

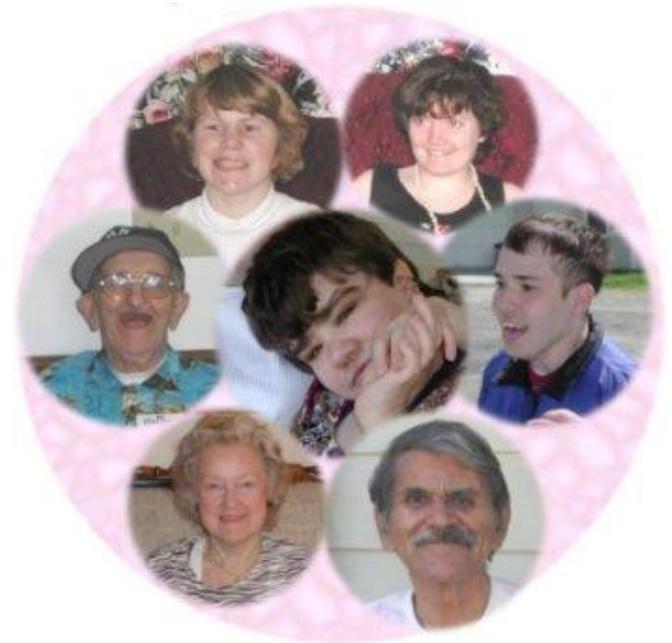
# New Models of PBRNs: The Developmental Disabilities- PBRN

Carl V. Tyler MD, MSc

Director, DD-PBRN

Case Western Reserve University

Cleveland Clinic



# Background-Context

- Definition of Developmental Disabilities (DD)
- History of Persons with DD, Medicine, & Research
- Deinstitutionalization & Community-based Health Care
- Health Disparities in Persons with DD
- Medical Model of Care → Social Model of Care → Modified Social Model in a reluctant & uneasy alliance with the health care system



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# Initial Collaboration: Training Grant to Improve Primary Care

- Funded by Ohio DD Council
- Aim to improve health & primary health care of adolescents and adults with DD
- Brought together self-advocates, family members, service providers, disabilities professionals, medical educators, nurses, physicians
- Produced 3 module training DVD; curriculum for direct support professionals; tools for primary care physician education in DD medicine

# Learning Collaborative in Developmental Medicine (LC-DM)

- Organized as a multi-stakeholder, community-based quality improvement initiative under the Medicine Institute of the Cleveland Clinic
- Funded by Cleveland Clinic Medicine Institute
- Goal: To improve the health care of adults with intellectual and other developmental disabilities (IDD) served by the Cleveland Clinic (CC).
- Stakeholders included self-advocates with IDD, family members, residential service providers, advocacy agency representatives, disabilities professionals, nurses and primary care physicians.
- 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.

