Developing Strategies to Engage Adult Providers in Health Transitions of Youth with Special Health Care Needs

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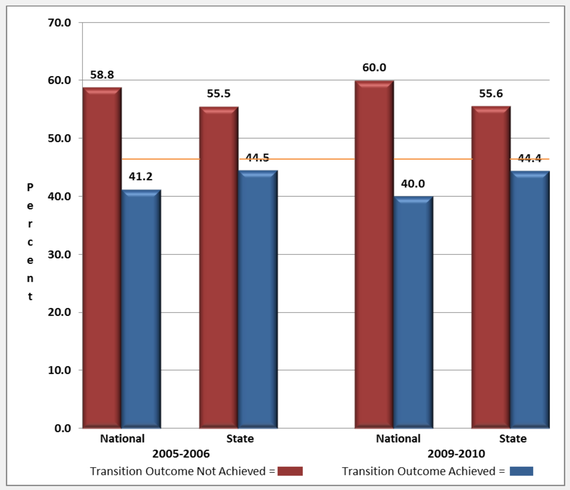
Introduction

Youth health transition initiatives have primarily involved pediatric providers and focused on promoting self-care management capabilities of youth with special health care needs (CYSHCN) and their families. However prepared adult providers are essential for youth to complete the successful transfer to adult health care or an adult approach to care.

Wisconsin

Survey data from Wisconsin indicate that over half of youth do not achieve their health transition outcomes.

2005-2006 and 2009-2010 National Survey of Children with Special Health Care Needs



MCHB Outcome #6

"Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence – CSHCN age 12-17 years only"

Data Source: http://childhealthdata.org

- Factors decreasing the likelihood of receiving youth health transition services:
  - o Presence of emotional, behavioral, or developmental issues (32% receive services vs 51% of those without issues)
  - o Lack of adequate insurance (35% receive services vs 50% of those with insurance)
  - o Lack of a medical home (36% receive services vs 55% of those with a medical home)
  - o Male gender (38% receive services vs 52% of females)

Transition Barriers Identified

Literature Review & Key Informant Interviews

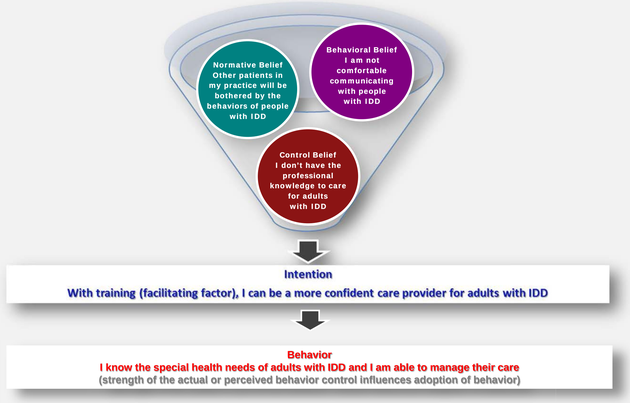
- Inadequate access to adult health care providers
- Insufficient adult provider reimbursement
- Challenges in long-term relationships among pediatricians, parents, and patients
- Insufficient collaboration between pediatric and adult providers
- Insufficient adult provider training: childhood-onset conditions, family supports
- Insufficient anticipatory education of parents and patients on transition and adult health care

Goals

- Increase adult health care provider awareness of their role in supporting health care transitions
- Positively affect provider attitudes and perceptions about caring for people with intellectual and developmental disabilities
- Develop effective transition education outreach that supports increased adult health care provider clinical capacities for active participation in transitions to adult care

Conceptual Framework

Ajzen's Theory of Planned Behavior



(Adaptation of Ajzen's Theory of Planned Behavior; IDD: Intellectual and Developmental Disabilities; Ajzen & Madden, 1986)

Strategies: Training Plan

Initiate (2016)
- UW Health **communication blitz** featuring *Health Facts for You: Youth Health Transitions*
- UW Health **adult primary care provider questionnaire**
- **Connect** with other **organizational stakeholders** (e.g., WI Primary Health Care Association [WPHCA]; American College of Physicians [ACP] WI Chapter; WI Academy of Family Physicians[WAFP])

Educate (2016-2017)
- ***Lunch N' Learn*** for family medicine/internal medicine community-based practices
- UW School of Medicine and Public Health **Department of Medicine *Grand Rounds***
- **Nurse Practitioner course presentation** (e.g., UW School of Nursing)

Collaborate (2016/2017)
- **Baylor College of Medicine Transition Conference (October 27-28, 2016):** invite all UW Health family medicine and internal medicine providers and UW School of Medicine and Public Health and UW School of Nursing faculty and students
- **Youth-to-Adult Health Transition Forum (Spring or Fall 2017):** convene statewide multidisciplinary stakeholders

Innovate (2017+)
- MCH Youth Health Transition grant for a community-based adult primary care practice to **pilot the evidence-based Illinois AAP Transition Care program for adult medicine** (Sanabria, K.E., Rush-Ross, H.S., Bargeron, D.A.C., & Kalichman, M.A. (2015). Transitioning youth to adult healthcare: New tools from The Illinois Transition Care Project. Journal of Pediatric Rehabilitation Medicine, 8, 39-51. doi: 10.3233/PRM-150317)

Key Activities

- Convened three meetings of an Adult Health Transition Advisory Group
- Established an overarching training plan
- Produced an annotated transition resource toolkit
- Designed a training outline: Lunch N' Learn with six training options
- Adapted two provider assessments
  - o Attitudes Survey
  - o Adult Primary Care Provider Questionnaire
- Developed a training evaluation tool
- Identified one new adult health transition champion

Resources

- Annotated Transition Resource Toolkit
- American College of Physicians (ACP) toolkit: https://www.acponline.org
- Illinois Transition Care Program
- Baylor College of Medicine Annual Chronic Illness and Disability Conference
- Special Hope Foundation: http://specialhope.org

Recommendations

- Ensure fidelity to adult health provider focus
- Persevere: prolonged system process negotiation can produce unexpected gains
- Enable sustainability
  - o Key: Identify transition advocates and champions from within the organization/health care system
  - o Initiate and develop a system-wide evidence-based transition clinical practice guideline or policy
  - o Utilize existing evidence-based resources (e.g., Got Transition™)
- Collect ongoing data to demonstrate value-added

Acknowledgements

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