

# Transforming Care for Individuals With Developmental Disabilities: Innovations in Education

Catherine Mann, EdD, RN, CNE-C & Lisa Ball, PhD, RN, FNP-BC

## INTRODUCTION

- Estimated five million Americans have an intellectual/ developmental disability (IDD) (U.S. Department of Health and Human Services, 2015).
- Estimated 15% of children aged 3-17 years have a developmental disability (Center for Disease Control, 2015).
- Individuals with IDD have historically had disparities in health care, including decreased access, under-utilization of services and poor health outcomes. As this populations' life expectancy continues to rise they will experience more health issues (Heller & Sorensen, 2013).
- There is an established need to designate individuals with IDD as underserved population (Kornblau, 2014). Recommendations to improve care and meet these needs include:
- Development of best practice guidelines for prevention, promotion, and treatment of the health care needs of people with IDD;
- Establishment of guidelines of the population health needs of the IDD population for local and state health departments;
- Inclusion of IDD knowledge, education, programs, and training in certification programs such as the Joint Commission, and state licensure programs for health providers (Kornblau, 2014, p.14-15).

## PURPOSE

To share innovative graduate, undergraduate, and community education strategies and resources to improve care for individuals with developmental disabilities

## BACKGROUND

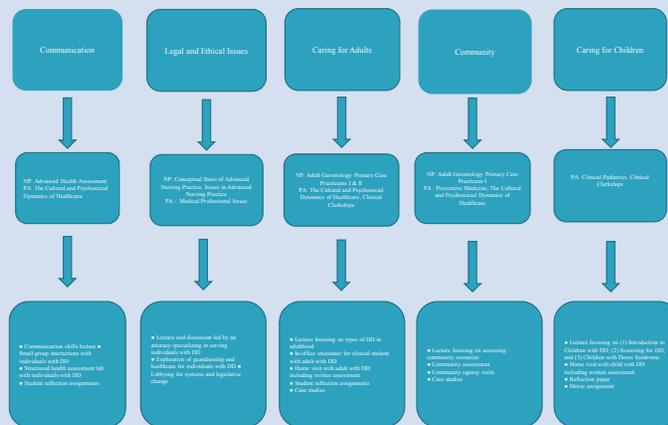
### Partners in Health Education for People With Disabilities

- Curriculum that is designed to be a highly interactive, interconnected set of learning experiences for students who are in a healthcare training program.
- Eight components designed to improve a student's awareness, attitude, comfort level, and confidence in developing more meaningful relationships with their patients with IDD, and their families and caregivers.
- 2005-2010, they sponsored pilots to field-test the implementation of the curriculum at 16 medical school and residency programs.
- 2012, pilot projects were launched in four NYS colleges with Nurse Practitioner (NP) and Physician Assistant (PA) students.
- PHEPD at Daemen College initiated December 2012
  - Cohort 1 - Advanced Certificate Completion 12 NP, 12 PA
  - Cohort 2 - Advanced Certificate Completion 3 NP, 3 PA
  - Cohort 3 - Integrated Curriculum 43 NP, 65 PA
  - Cohort 4 - Integrated Curriculum 27 NP, 65 PA

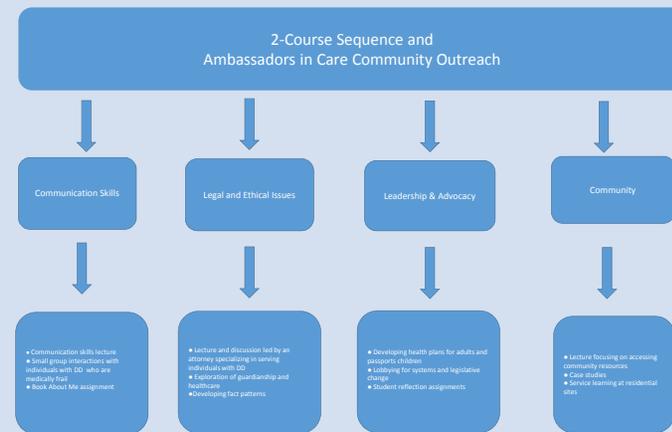
### Field-Initiated Ideas for Individuals who are Medically Frail

