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**Background: Barriers in Healthcare**

- Lack of access to facilities and providers
- In-accessible equipment and formats
- Poor communication
- Low health literacy
- Need for longer office visits
- Provider lack of knowledge
- Attitudinal barriers
- Financing of health care
Background

• Receive primary care at lower rate & with poorer outcomes (e.g., more emergency room for non-emergency purpose, less preventive screenings)
• Poorer outcomes in acute care (e.g., mortality from preventable causes)
• Difficulties with transitions (e.g., moving from child to adults services, transitions from hospital)
• Lack of health promotion designed for needs with poor health and fitness outcomes
• Brought together disability community and healthcare stakeholders
• Reviewed and synthesized best practices and innovations in healthcare for people with disabilities
• Developed action plans for improvements
• Working on dissemination
Getting Meaningful Participation

- Advisory Committee of disability advocates, managed care, professionals
- Pre-conference training of advocates (funded by Special Hope Foundation-WITH)
- Opening with panel of people with disabilities
- Cultural performances

http://rrtcadd.org/?s=daphne
Presenters
Performances

Bodies of Work
Still Point
Work Groups
Action Plans

Action Plans

Recommendations
Presentation Objectives

Participants will be able to summarize and respond to – for people with disabilities:

• Current innovations and efforts for improvement of health promotion, and primary, acute and transitional health care
• Research and policy recommendations for health promotion, primary, acute, and transitional health care
• Discuss action plans for improvements in health care for people with disabilities that they can implement with their own available resources.
Presentation Agenda

• Review the 7 main themes for conference, examples of work within those themes
• Post conference action plans with emphasis on health and health care people with intellectual disabilities
• Small work groups to discuss themes and action plans
• Reports out
Involve people with disabilities in all aspects of health promotion and health care

• Involvement is best practice
  – Ex: Affordable Care Act (still the law) Section 2401 Community First Choice Option. Arkansas established Implementation Council made up of consumers
  – Ex: Rush Tower – people with disabilities toured the mock rooms and facilities and made recommendations
  – Ex: S. Magasi’s work on Peer Navigators

• Research is needed
  – Data on whether such involvement improves outcomes
Post Conference Action Plans

• Working with Rush security to train staff on interacting with people with intellectual disabilities and/or autism. Willing to recruit an advocate to Emergency Management Committee.

• Incorporate advocate (self-or not) voices into research throughout the entire process.
  – Members of research teams
PATH-PWD Theme #2

**Training** for health professionals, people with disabilities and their families in healthcare needs, rights, and best practices including developing a repository of training available.

- Improve education of health care professions regarding care of people with disabilities across disabilities
  - Ex: AADMD has developed a curriculum
  - Rush has persons with disabilities who lecture to first year medical students
  - Ex: Villanova – works with standardized patients with disabilities
  - Ex: Alliance for Disability in Healthcare Education competencies

- Research is needed – Does education improves outcomes?
Post Conference Action Plans

• At least two advocates at the Conference have joined Alliance for Disability in Healthcare Education and are providing feedback on healthcare provider competencies with focus on competencies for people with ID – developing lay language version
• Collaborate first responders (police, fire, EMS)
• Extend programs that work with standardized patients with disabilities for OSCEs
Action Plan

• Address healthcare within community agencies for people with ID
  – Include health care providers in community agencies
  – Train Direct Service Providers in health promotion and prevention
PATH- PWD Theme #3

*Increase access to quality healthcare and health promotion,*

Best practice

- ODEP – goal with federal funding 7% of employees across job classes
- Kaiser makes specific efforts to hire people with disabilities
- Rush has specific efforts, one of which is collaboration with PACE program on National Lewis University to bring interns with IDD as interns

• Research is needed- Does representation of people with disabilities in workforce improve outcomes?
Action Plans

• Ensure representation of people with disabilities in the workforce
  – Find and promote best practices
Post Conference Theme #4

Develop, research, and **scale up** evidence based programs that result in positive health outcomes for people with disabilities

