

**HEALTH CARE TRANSITION FOR INDIVIDUALS WITH INTELLECTUAL AND/OR  
DEVELOPMENTAL DISABILITIES:  
A POLICY BRIEF**

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**Team Project Abstract  
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Background: With nearly half a million children with special health care needs (SHCN) reach adulthood each year, there is increasing importance for transition planning from child-focused to adult-focused health care systems. A 2002 consensus statement of the American Academy of Pediatrics, American Academy of Family physicians, and American College of Physicians-American Society of Internal Medicine emphasized the importance of supporting and facilitating the transition of adolescents with SHCN into young adulthood and identified critical steps for optimal transition, and this report was reaffirmed in 2015. Despite these recommendations, most medical schools have little or no curricula on disabilities training, and only 40% of individuals with SHCN receive the necessary services for appropriate transition to adult life and adult health care services.

Objective: To outline the current status of health care transition, including evidenced-based barriers and potential strategies to overcome such challenges.

Methods: Team members conducted a review of evidenced-based literature and other resources.

Progress-to-Date: Barriers to health care transition have two main themes:

**Family-focused**

- Strong patient and family attachment to pediatricians
- Ambiguity about available supports
- Perceived lack of knowledge and experience of adult providers

## **Physician-focused**

- Provider feelings of anxiety, discomfort, and other negativity associated with individuals who have disabilities
- Shortage of adult providers trained and experienced in treating patients with disabilities
- Lack of patient and family involvement in transition process
- Lack of equipment and other supports

Based on these barriers, strategies have been proposed in the literature which include:

- Specific transition clinics staffed jointly by pediatric and adult physicians
- Greater communication among providers
- Portable summaries of care needs
- Documentation of guidelines and individualized plans
- Web-based training to develop patient management and communication skills

Furthermore, the school environment should be utilized as a transition education setting. The curriculum developed by University of South Florida School of Medicine and University of Michigan Medical School have been shown to be successful in improving medical students' knowledge of both health concerns and societal barriers of patients with disabilities. In addition, the concept of a patient-centered medical home (the main characteristics of which are being patient-centered and providing comprehensive and coordinated care) has been suggested as a way of improving the transition process.

## Recommendations:

Provide individuals and families with adequate, accessible resources and tools:

- Assign specific staff to assist with coordinating transition services
- Make transition support services the standard of care
- Identify multimedia tools such as [TakingChargeofMyHealth.org](http://TakingChargeofMyHealth.org) that can promote independence and self-advocacy among individuals with disabilities

Improve provider education and training:

- Reform medical school training to include experiences with patients with disabilities and demonstrations of best practices for individuals with special health care needs
- Provide practicing providers with similar educational opportunities via online CME courses and other programs
- Address societal and economic issues such as how to approach a lack of patient and family interest in transitioning, reimbursement conflicts, and equipment and accessibility management