- Innovative strategies or approaches to service delivery and supports for children and adults who are medically fragile, their families, and caregivers
- 2013, four pilot projects were launched in NYS.
- Daemen's initiative included 2-course service learning sequence and community outreach education program. People educated included (1) Year 1: 2-Course Sequence Cohort – 7 RNs trained; and (2) Year 2: 2-Course Sequence Cohort – 17 health profession students (RN-BS, PA, PT, AT)
- Year 2: Ambassadors in Care Cohorts – 61 RNs, 22 health profession students (nursing, PT, social work), 6 nursing faculty, 14 community agency personnel, 10 individuals, and 4 family members (total 117)
- Daemen College initiative aimed at healthcare professionals and healthcare profession students. Daemen Objectives:
  - Identify legal and ethical issues.
  - Demonstrate the ability to provide up-to-date information on community resources available
  - Formulate areas that need further development to improve care.
  - Act as advocates
  - Recognize opportunities to act as leaders and change agents to improve care

## INTEGRATION OF PHEPD INTO GRADUATE CURRICULUM



## UNDERGRADUATE INITIATIVES



## QUALITATIVE OUTCOMES

### PA Small Group Interaction and Blogging

- "One big thing I took away from this discussion is that it is important to develop a good rapport with a person before you expect them to open up about anything. I think by the end of the discussion he was slowly starting to open up a little bit more, so I wish we had more time to talk to him"
- "Before the discussion group, I had minimal experience in interacting with people with disabilities, so I was nervous. I was unsure of what to say and how to react because I did not want to offend our visitors...Now I feel confident that when I come in contact with people with disabilities, whether in healthcare or in the community, I can effectively communicate with them"

### NP Health Assessment Lab with Individuals with DD

- "This experience gave me the opportunity to speak and get comfortable with an individual with as disability. It was helpful to hear what they had to say and how they want to be treated"
- "It will help us to not make mistakes with them when we are new NPs. We will start off stronger with our new found 'tricks' and tips"

### Home Visit/Assessment

- "The healthcare system and government make all the processes and approvals far more complicated than they should be – ultimately delaying the care of people with developmental disabilities. If all providers were educated about the options for people with developmental disabilities, the lives of the families involved would be less stressful"
- "I gained confidence on conducting a medical history with a family, learning how to be respectful, receptive, and friendly. I learned about his disability, which I was not familiar with beforehand, and I also learned about many services that his family receives to make sure he is succeeding"

### Leadership Reflections

- "I would like other mid-level healthcare providers to realize that they need to directly interact with patients with disabilities. Healthcare providers need to not be afraid to touch and interact with individuals with disabilities. People all deserve quality, hands-on healthcare" (PA student)
- "I have come realize that there are many different types of disabilities and they have a tremendous impact on the physical, cognitive, and emotional well-being of my patients. In order to address and provide good care, I must look at the whole patient and attempt to recognize the needs that may impact the care I am providing. It encompasses the 'it takes a village' idea, knowing that there are many layers and services that are needed to work together throughout an individual's lifetime" (NP student)

## QUANTITATIVE OUTCOMES

Area of Knowledge, Skills and Competence	Pre PHEPD n=13	Post PHEPD n=106
1. Learning for Developmental Disabilities	55%	94%
2. Technology to assist people with Developmental Disabilities	47%	96%
3. Legal Rights: Americans with Disabilities Act	47%	79%
4. Education Rights: Individuals with Disabilities Education Act	45%	83%
5. Early Childhood Intervention Services	55%	94%
6. Medical Home	45%	89%
7. Foreign Birth Language	42%	85%
8. Communicating effectively with caregivers of children and adults with disabilities	66%	94%
9. Selecting appropriate accommodations to overcome barriers to providing health services	56%	93%
10. Communicating difficult news to patients and their families	75%	93%
11. Making appropriate referrals to community agencies and services	48%	88%
12. Working with staff from community agencies and services	53%	89%
Skills and Competence		
1. Providing quality care to patients with disabilities	85%	97%
2. Strategies to work with families and caregivers of patients with disabilities	76%	96%
3. Skills to work and communicate with children with disabilities	70%	96%
4. Skills to work and communicate with adults with disabilities	75%	94%
5. Outreach and partnerships with community agencies to support new medical needs	47%	96%
6. Techniques to interact with patients who have communication strategies	66%	97%
7. Strategies to conduct basic health care assessment of patients with mobility challenges	66%	95%
8. Strategies to work with patients who have assessment challenges	75%	95%
9. Building working relationships with health care for family with disabilities at home	66%	92%
10. Knowing how to make accommodations for people with different disabilities	59%	97%

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