. We are currently in the 2nd year of the 3 year project; more than 200 students have completed the curriculum to date at the four college project sites.

Grantees: State University of New York at Binghamton, Decker School; Daemen College; Hofstra University; Wagner College; and Evaluation and Technical Assistance Grantee, NYS Disabilities Advocacy Association and Network (NYS DAAN).

Goal of the Curriculum: Partners in Health Care for People with Disabilities (PHEPD) is an evidence-based interactive curriculum designed to improve the awareness, attitudes, knowledge, skills, clinical care competencies, and confidence of health care professionals who work with patients with disabilities and their families/caregivers. An Advanced Specialty Certificate in Developmental Disabilities is also under development using the PHEPD curriculum as part of the project.

Primary goals of the curriculum include:

- Acquiring knowledge about the diagnosis and care of patients with intellectual or developmental disabilities.
- Introducing students to people with disabilities, and their families/ caregivers in non-medical settings.
- Engaging with community-based and non-medical professionals to complement services for patients:
- Clinical experiences to apply skills and strategies and become more comfortable with patients with disabilities;
- Promoting benefits of collaboration with patients, families, caregivers, and community partners.

Other goals include:

- Identifying effective ways to ensure that the curriculum materials and resources can be updated efficiently;
- Creating continuing education opportunities for a wide range of clinicians and support staff;
- Finding effective ways to make sure faculty and preceptors are adequately prepared to teach and mentor students in treating and caring for patients with developmental disabilities.
- Introducing Universal Design strategies to prepare professionals to serve patients with and without disabilities.
- Promoting increased Inter-professional training, coordination and collaboration among healthcare professionals and community-based service providers.

Why is the PHEPD Curriculum needed?

Overview of current research and demographics support the need for health care professionals to have the knowledge and competencies to serve patients with intellectual and other developmental disabilities. There is a growing number of children being diagnosed with developmental disabilities; and more adults with developmental disabilities living longer. More people with developmental disabilities are fully integrated participants in their communities, and access community-based preventative and ongoing health care services.

The PHEPD curriculum is designed to increase knowledge, skills and professional competencies: Research indicates health care professionals often do not receive any specific training or experience with patients with disabilities. As a result, many acknowledge a lack of knowledge in treating patients with disabilities; interacting with their families/caregivers; and working in partnership with community-based agencies.

This is a brief introduction and summary of the project. For more information: Kathryn Cappella, NYS Disabilities Advocacy Association and Network, kcappella@supportcenteronline.org 585-533-1154

What is included in the PHEPD Curriculum?

The PHEPD curriculum consists of 8 common core components:

- 4 required didactic lectures: Orientation to PHEPD; Introduction to Developmental Disabilities; History and Legal Rights; Effective Communications.
- 2 home visits, including patient and family interviews,
- 2 community agency visits,
- Ongoing peer group discussions,
- Ongoing personal log of reflections,
- 1-2 case studies,
- Ongoing clinical experiences, and
- Participatory evaluations for students and instructors to assess improvements.

Curriculum components complement and reinforce each other. They are intended to promote practical application and successful interaction with people with disabilities and their families. The curriculum intentionally aligns with required professional competencies and is seamlessly integrated into the existing professional curriculum. Colleges may propose variations while maintaining fidelity to the curriculum goals; and may develop and offer additional lectures and experiences for students. Student evaluations measure impact on learning, behavior, attitudes, clinical diagnosis, care and treatment across a range of healthcare settings.

Key results include:

- Increase in awareness, knowledge, skills, strategies, confidence, and “*comfort-ability*” of health care professionals to successfully treat and care for patients with intellectual and developmental disabilities;
- Increase access to preventative care services for children and adults with intellectual and developmental disabilities; and understanding of common secondary health care conditions.
- Reduce the fear, dispel the myths, and knowledge of strategies, reasonable accommodations, and effective communication methods to engage and interact with patients and families.
- Increased awareness of specific intellectual and developmental disabilities, disability laws and rights; and the importance of collaboration and effective communication and advocacy by medical professionals to improve the outcomes of care for patients with developmental disabilities.
- Greater appreciation of the diversity of people with developmental disabilities; and value of individualized, person-centered care, personal choice and self-determination; and recognition of patients and families as engaged, effective, and valued partners.
- Importance of health literacy to ensure patients and their families/caregivers can make informed decisions.

Lessons learned:

- Disability awareness is an important aspect of cultural competence training and included throughout the curriculum.
- Health care professionals need explicit training about specific disabilities, diagnosis, secondary conditions, legal rights, accommodations, and effective communication.
- There is a valued impact and cost-benefit when health care professionals are prepared to be advocates and partners with their patients and family members to improve health care outcomes. (fewer visits, improved care plans)
- Health care professionals need strategies to improve communication with patients and family/ caregivers.
- Community-based resources can support and complement health and wellness plans for patients with disabilities.
- Health care professionals benefitted from learning about the wide range of available community-based resources and their potential to assist their patients and families.
- Consistent, respectful language is a critical first step to promoting a positive attitude and relationship:
- Person-centered care is integrated care where disability is not the initial, primary definer for medical care.
- Understanding a person’s rights promotes improve awareness, better care and services.
- Knowledge of legal rights and laws, such as the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA) are critical to ensuring full community integration, and achieving accessibility, access and equity.

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