

# Navigating Health Care Transition: An Exploration into the Experiences of Parents and their Adolescents with Special Health Care Needs Utilizing a Transitional Care Service

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## Abstract

Adolescents with special health care needs encounter barriers and challenges during transition to adult health care that have the potential to impact health outcomes and satisfaction with the experience. The use of transitional care services can provide resources and support throughout the transition process to the adolescent and their parent/caregiver. This descriptive survey study was conducted to evaluate adolescent and/or parent/caregiver satisfaction with the transitional care services provided by an urban, academic, pediatric health care facility. Nineteen of 39 (49%) eligible participants completed the survey. Findings indicate that adolescents and their parent/caregiver were satisfied with the resources and support offered by a transitional care service and experienced positive health outcomes, reinforcing the need for collaboration between pediatrics and adult care providers. Transition of care barriers/facilitators included: concerns with the transition, making the connection, and facilitating the transition.

**Keywords:** adolescents with special health care needs, parent/caregiver, transition, adult health care, perceptions, satisfaction, facilitators, and barriers.

## Background and Significance

- Transition to adult care is often disorganized as a result of barriers that include, emotional and cognitive developmental challenges, lack of individual and family-centered social supports, difficulties in communication and coordination of care between pediatric and adult health care systems, and gaps in health insurance at the age of transition<sup>1</sup>
- The 2016 National Survey of Children's Health indicated more than 14 million children have special health care needs. Over one-quarter of households with children have at least one child with special health care needs.
- The literature has identified that without established transitional care programs 25% of adolescents who transfer to adult health care services do not regularly attend follow-up visits<sup>2</sup>

## Clinical Question and Objectives

**Does the utilization of a transitional care service improve patient and parent/caregiver satisfaction with the transition experience?**

- To evaluate the satisfaction of the adolescent with special health care needs and their parent/caregiver who utilized the Multidisciplinary Intervention Navigation Team at the Children's Hospital of Philadelphia.
- To identify the barriers and facilitators that had the highest impact on the transitional care experience.



## Methods

### Setting

- The Children's Hospital of Philadelphia Multidisciplinary Intervention Navigation Team

### Population

- English-speaking adolescents with special health care needs who were ≥ 18 years of age, utilized the MINT service, received care from three or more subspecialists and/or had an intellectual/developmental disability and English-speaking parent/caregiver of an adolescent with special health care needs who had an intellectual and/or developmental disability.

### Survey Instrument

- Developed by this researcher and members of the MINT service
- A 23-item survey, using the Six Core Elements of transition as the guiding framework.
- The survey was comprised of four sections:
  - (a) Pediatric care transition experience
  - (b) MINT service transition experience
  - (c) Adult care transition experience
  - (d) Feedback regarding the MINT service

## Results

**Table 1: Patient and parent concerns regarding transition**

Concerns	Percentage	N
Changing medical providers	94.4%	17
Location of providers	27.8%	5
Different quality of care in adult health care	77.8%	14
Loss of relationship with the pediatric care team	66.7%	12
Learning a new health system	27.8%	5
Insurance coverage	22.2%	4

**Table 2: Thematic Analysis**

Theme	Patient/Parent response
Concerns about the transfer to adult health care	<i>My disability is rare, and I was worried nobody would know about it.</i>
Making the connection with a new health care team	<i>We miss the "connection" with our pediatric providers, and we felt dropped. More follow up with families after the transition to make sure there are no issues and to make sure the new appointment went well.</i>
Facilitators of the transition experience	<i>The MINT service was always very quick to get back to me. They were great at problem-solving. Everyone was positive, kind, generous and professional. The process is fantastic, the service held my hand" and "[MINT nurse practitioner] was wonderful, he "walks gently," was very perceptive and sensitive to what we were going through. I appreciated the help researching providers, figuring out who accepted our insurance and a liaison to make sure I didn't forget anything.</i>

## Discussion/Recommendations

- The transition experience is frightening and challenging to both patients and parent/caregivers.
- Parents did not feel emotionally prepared for the transition experience.
- Start the conversations earlier regarding transition to an adult care provider.
- Education and psychological support needed during and after the transition.
- Foster interprofessional collaboration between pediatric and adult care providers.
- Increase training opportunities for family and adult nurse practitioner students, medical students and residents with medically complex adolescents.
- Future research to assess what role lower reimbursement plays in the adult provider's willingness to engage in transition visits.

## References

Data resource Center for Child & Adolescent Health. National Survey of Children with Special Health Care Needs. <http://childhealthdata.org/learn/NSCH>. Published 2016.

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