

# Health Care Transition for Adolescents with Special Health Care Needs: A Report on the Development and Use of a Clinical Transition Service

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## ABSTRACT

**Background:** A growing population of adolescents with special healthcare needs is aging into adulthood. These emerging adults face the transition challenges of their healthy peers but also potentially heightened risks and challenges related to their conditions. We describe the process of developing a pilot program to support healthcare services for emerging adults with chronic conditions and present preliminary data on utilization.

**Results:** An outpatient multidisciplinary consult model was developed based on patient, family and physician feedback. Patients with diverse conditions were equally referred from primary care, subspecialists and families and community agencies. Services provided included needs assessments (100%), referral to adult physicians (77%), care coordination (52%) and referrals to adult community services (10%). Clinical billing did not fully support the cost of providing services.

**Conclusion:** The pilot program offered multidisciplinary transition services that were utilized by a diverse patient population. Local and national resources for health care transition are provided.

**KEYWORDS:** transition to adult care; adolescent; young adult

## INTRODUCTION

Medical advances have dramatically improved survival rates for many conditions that had once been fatal in childhood. Survival rates in excess of 90% are now realities for children with conditions such as spina bifida, sickle cell disease, cystic fibrosis and cancer. Our success has created a new challenge: How will we care for these emerging adults with chronic conditions?

This article will review current data on transition in Rhode Island and provide results of a pilot program to support healthcare services for emerging adults with chronic conditions. Local and national resources for health care transition are provided.

Although all adolescents need to transition to adult roles in personal, social, educational/vocational and health domains, those with chronic conditions or disabilities can anticipate heightened risks and challenges in this process. Emerging adults with chronic conditions are a significant subset of any primary care practice. In Rhode Island, 1 in



Children in the transition clinic created this mural.

5 children between the ages of 12-17 are reported to have a special healthcare need,<sup>1</sup> defined by the U.S. Department of Health and Human Services as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.<sup>2,3</sup> Pediatricians and family practitioners need to prepare patients and families to transition to adult care models (even if continuing care within their practices) and internists need to be aware of issues common in transitioning this group.

Health care transition is defined as "a deliberate shift from pediatric to adult-oriented providers, settings and content of visits to provide comprehensive, age-appropriate care."<sup>4</sup> It is a key element of the patient-centered medical home and a core outcome measure for healthcare systems. However, national surveys indicate only 40% of eligible children report transition care. Rhode Island slightly surpassed the national average, but significant gaps included patients who reported a lack of discussions about transition to adult providers, changing health needs and insurance, and a lack of encouragement to assume increased responsibility for care. Adolescents with special healthcare needs (ASHCN) who lacked a medical home, were uninsured or of racial/ethnic minorities were less likely to receive transition services.<sup>5</sup>

Rhode Island Department of Health (RIDOH) surveys have reported a marked lack of comfort among adult primary care providers in caring for ASHCN and reported gaps in care during periods of transfer. Specific needs cited included written

transfer summaries and communication with pediatric care providers.<sup>6</sup> Fewer than 1 in 5 pediatric practices had a coordinated process for transferring ASHCN.<sup>7</sup> A survey of pediatric subspecialists practicing within Rhode Island identified availability of adult subspecialists, primary care providers and time within visits to address transition issues as the issues most frequently affecting their adolescent patients. Among options for adding services, the provision of a step-wise process of transition for providers and families, a written medical summary, written transition information and information on non-medical transition resources were priorities.<sup>8</sup>

## MATERIAL AND METHODS

The Rhode Island and Hasbro Children's Hospitals Transition Consult Clinic was developed as a resource for health care transition of ASHCN. The structure and content was developed with input from key stakeholders, including RIDOH's Office of Special Healthcare Needs, the Rhode Island Parent Information Network (a family and patient advocacy network), CEDARRS (a pediatric community care coordination program), the Adolescent Leadership Council, adult community services providers, clinical managers (nursing) and subspecialty and primary care physicians. Preliminary needs assessments incorporated state-specific data from the 2009-10 Survey of Children with Special Health Care Needs, RIDOH data, pediatric and adult provider surveys<sup>8</sup> and the input of patients and families at state forums and as represented by advocacy groups. An outpatient consultation model was proposed and included a multidisciplinary team supported by the hospitals and RIDOH. Interim goals for patient referrals, assessments and interventions were established. Data was collected on referrals, patient needs and interim outcomes, provider hours, services, and billing. Data collection on patient satisfaction and longer-term outcomes is ongoing.

Pre-visit contacts were conducted by the clinical coordinator or physician and sought brief information on condition and anticipated needs and goals from the referral source. Available medical records were reviewed. New patient visits incorporate a broad needs assessment, including a structured transition readiness tool, a review of the medical history and a physical exam. A post-session team meeting reviews the needs assessment and drafts a transition plan. Subsequent visits are scheduled as needed to allow review of emergency plans, medical summaries and written transition plans as well as follow-up of active medical issues and referrals. Summaries are provided to patients, families and primary and subspecialty providers in written and, if preferred, electronic versions. During the pilot period, our clinics adopted an outpatient electronic medical record (EMR). In-house technical support assisted in creating within the EMR a transition template, flowsheet and order set with patient handouts.

