Providers’ Views on Transition of Healthcare for Youth with Developmental Disabilities

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First, some definitions...

- **DD**: developmental disability
  - includes autism spectrum disorders (ASD), cerebral palsy, learning disabilities, Down syndrome, and global developmental delay

- **Health care transition**: a dynamic, lifelong process that seeks to meet a patient’s individual needs as they move from childhood to adulthood
  - Goal of transition: to maximize lifelong functioning and potential through the provision of high-quality, developmentally-appropriate health care services that continue uninterrupted as the individual moves into adulthood.
  - Patient-centered
  - Elements:
    - Flexibility
    - Responsiveness
    - Continuity
    - Comprehensiveness
    - Coordination

- **Youth**: adolescents and young adults
  - “Transition-age youth” usually refers to those between the ages of 18-21
The Problem

- **Problem**: Youth with DD have conditions that may limit their ability to function, with resulting social, emotional, or behavioral sequelae, and experience difficulty transitioning from child to adult health care. Also, adult providers may lack training and comfort level in working with patients with DD.
  
  - For example, youth with ASD need an adult provider who understands autism but doesn’t see every health or behavior problem as a result of autism.

- **National Need**: 1 in 6 children in the U.S. has a DD. Each year, almost half a million of these children transition into adulthood.
  
  - As for ASD, 1 in 68 children (1 in 42 boys) meets ASD diagnostic criteria.

- **State Need**: In Vermont in 2006, 540 children and adults with ASD (with 126 in Chittenden County alone) were being served by the Vermont Community Mental Health and Developmental Services programs. Since then, the number of children with ASD has grown approx. 20% per year.

- **Community Need**: Hinesburg Family Practice currently sees 11 patients with a Code 299 diagnosis (pervasive developmental disorders) per year. These patients accounted for 25 visits during FY 2014. The patients range in age from 5 to 53 years (median age: 17 years).
Public Health Cost

• Autism has been described as a global public health crisis
• Autism’s costs to the nation have reached $137 billion per year.⁵
• Children with parent-reported ASD found to have higher levels of health care office visits and prescription drug use compared to children without ASD.⁶
• After adjusting for child demographic characteristics and non-ASD-associated illnesses, ASD was associated with $3020 higher annual health care costs.
• Children with autism found to have much higher than expected rates of medical conditions, including epilepsy, schizophrenia, IBD, IBS, CNS/cranial anomalies, DM type I, muscular dystrophy, sleep disorders.⁷
• Other comorbidities: anxiety, depression, ADHD, social isolation... it adds up!
Community Interview 1:

Name withheld, parent advocate, 16 y.o. son with ASD

- Described a fragmented system and process to get services
- Continuity of care does not exist
- Parents as advocates and navigators
  - Shared knowledge, resources with providers
- Describes herself as an informed healthcare consumer and was still challenged
- Monthly team meeting:
  - Parents
  - Patient
  - Director of school
  - Primary point person at school
  - Teacher in regular HS
  - Case manager from school system
  - Howard Center case manager
  - Psychologist (via e-mail)
  - Social skills therapist
  - No physician (although the pediatrician has the most continuous role)
- Would like to see the development of a system of care
  - Website with info. on services available in your community
  - Helps you self-navigate as a parent, a provider, or an educator
Community Interview 2: Dr. Name withheld, M.D. – pediatrician

- Expressed **difficulty navigating** services
  - (e.g. Howard Center Developmental Services, child & adolescent psychiatry assessments)
  - Patients qualify but still have difficulty getting them
- “Who would I transition him to?”
  - “What adult provider is open and **willing** to take on these kids?”
  - Even typically-developing kids have transition challenges
- In an ideal world, would parallel the Pulmonology: Cystic Fibrosis transition model
  - Young adult patient gets handed off from pediatric pulmonologist to adult pulmonologist who is trained in pediatric CF
  - **Continuity of care** from specialists
  - **Ongoing communication, meetings**
  - Who has this role in DD? Psychiatry? Family Medicine? Med-Peds?
Family Medicine & Healthcare Transition

- Due to continuity of care, family physicians play a unique and important role in the transition process

- Three distinct goals of the provider:
  1. Providing developmentally appropriate care for youth and young adults who remain within the practice as they transition to an adult approach to health care,
  2. Transitioning youth and young adults to different adult providers when they move or go away to college, and
  3. Accepting and integrating new young adult patients who have transferred from other providers.

