



<h1>AGENDA</h1> Developmental Disabilities- Practice- Based Research Network (DD-PBRN)	May 12, 2014	
	8:00am-12:00pm	
	Conference Room A Independence FHC 5001 Rockside Road Crown Centre II Independence, OH 44131	
	Facilitator:	Carl Tyler, MD, MSc
	Agenda Items	
8:00-8:10 AM	Welcome and Introductions	
8:10-9:00 AM	Presentation: Nursing Services for Persons with Developmental Disabilities (Nursing Working Group)	
9:00-10:30 AM	Developing our First PBRN "Card" Study (Drs. Werner and Stange - PBRN Shared Resource- Case Western Reserve University)	
10:45 - 11:00 AM	Updates: (2) Presentation proposals to the annual national PBRN conference were accepted! Linda Council RN was awarded a scholarship to attend the conference	
11:00- noon	Continued Discussion regarding Research Ideas from the Nursing Services presentation above Open Forum	

From 9- 10:30 AM, we will be brainstorming to create our first network card study. One idea proposed is to gather data about the quality of health care encounters from the perspective of the family member or staff person accompanying the individual. We value your input to this first study from our network.

The Learning Collaborative as a Preliminary Step to PBRN Development

Tyler CV, Norwood C, Biswas A, Werner J

Background: Effectively engaging community stakeholders and clinicians *following* the establishment of a PBRN may prove difficult. This is particularly relevant when working with marginalized populations generally suspicious of the health care system and health-related research. As an alternative, a more organic strategy that ensures community engagement in a nascent PBRN is to create critical group affiliation and cohesion by first establishing a Learning Collaborative.

Methods: We describe the conceptual model and characteristics of learning collaboratives, then detail the development, organization, structure, and products resulting from a year-long learning collaborative which subsequently evolved to form a PBRN.

Results: The Learning Collaborative in Developmental Medicine (LC-DM) was organized as a multi-stakeholder, community-based quality improvement initiative under the Medicine Institute of the Cleveland Clinic with the goal of improving the health care of adults with intellectual and other developmental disabilities (IDD) served by the Cleveland Clinic. LC-DM stakeholders included self-advocates with IDD, family members, residential service providers, advocacy agency representatives, disabilities professionals, nurses and primary care physicians. The LC-DM members met face-to-face every other month for 4 hours; each meeting focused on improving the health care of a specific sub-population, e.g. adults with Down syndrome, cerebral palsy, and autism spectrum disorder. With support of the Shared Resource in PBRN of the CWRU-CTSC, the LC-DM membership agreed to form a PBRN. We describe that transition process and our initial work of educating and acculturating the membership to a practice-based research focus.

Conclusion: Clinicians, researchers, and other stakeholders seeking to improve health care of specific target populations may consider learning collaboratives as a logical first step prior to establishing a PBRN.

Hybrids, Chimeras, or New Species? Emerging Models of PBRNs

Session Summary: The increasing emphasis on team-based health care and community engagement is affecting how established primary care PBRNs are conducting their work and how nascent PBRNs are forming. Are these newer models of PBRNs hybrids of established models, chimeras of previously distinct models, or entirely new species of PBRN altogether?

In this session we begin with a literature overview and discussion examining the core features, structures and functions of traditional primary care PBRNs. Next, representatives of three “newer generation” PBRNs will describe their networks and define: (1) similarities and differences between theirs and traditional networks; (2) forces, decisions, and influences that led to the development of their network; and (3) advantages and disadvantages associated with their unique network characteristics. Finally, we provide time for participants to examine their own networks and to consider ways they might integrate and adapt the best features of newer generation PBRNs into their existing or emerging networks.

Short Summary: Representatives of three “newer generation” PBRNs will describe their networks and define: (1) similarities and differences between theirs and traditional networks; (2) forces, decisions, and influences that led to the development of their network; and (3) advantages and disadvantages associated with their unique network characteristics. Attendees will consider ways they might integrate and adapt features of newer generation PBRNs into their existing or emerging networks.

Measureable Objectives: (1) Articulate core features, structures, and functions of traditional PBRNs. (2) Define characteristics of newer-generation PBRNs that differ from traditional ones. (3) Identify features of newer generation PBRNs that might be integrated and adapted to attendees’ established or emerging networks.

Outline: (1) Lecture: Literature summary followed by full group commentary: Characteristics of traditional PBRNs (15 minutes). (2) Presentations by 3 PBRN representatives: Characteristics of newer generation PBRNs (10 minutes each, total of 30 minutes). (3) Small group discussion: Integrating and adapting features of newer generation PBRNs to attendees’ own PBRNs (15 minutes). (4) Full group: Summaries of small group discussions and reflections (10 minutes).