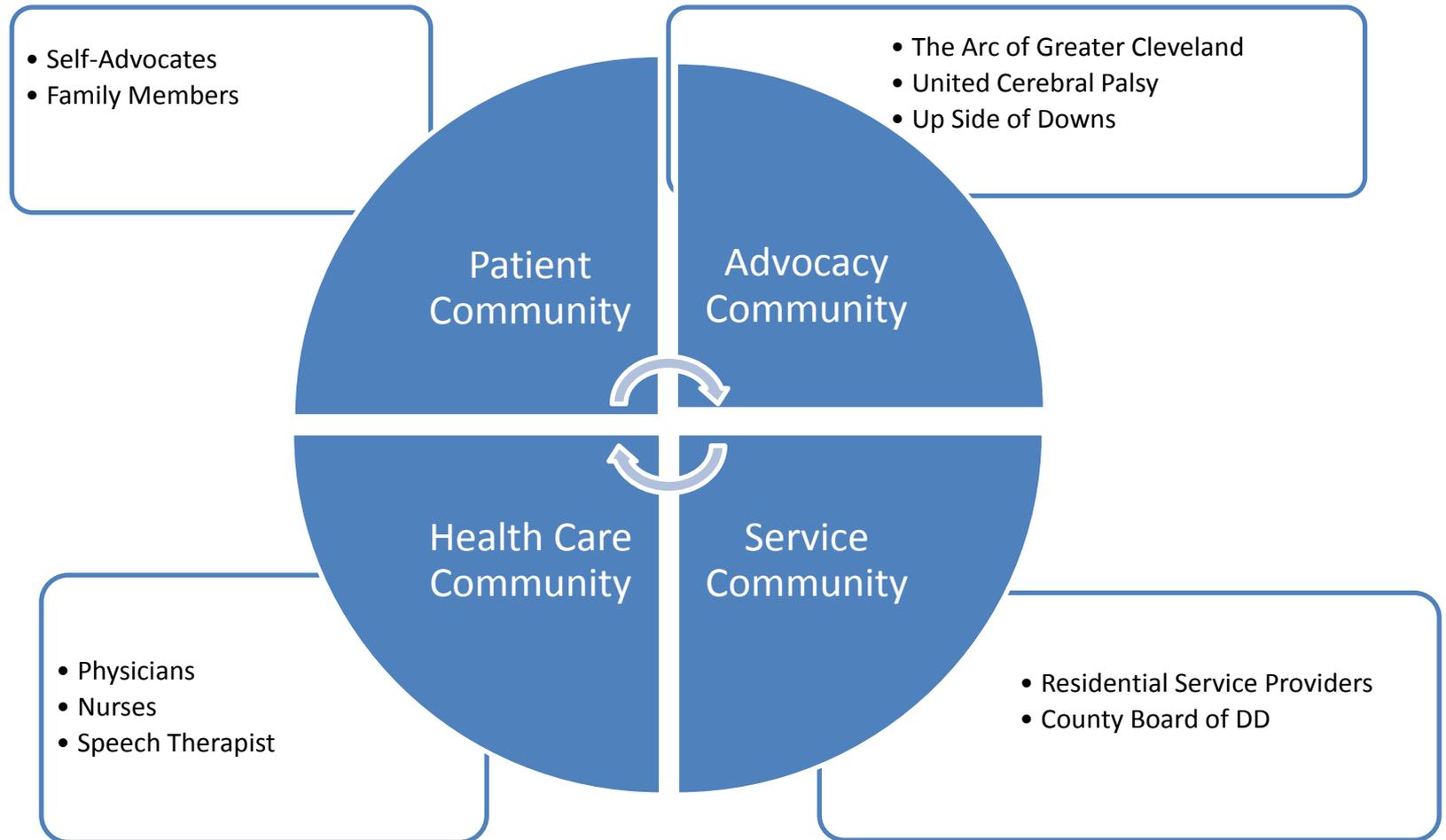
# Evolving Vision of a PBRN

- Learning Collaborative was internally funded as a time-limited 1- year pilot project
- PBRN Shared Resource at Case Western Reserve University offered technical assistance to LC-DM members to establish a PBRN devoted to individuals with IDD
- LC-DM members recognized their potential to conduct research as a logical “next step” to their experience as a learning collaborative seeking to improve health care at the health system level

# Timeline of Collaborations, Participants & Stakeholder Groups

Collaboration (Years)	Training Grant (2009-2011)	Learning Collaborative (2012-2013)	DD-PBRN (2013-present)
<b>Stakeholder Group</b>			
<b>Patient</b>	Self-Advocates Family Members	Self-Advocates Family Members	Self-Advocates Family Members
<b>Advocacy</b>	The Arc of GC Upside of Downs	The Arc of GC Upside of Downs United Cerebral Palsy	The Arc of GC Upside of Downs United Cerebral Palsy Milestones (Autism)
<b>Service</b>	Residential Service Providers: (Welcome House, Help Foundation) Disabilities Professionals County Board of DD	Residential Service Providers (Welcome House, Help Foundation) Disabilities Professionals County Board of DD	Residential Service Providers: (Welcome House, Help Foundation, Koinonia, ViaQuest) Disabilities Professionals County Board of DD
<b>Health Care</b>	Nurses Family Physicians Residency Faculty Medical School Faculty	Nurses Family Physicians Internists Pediatrician Speech Therapist	Nurses Family Physicians Internists Pediatrician Speech Therapist Social Workers

# Stakeholders Represented in DD-PBRN



# Early Transition Activities

- LC-DM members introduced to core content information regarding the history, role, value, methods & examples of practice-based research
- Face-to-face sessions devoted to crisis areas salient to care of persons with IDD (electronic health record-based care; changes in funding for nursing services) as potential topics for research
- PBRN Shared Resource staff facilitated initial brainstorming session to develop a focus area for first research project

# Comparison of Early Generation vs. DD-PBRN

## Early Generation PBRNs

“PBRNs capture health care events that reflect the selection and observer bias that characterize primary care in community-based patient populations.”

