Objectives

• To provide examples of practice-to-research from the presenter’s personal experience
• To introduce core concepts related to practice-based research and apply them to developmental medicine
• To pose potential research/quality improvement questions relevant to primary care
From Hospital Rounds to Case Report:
Recognizing Klinefelter’s syndrome in Adulthood

• Trigger: On hospital rounds, faculty primary care physician noted a middle-aged male admitted with venous ulcers had a cherubic-appearing face suspicious for hypogonadism.
• Response: After confirming the diagnosis of Klinefelter’s syndrome (KS), he conducted a literature review which indicated KS went frequently undiagnosed, especially in childhood. Published case report in primary care journal.
• Implications: Primary care physicians need to be alert to the manifestations of undiagnosed KS throughout the lifespan.


From Clinical Care to Case Series:
Health Care of Persons Newly Deinstitutionalized

• Trigger: Family physician assumes care of a group of adults with IDD newly deinstitutionalized to community from developmental centers.
• Findings: He found a pattern of deficits in prior health care.
• Response: He summarized these in a primary care journal.
• Implications: Primary care physicians need to focus on a set of specific health conditions when assuming care of persons newly deinstitutionalized.

From Clinical Observation to Case Control Study:
Gallbladder disease in Adults with Down syndrome

- **Trigger:** Primary care physician noted within a short period of time, several adults with Down syndrome in his practice required cholecystectomy.
- **Response:** Conducted a case control study of adults with DS using matched control sample from family medicine residency clinic.
- **Findings:** Adults with DS bore an adjusted relative risk of 3.22 for symptomatic gallbladder disease.
- **Implications:** Patients, caregivers, and health professionals need to be alert to signs and symptoms of gallbladder disease in adults with DS.


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From Pharmaceutical Talk to Cohort Study:
Osteoporosis in Community

- **Trigger:** Pharmaceutical representative providing talk about bisphosphonate has access to DEXA machine for screening.
- **Response:** In cooperation with DD county board nurses, conducted osteoporosis screenings at day programs in Cleveland Clinic.
- **Findings:** In this middle-aged cohort, prevalence of osteoporosis was 25% and osteopenia was 20%. Published study in intellectual disabilities journal.
- **Implications:** Osteoporosis prevention and screening is particularly important in this population.

(Tyler CV, Zyzanski SJ. Screening for osteoporosis in community-dwelling adults with mental retardation. Mental Retardation 2000; 38(4): 316-21.)
Invited Lecture Leads to Survey: Nursing Perspectives on Cancer Screening

• Trigger: Primary care physician invited to speak at annual local DD nurses meeting about cancer screening.

• Response: He administers survey to 100 DD-nurse attendees about their perceptions regarding quality of & barriers to cancer screening.

• Findings: Nurse survey findings published in intellectual disabilities journal.

• Implications: Nurse insights to cancer screening barriers led to quality improvement study

Research as a Wilderness Canoe Trip

Background: Finding your place on the map
Closing the Gap: Defining your destination
Methodology: Finding the right outfitter
Aims: Marking off your itinerary
Building your network: Assembling your high-adventure team
Anticipated findings: Flora and fauna
Next Steps: Finding the right portages
Why examine the health care of individuals with IDD?

• Demographic imperatives
  – Increased survival and life expectancy

• Community-based Health care
  – Ill-prepared, poorly organized, under-funded

• Health Disparities
  – Documented in measures of mortality, morbidity, quality of life
Where do the disparities in health care lie?

- Diagnosis and treatment of acute and chronic medical conditions
- Diagnosis and treatment of mental health disorders
- Lack of health promotion/disease prevention activities
- Palliative care

How do we close the gap in health care disparities?

- Creating attitudinal change and a culture of shared societal responsibility
- Constructing a science of health promotion, primary & secondary disease prevention tailored to persons with IDD
- Developing robust clinical Information Technology infrastructures, care delivery systems & care coordination
- Educating health care workforce
How do we close the gap in health care disparities?

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Methodology

[Finding the right outfitter]
Why Choose Primary Care Practice-based Research?