**Table 1.** Prevalence of conditions seen in transition consult clinic:

	N	%
<b>Cognitive disability</b>	9	29
<b>Cerebral palsy</b>	5	16
<b>Metabolic disorder</b>	5	16
<b>Sickle cell disease</b>	5	16
<b>Wheelchair-reliant</b>	5	16
<b>Autism spectrum disorder</b>	4	13
<b>Rheumatologic (lupus, idiopathic arthritis)</b>	3	10
<b>Muscular dystrophy</b>	3	10
<b>Survivor of childhood cancer</b>	2	6
<b>Chronic kidney disease</b>	2	6
<b>Crohns Disease, Down syndrome, seizure disorder, congenital heart disease</b>	1 each	3

## RESULTS

The outpatient consultation model was trialed over a two-year period. Due to limitations of provider availability, 21 sessions were scheduled. Fifty-five patients were referred, 31 patients were seen for a total of 40 patient visits and 11 did not keep appointments or rescheduled. Primary-care pediatricians, subspecialists and families and community agencies each represented ~1/3 of referral sources. One-third of patients not seen following referrals did transition their care to a primary care site providing services to pediatric and adult patients, but did not schedule specific transition consultation visits. Several other families requested specific service referrals but declined on-site consultation visits when contacted by telephone.

### Patient characteristics

Patients ranged in age from 16-24 years (mean 19.6). Medical conditions varied, with more than half of patients carrying multiple diagnoses (Table 1).

### Needs assessments and transition readiness

Parents identified more needs than adolescents. Adolescents often responded, "I don't know but want to learn to" regarding learning to contact their doctors and arrange visits independently, managing their money and budget, applying for jobs and obtaining financial assistance. Self-management skill needs most often reported included: describing medical condition, identifying risk signs/symptoms for condition, reporting medications and allergies, talking independently with a physician and knowledge of changes in insurance and benefit eligibility with change in age. All patients noted at least 1 skill they performed independently. Of 29 assessed self-care skills, slightly over half (52%) reported: "I am learning to do this"; or, "I have started doing this;" or, "I always do this when I need to." Almost half of families reported earlier discussions with primary or subspecialty physicians regarding a need to change providers as the ASHCN aged into adulthood. All families reported receiving at least one new care or service option when meeting with the advocate/adult services specialist.

**Table 2.** Transition Services Provided

	#	% of eligible*
<b>Referrals:</b>		
Care coordination	16	52%
Adult community services	3	10%
Adult subspecialist(s)	7	58%
Adult Primary Care	10	77%
Adolescent Peer Group (TALC)	11	84%
<b>Medical Summary:</b>	9	29%
<b>Emergency Care Plan:</b>	9	29%
<b>Transition Plan:</b>	9	29%
<b>Transition flowsheet</b>	7	22%
<b>Transition needs assessment</b>	31	100%
*Some patients were already enrolled in care coordination programs, had adult primary or subspecialists or other pieces of transition in place.		

**Patient outcomes**

An electronic medical record recording services and recommendations was created for all patients. Discrete elements of services are detailed in Table 2.

**Time, effort and charges**

Visits ranged from 45-120 minutes. All patients saw the physician, nurse coordinator and advocate/adult service specialist in their initial visit. Interactions with the adolescent peer group coordinator and family therapist were determined by needs assessments and patient and family's willingness. Pre-visit preparation averaged 20 minutes for the nurse coordinator and 20 minutes for the physician. Post-visit follow-up ranged from 15–45 minutes for the physician and 15–120 minutes for the nurse coordinator. The advocate/adult service specialist provided from 15 minutes-5 ½ hours of follow-up. Follow-up efforts ranged from summarizing visits and transition plans to direct contacts with schools, subspecialists and other agencies to home visits for additional needs assessment. Billing ranged from \$107-\$462.

An assessment of patient and family satisfaction with services and longer-term follow-up, including tracking progress through the EMR flowsheet, is ongoing. It remains to be established whether the services are financially sustainable on clinical billing. Transition clinics in other states are often additionally supported by institutional and grant funding.

**CONCLUSION**

Addressing transition issues in a busy primary or specialty practice is a significant challenge. Minor adaptations of our electronic health record to include flowsheets, timelines and easy-to-access screening tools support incorporating transition discussion into brief visits and monitoring progress on self-management skill development. The introduction of the concept of transition at an early age can allow for gradual introduction of necessary skills and empower patients and families to chart pathways to independence or condition-appropriate supports with guidance from their physicians. Explicit transition policies for practices cue patients and families to expectations and their responsibilities in this process.

(Note: Patients with significant issues or seeking added supports can be referred to the Transition Consultation Clinic at 444-6118.)

**Useful online resources**

- RI DOH transition materials <http://www.health.ri.gov/special-healthcareneeds/about/adolescenttransition/index.php>
- RI Parent Information Network <http://www.startingpointsforriparents.org/transitions>
- National transition website: <http://gottransition.org>

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