



# UNIVERSITY of NEW HAMPSHIRE

## *Engaged Scholars Academy Project Summary*

**Joan Earle Hahn, PhD, APRN, GCNS-BC, GNP-BC, CDDN**

**PROJECT TITLE:** *Engaging partners to explore disability and access to primary health care.*

### **PROJECT DESCRIPTION**

At the University of New Hampshire (UNH) “*engaged scholarship*” is defined as “*a mutually beneficial collaboration between the UNH and community partners for the purpose of generating and applying relevant knowledge to directly benefit the public.*” A theme embraced by the College of Health and Human Services is “*knowledge for healthy living.*” A part of the mission of the Department of Nursing at UNH is “*to enhance the health of individuals, families, groups and communities by preparing nurses who are skilled, knowledgeable, reflective leaders and practitioners.*” This project builds on this scholar’s work to gain knowledge to improve the health and well-being of persons with disabilities who have faced health disparities, one of which is the lack of education for health care professionals about the needs of persons with disabilities.

### **BACKGROUND INFORMATION/STATEMENT OF THE ISSUE/PROBLEM**

Persons with disabilities (PWD) face health disparities in health care, one of which is the paucity of universal education of nurses and other health care professionals. Another underlying barrier is nurses’ and other health care professionals’ lack of experience with persons with disabilities. Relatively little research has documented the views of persons with disabilities in the primary health care setting. The views of nurses about disability are confounded by misunderstanding of disability (Scullion, 1999). Nurses’ misunderstanding of the needs of persons with disabilities can lead to the consequences of frustration, anger and even physical discomfort (Balandin et al, 2007). This scholar’s research has been focused on improving the quality of health care for individuals living with disabilities, primarily adults with developmental disabilities who are aging. A key goal is to improve access to health care by way of education of health care professionals about the culture and experiences of persons with disabilities in health care.

### **PROJECT DETAILS**

#### **Goals and Objectives**

This project intends to increase knowledge about the experience with disability in primary care by capturing the lived experience of adults aging with disabilities (age 55 and older) and health care providers in the primary care setting along with a plan to disseminate this knowledge to health care providers, aging persons with disabilities and UNH nursing students. The proposed project will bring together “partners” from the community from a number of arenas to explore the perceptions of health care providers and persons with disabilities about their experience with disability in the primary care health setting. The aim is to increase knowledge about disability that can be shared for the purpose of education of health care professionals and nursing students.



## **Target Population/Audience**

The target population will be approximately 20 primary healthcare providers and 20 persons, age 55 or older, who have conditions or impairments and self-identify as having a disability or having had experienced disability in the health care setting. The inclusion criteria will include the ability to participate in a 20 to 45 minute interview in a means of communication that can be understood by the interviewer.

## **Methods**

Persons who express interest in participating in this project will be contacted by phone or face to face to review the project goals and participant activities.. Before beginning any activities, participant consent will be obtained after institutional review board approval is received for the project. Open-ended questions using a guided questionnaire will be asked of each participant using a phone or face-to-face interview. Should a group of health care providers or persons with disabilities prefer to meet with others at their setting, an option for a focus group will be offered. Interview or focus group data will be recorded (with permission) and transcribed verbatim. A content analysis will be conducted to determine themes and concepts. Once repetition of themes and concepts occurs (or saturation), the interview/focus group process will end.

The proposed steps are to:

- Obtain Institutional Review Board approval for the project.
- Work with a community agency, Southern New Hampshire Area Health Education Center (SNHAHEC) to identify community health care partners that will provide the opportunity to learn more about primary care health experiences with persons with disabilities (PWD).
- Work with community partners to enlist their participation to distribute invitations to persons with disabilities to participate in one-to-one face-to-face interviews and/or a focus group inclusive of other persons with disabilities.
- Explore questions with the primary health care providers and persons with disabilities about their experiences in health care using interview and/or focus group participation methods.
- Conduct content analysis of interview data
- Work with SNHAHEC on a mutually beneficial health education project about improving access to health care for persons with disabilities in primary care, based on information grounded in the “expertise” of health care providers and persons with disabilities.
- Design instruction that enriches nursing student education to promote health and well-being of persons with disabilities that has been grounded in the health care providers’ and persons with disabilities’ expertise.



## **Evidence of External Collaboration and Partnership**

The partner community agency that works to build health education partnerships will assist the UNH faculty scholar in this project by helping to form linkages to health care providers and adults with disabilities. The UNH faculty scholar will provide mutually beneficial acquired knowledge acquired about what promotes or hinders access for persons with disabilities in primary health care. Thus, all involved partners can then share the knowledge gained in both academic education for nursing and other students and community training opportunities for health care providers and persons with disabilities. The intent is to benefit persons with disabilities who would be able to access providers who are knowledgeable about “disability.”

## **Expected Impact**

The expected impact on the external partner(s) is advancing their knowledge about the learning needs about disability in the local community health care environment. It is anticipated that a collaborative approach among project partners will result in dissemination of this work via training sessions and/or public forums.

## **Scholarly Connection**

This scholar’s work will broaden and further a research trajectory that has centered on interventions to promote health and prevent functional decline of older persons with disability and the development and testing of curriculum and training materials for nurses, health care professionals and persons with disabilities. Research contributions to nursing address the often-underserved population, persons with intellectual, developmental and other disabilities. This work will be extended through engaged scholarship that uses a more qualitative methodology that more directly examines the views of the constituents of health care.

## **EVALUATION PLAN**

The evaluation plan will look at completion of objectives, primarily capturing the ability to gain knowledge about health care providers and persons with disabilities experience in primary care, disseminate that knowledge through at least one workshop inclusive of persons with disabilities and healthcare providers, development and testing a module for nursing and/or nurse practitioner students, and publication of at least one article about the findings of this project.

## **REFERENCES:**

- Balandin, S, Hemsley, B, Sigafoos J, et al. (2007). Communicating with nurses: the experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research*, 20, 56-62.
- Scullion, P. A. (1999). Conceptualizing disability in nursing: Some evidence from students and their teachers. *Journal of Advanced Nursing*, 29, 648-657.