

# Understanding Health Care Transition for Adolescents with Developmental Disabilities: A Family and Professional Perspective

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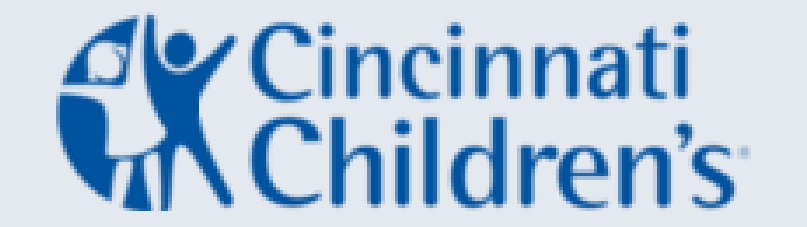
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## Introduction

- Adolescents and young adults with developmental disabilities have difficulties transitioning from pediatric to adult health care.
- "Health care transition is the purposeful and planned process moving from the pediatric to the adult health care system." (Blum, 2003)
- Research suggests that both families and health care providers face difficulties with the health care transition process. (Geenen et al., 2003)
  - Barriers for families and adolescents include finding knowledgeable adult providers, difficulty with managing one's own care, and lack of access to a service coordinator
  - Barriers for providers include a lack of training in developmental disabilities, a limited amount of time to focus on transition, and a lack of financial reimbursement for transition services

## Study Objectives

- Gain more detailed information about the transition to adult health care by asking parents/caregivers of adolescents with developmental disabilities to share their perspectives and experiences
- Assess the knowledge, experience, and perspectives of pediatric health care providers regarding health care transition and the supports and barriers to the transition process for adolescents with developmental disabilities

## Method

### Participants

- Participants in the Parent Focus Group were five parents of adolescents with developmental disabilities, recruited from an ongoing research study at Cincinnati Children's Hospital Medical Center (CCHMC) about issues with the transition to adulthood
  - Parent participants had adolescents with developmental disabilities between the ages of 15-17 that included Autism Spectrum Disorder, Spina Bifida, Down Syndrome, and Intellectual Disability (n = 2)
- Participants in the Professional Focus Group were eight healthcare professionals who worked with adolescents with developmental disabilities or special health care needs at CCHMC
  - Disciplines represented included Pediatric Nurse Practitioner (n=2), Nurse Care Manager (n = 2), Child Life Specialist, Developmental Pediatrician (n=2), Social Worker
  - Participants worked with adolescent patients with developmental disabilities, sickle cell, and transplant issues

## Procedure

- Examples of Focus Group Questions for Parent Participants*
  - What aspects of healthcare transition are you familiar with? Not familiar with?
  - In terms of services and supports, what has worked or what has been helpful so far?
- Examples of Focus Group Questions for Healthcare Professional Participants*
  - How do you initiate the health care transition process and follow-up with your patients?
  - What are some of the barriers for you regarding transition planning and preparation?

## Analysis

The parent and professional responses to the questions were coded for recurring themes in a three-step process:

- The researchers discussed field notes and patterns of observations from the focus groups
- Two researchers coded each focus group transcription to identify recurring themes
- The researchers met and consensus-coded to reach agreement on final themes and subthemes

## Results

### Themes from Parent/Caregiver Focus Group

#### Communication

- Communication between providers and families
- Communication between multiple providers

"I've had other parents talk to me about it [transition]...but I haven't had an actual provider talk to me about it."

#### Care Coordination

- Coordinating care with other providers and agencies
- Overall Awareness with Health Care Transition for Families*

"There are a lot of great physicians and therapists and all kinds of medical personnel out there...they just might not be aware of how great that need is [serving adolescents with developmental disabilities and their families]. So I think sometimes it is just awareness is probably a key because if you don't know there is a problem, how can you work on a solution?"

#### Supports for Transition

- Resources

"If you don't have a care coordinator, which specialist should you prioritize and who can help you bridge that gap without the care coordinator?"

## Themes from Professional Focus Group

### Barriers

#### Legal Issues

- Guardianship and legal ramifications of turning 18
- HIPAA regulations and information sharing
- Insurance Issues

"It's hard for the adult care system to figure out how to integrate the family meaningfully and with HIPAA."

#### Providers/Facilities

- Lack of communication
- Contrasting environments between health care settings
- Adult providers' lack of knowledge and comfort
- Pediatric patients not using primary care providers
- Saturation of knowledgeable adult providers

"At Children's we really nurture and care. And then when you go to an adult facility, immediately it's kind of switched."

#### Patient/Family

- Patient's ability to self-manage
- Lack of knowledge of health care transition
- Level of family involvement

#### Other Supports

- Sustainability of transition tools and processes

"We seemed to have check sheets at one time, then comprehensive lists, and then those kind of fall off. Then somebody else will come up with some big, beautiful check list and that kind of falls off."

### Facilitators

#### Providers

- Use of social workers and transition coordinators
- Effective communication
- Using a team approach

#### Family/Patient

- Family role in the transition process
- Providers' ongoing support to family/patient

"I hear you say a policy would be really instrumental. It's not just our [pediatric health care] policy. It sounds like they [adult health care] would need a policy too...You really do need a system of care, a policy, and a role."

#### Other Supports

- Transition policy
- Developmental disability services
- Institutional support

"If you think about how we want the primary care doc to take more of this role [transition coordinator], they're not going to have that sort of resource. It's a really good resource to have. There's got to be institutional investment."

## Discussion

- Both parents and providers mentioned an overall lack of knowledge regarding healthcare transition and what it encompasses for youth with developmental disabilities
- Regarding all of the areas of transition for youth with developmental disabilities, healthcare transition did not seem to be the biggest priority for parents
- Parents and providers both communicated the need for greater collaboration among pediatric and adult healthcare providers, community agencies, and schools, as well as families
- There was a general consensus among parents and providers that there is a need for resources and easily accessible information regarding best practices for healthcare transition

## Limitations

- Small sample size
- Limited diversity of providers (e.g., no community-based primary care providers)
- Limited knowledge of transition for the family participants
- Selection bias

## Next Steps

- Additional focus groups should be conducted with larger, more diverse samples
- Specific supports for the healthcare transition process should be identified, developed, and made accessible to providers, adolescents, and their families
- Investigate the perspectives of adolescents with developmental disabilities on their own healthcare transition needs
- Explore the perspectives of school personnel regarding their knowledge of healthcare transition and the role they might play in supporting healthcare transition for adolescents

## Selected References

- Blum, R.W., Britto, M., Sawyer, S.M., & Siegel, D.M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 33*, 309-311.
- Geenen, S.J., Powers, L.E., Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health, 32*, 225-233.

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