- Current best practices include:
  - Care plans
  - Navigators
  - Joint Commission Tracers
  - Health resumes/passports
  - Health promotion interventions

- Research needed to examine impact of these practices on outcomes
Action Plans

• Video project with WITH Foundation
• Connect organizations that have programs that can be shared and extend to others
• Develop a repository of practices and resources
PATH-PWD Theme #5

Identify and develop valid, reliable, practical and sensitive instruments to measure outcomes relevant to persons, systems, and providers

• Research Action Plan
  – Measures of shared decision making – there is a call for AHRQ proposals
  – Include shared decision making with people with IDD in any proposals
PATH-PWD Theme #6

Improve *communication, planning, and support in transitions* - *transitions are a dangerous time*

- Best practice – health resumes/passports are among efforts
- Working with managed care
- Research – do these make a difference?
Post Conference Action Plans

• Improve use of tools that exist – health resumes, care plan, current training
• Explore with service agencies how to improve health of people with ID
PATH- PWD Theme #7

Identify & analyze data sources to better understand definitions of disability, service needs and use, social determinants of health and healthcare disparities, health care experiences, and health outcomes

• Research – can we use large data sources to do this?
Action Plans

• Use big data sets to identify trends in health care and identify areas for improvement
• Current study on patients with autism
Work Groups

Energy during conference led to 5 work groups
1. Training and education of healthcare professionals
2. Involve people with disabilities in all aspects of healthcare
3. Develop research capacities
4. Extend use of existing programs and research outcomes
5. Advocacy efforts
Work Group: Training and Education of Healthcare Professionals and First Responders

• Ensure that competency language in Alliance for Disability in Healthcare Education (ADHCE) is accessible and reflects consumer control

• Hold meetings of people with disabilities to develop lay consumer-controlled language for two competency areas.

• Develop for all competencies and make available to people with disabilities
Training and Education of Healthcare Professionals and First Responders

• Move the work of this group to the ADHCE, whose membership increased as a direct result of the PATH-PWD
• Ensure that the competency language being developed is accessible (including ADHCE effort)
• Develop a plan for language for consumer-control, in competency work and elsewhere
• Organize and conduct a meeting of people with disabilities to give additional feedback to ADHCE’s competency projects.
Work Group: Involving People with Disabilities in All Aspects of Healthcare

• Explore employment of people with IDD in healthcare industry
  – Training and education to develop skills for employment

• Identify existing programs, evaluate outcomes, identify best practices.

• Write report on existing programs with recommendations to advance
Work Group: Developing Research Capacities

• Brainstorm how people with disabilities can be more involved, remembering the mantra “nothing about us without us”

• Focus on health promotion - based on interests of group members

• Write 5-year Research & Training Center grant at UIC - people with disabilities and health, incorporating themes emerging from conference
Work Group: Extend Use of Existing Programs

• Compare models of “health resumés” for people with ID
• Review “navigator” programs already in place for people with ID
• Discuss how outcomes can and should be measured
• Connect organizations that have programs that can be shared and extend to others

Possible 5/31/18 goals:
• Funding from WITH Foundation for video
• Determine use of a health resumé across country for possible use in state government work (e.g., in Illinois)
• Clarify and define “navigator” role for people with ID
• Use University Healthsystem data base to address outcomes at institutions with some defined programs for people with ID vs. not
Work Group: Advocacy Efforts

- Focus on Federal policy issues, especially Medicaid cuts
- Identify and evaluate who is doing what on which advocacy topics
- Share resources using Dropbox as a central repository
- Expand knowledge base on advocacy topics across and in healthcare professions
Involving People with Disabilities in Healthcare Systems

• Define, gather information, and disseminate information about “model” programs of involvement, including groups outside the disability community

• Evaluate, summarize and recommend model programs

• Write a journal article about the importance of involving people with disabilities at all levels in healthcare systems
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• Hosts:
  – Rush University Medical Center
  – University of Illinois at Chicago