- Consistent with the AAP/AAFP/ACP Clinical Report on Health Care Transition, transition should consist of joint planning with youth to foster development of self-care skills and active participation in decision-making.
Intervention & Methodology

- **Intervention**: Anonymous 12-question survey to assess providers’ perceptions and roles in the healthcare transition of youth with DD.

- **Method**:  
  - In September 2014, providers at Hinesburg Family Practice in Hinesburg, Vermont were given an anonymous survey to fill out.  
  - The survey was developed and adapted from Got Transition resources on healthcare transition in typically-developing youth  
  - Questions assessed how often providers saw patients with DD, who the care coordinator was, how often family members expressed concerns about transition, how often the providers discussed transition issues with patients (managing own health), referral services (types and ease of referral), and the providers own training and comfort in providing care to patients with DD  
  - The data were then analyzed and the results presented to the staff at Hinesburg Family Practice.
Results

• A total of 4 providers responded to this survey
  • 50% female, 50% male
  • All are board-certified MDs in Family Medicine
  • All are providers at Hinesburg Family Practice
  • Hinesburg Family Practice is a Patient-Centered Medical Home

• All providers see at least one patient with DD at least yearly, with most (75%) seeing them monthly
Who is the care coordinator for services?

- The physician
- Social worker
- Patient's caregiver/parent
How often do you actively work with your transition-age patients to gain skills to manage his/her own health and health care?
To which of the following services do you refer your patients with DD for assistance with transition of care or for obtaining more comprehensive levels of adult services?
How would you rate the services available for transition-age youth with DD?

- Very few exist, if any
- Services exist, but difficult to find/navigate
- Services exist and available to patients, families, providers
Do you feel that you have the training and are comfortable providing comprehensive care yourself for young adults with DD?
Selected comments to Question 12 - *What is the biggest challenge in navigating the system of care and making treatment recommendations for young adults with DD?*

- “Working with parents to convince them that transitions are needed and beneficial to their disabled child.”
- “Not knowing what resources are available or what the patient qualifies for.”
- “When the patient also has psych concerns, there are often waitlists for full evaluations.“
- “Knowing where to refer (who takes responsibility).”
- “Without a strong [parent] advocate, I can refer them to sources for help, but it is often hard to know if things were followed through on.”
- “[One] challenge is privacy rules with mental health providers, it makes communication challenging.”
Discussion

**Discussion:**

- According to most providers, the patient’s parent/caregiver was the main coordinator of services.
- Most providers reported *rarely* working with their transition-age patients with DD to gain self-management skills regarding their own health and healthcare.
- A variety of community services are utilized, although providers expressed difficulty in navigating appropriate services for their patients with DD,
  - A more systematic and comprehensive pathway or “care map” is needed.
- Most providers indicated that they are *somewhat* comfortable in providing comprehensive care to young adults and adults with DD, suggesting that more training may be beneficial.

**Limitations:**

- Small sample size of only 4 respondents.
- Limited sample of patients (only 11 identified with PDD at HFM).
- Providers’ responses may not reflect the views of those at other practices.
Future Recommendations

• Survey other Vermont family physicians, as well as pediatricians (focusing on transitioning the care) and internists (feeling comfortable providing care) to see if perceptions and roles differ based on specialty

• Survey patients with ASD and their caregivers and family members to assess their views and comfort level as related to the Medical Home and transitional services

• Long-term goals:
  • Share results and collaborate with Vermont Interagency Autism Planning Advisory Committee (APAC)
  • Identify barriers to coordination of healthcare transition
  • Develop a training protocol and distribute resources to assist providers in coordinating healthcare transition for their patients with ASD
Helpful Resources

For transition-age patients:

- Healthcare Transition Plan for Teens
- Healthcare Management Skills Checklist
- Pediatric vs. Adult Care: PKU model
- Transition Information Form

For providers:

- *Six Core Elements of Health Care Transition 2.0 for use by Family Medicine and Med-Peds Providers*
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