“PBRNs provide access to the practice experience and care provided by full-time primary care clinicians.”

## DD-PBRN

DD- PBRN will capture phenomena relevant to primary health care of persons with DD that may precede, occur during, or subsequent to actual health care events. Selection and observer biases vary according to networks and participants under study.

DD- PBRN will access the experience of 3 stakeholder groups: primary care clinicians, their patients, and other persons in the community who are relevant to the primary health care of persons with DD (e.g., the advocacy and service communities.)

# Comparison of Early Generation vs. DD-PBRN

## “Early Generation” PBRNs

“PBRNs focus their activities on practice-relevant research questions, apply appropriate, multimethod research design, and generally avoid the tendency to permit research methods to define the question.”

“PBRNs strive for the systematic involvement of network clinicians in defining the research questions, participating in the study design, and interpreting study results.”

## DD-PBRN

DD-PBRN will focus activities on the primary health care of persons with DD and apply appropriate multi-method research designs that vary according to the research questions proposed; studies vary in site, target stakeholder group and stakeholder perspective.

DD-PBRN will strive for the systematic involvement of primary care clinicians, their patients, and other stakeholders in the community who are relevant to the primary health care of persons with DD in defining the research questions, participating in the study design, and interpreting study results.

# Influences, Forces, Decisions Leading to New Model PBRN

- Strong ethic within disabilities community of “Nothing about us without us.”
- Shared success experience through production of training materials
- Changing perceptions of members of the disabilities, service, and health care communities about one another
- Personal knowledge and relationships between individuals in the PBRN Shared Resource and the leader of the LC-DM

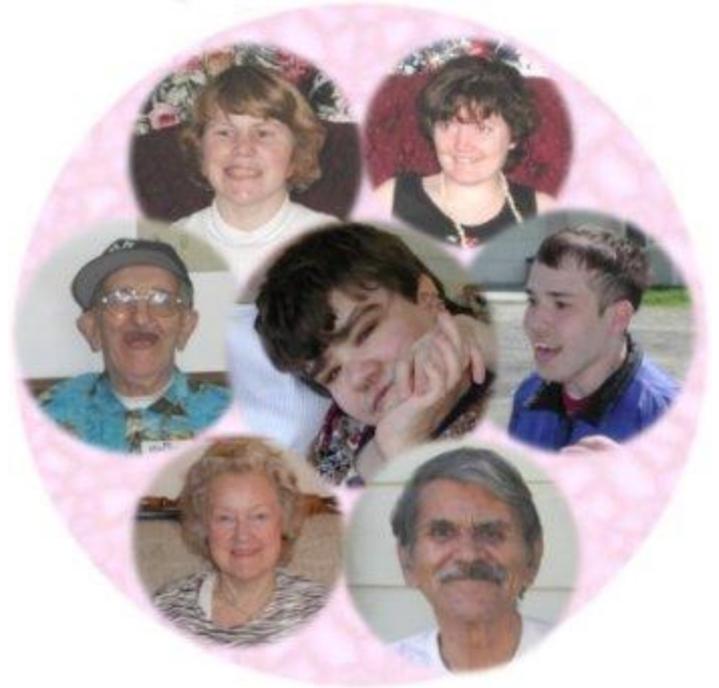
# Potential Advantages/Disadvantages of Newer Models of PBRNs

## **Advantages of Newer Model**

- Broader understandings of health & health care by including perspectives of all salient stakeholders
- Greater depth and breadth of potential research questions
- Greater possibilities in study design
- Wider potential funding pool

## **Disadvantages of Newer Model**

- Varied training needs of diverse stakeholders regarding the research process
- Maintaining interest and commitment of participants
- Potential for splitting into sub-groups/ sub-group agendas



## Contact Information

Carl Tyler MD, MSc  
Director, Developmental Disabilities PBRN  
[catyle@ccf.org](mailto:catyle@ccf.org)  
216-476-7084