- Majority of individuals with IDD now live in the community
- Most of their health care is community-based and de-centralized
- There is no sub-specialty of adult developmental medicine
- Most primary care practices have relatively small numbers of patients with IDD

Practice-based Research Networks

- Organizations of community practices
  - that collaborate with academic and community partners
  - to gain scientific knowledge that leads to improved health care
  - particularly primary care delivered in community practices (AHRQ 2013)
- Developed to assure that research leads to better health outcomes because it is informed by front-line community-based clinicians
- Clinicians are involved in the entire research process, including:
  1. determining the research agenda
  2. framing and defining the research questions
  3. informing the design of the study
  4. participating in data collection
  5. interpreting study results
  6. disseminating study findings
  7. incorporating new knowledge into clinical practice
Why a PBRN devoted to DD?

• **Disparities in Health and Health Care:**
  – Emerging evidence base documenting deficits in the health care of persons with developmental disabilities (DD),
    • Including preventive health services, chronic disease care, emergency care and in-patient care.

• **Existing PBRNs aren’t researching about developmental disabilities:**
  – Over 100 PBRNs registered with the Agency on Health Care Research and Policy (AHRQ), none were devoted to improving the care of persons with DD.
  – AHRQ Bibliographic library of 2035 citations, only 18 citations in any way related to DD, of which only 4 citations reflected actual practice-based research in DD.
  – Other research networks related to DD (not registered with AHRQ):
    • Two national networks devoted to persons with autism; one national network comprised of developmental-behavioral pediatricians.

• **Unique Community Partnerships:**
  – A PBRN focused on DD requires a strongly participatory community partner network that is intimately knowledgeable about this population.
Project Aims

• Identify health care professionals and partners in the disabilities service and advocacy community with an interest in improving the health care of individuals with IDD
• Develop a Practice Based Research Network (PBRN) of these persons and their practices
• Complete an inaugural study
• Evolve a sustainable infrastructure for the PBRN

Building your network
[Assembling your high adventure team]
Building the Foundation:
Education, training, relationships

Activity-Affiliation
• Core Facility in Practice-based Research of CWRU-CTSC
• Cleveland Clinic Learning Collaborative in Developmental Medicine
• Family Medicine Education Consortium: “Medical Homes for People with IDD”
• American Academy of Developmental Medicine & Dentistry
• American Association on Intellectual and other Developmental Disabilities: Health and Wellness Action Group

Focus
• Mentored education, training & support
• Building relationships with self-advocates, advocates, and disabilities networks
• Building relationships with Family Medicine Educators & Family Medicine Residencies
• Building relationships with physicians & dentists specializing in IDD
• Building inter-disciplinary relationships with other professionals in the disabilities field

Initial Groundwork

• Start-up Funding:
  – Case Western Reserve University (CWRU)- Clinical and Translational Science Collaborative (CTSC)- Core Facility in Practice Based Research

• Start-up Team:
  – Carl Tyler MD, MSc: PBRN Director
  – Anindita Biswas MA: PBRN Coordinator
  – Cindy Norwood, Executive Director, Arc of Greater Cleveland, parent
  – Michelle Abraham MSSA, Arc of Greater Cleveland, grant writer, research administrator, parent
Next Steps

[Finding the right portages]

Short Term Goals

• Devise an initial PBRN survey to characterize practices and patients
  – National Ambulatory Medical Care Survey
  – Disabilities-specific practices
• Enroll local and distance practices in PBRN
  – Cleveland Clinic, Metrohealth Medical Center, Rainbow Babies and Childrens Hospital
  – Investigate interest from NESCO, Mid-coast Collaborative for IDD
  – Kennedy-Krieger, University of Colorado
  – Utilize PBRN input to inform Center for Medicare and Medicaid Innovations Grant Proposal
Anticipated Findings

- Significant differences in encounter duration and content between individual PBRN practices and between PBRN practices & national sample
- PBRN will have more visits devoted to mental health and behavioral issues
- Wide variation in the characteristics of patients served by individual practices within PBRN
Interest in Learning More About Practice-based Research Network?

**Developmental Disabilities- PBRN**

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**Potential Research Questions**

- What are the biggest deficiencies in the health care of persons with IDD at the present time?
- What would help you the most to provide better health care to the people you support/diagnose & treat?
- Where do you see the biggest waste of money for health or services for persons with IDD?
Thank You!