

Transitions to Adult Care for Rhode Island Youth with Special Healthcare Needs

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ABSTRACT

The transitioning of youth from pediatric to adult care systems is often fraught with discontinuity, miscommunication and gaps in care. This is most significant for youth with special health care needs. A panel discussion on transitioning youth to adult care systems that was part of a learning collaborative held by The RI Care Transformation Collaborative (CTC) is presented here, illustrated by a pertinent case of a youth with type 1 diabetes.

KEYWORDS: health care transition, children with special health care needs, adolescent transition

INTRODUCTION

Moderator: Joanna Brown, MD MPH

RI Adolescent Patient Centered Medical Home Initiative

I'll briefly review the panel's purpose. The Care Transformation Collaborative is a collection of primary care practices seeking to improve primary care in Rhode Island. The transition from pediatric to adult care is a challenge to many practices, whether transitioning from a pediatric to adult-care practice or transitioning the approach to care within a practice to become more autonomous (e.g. a family medicine or combined medicine-pediatrics practice). As more children with complex, childhood-onset conditions survive to adulthood, there is a statewide need for more health care providers who care for adults to accept these adolescent/young adult patients with special health care needs. Panel members will use the following case to illustrate best practices in transition.

JD, a 17-year-old with type 1 diabetes presents to your office for the first time, with his mother. He has additional diagnoses of ADHD and depression, and complains of poor sleep. He takes methylphenidate and fluoxetine. He wears a Foo Fighters T-shirt and black jeans and pays more attention to his smartphone than you. His mother reports she's always scheduled his appointments and refilled his medications. She says they argue daily about checking blood sugars. He's had 2 recent DKA admissions. "He just says he's sick of taking insulin." She worries about losing her job over taking time off to care for him, and hopes it might help to go to a doctor's office that's "not just for little kids and babies."

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The case may understate the challenges. I've added our experiences to the scenario. JD is seen mid-morning, overbooked into a follow-up slot after a recent hospital discharge. Although I'm listed as his primary care doctor, he has not yet been seen in our office. A future physical is scheduled, but I do not have his pediatric records yet. I find 16 EMR documents from recent admissions. After a brief effort seeking responses from JD, his mother opts to answer my questions to move the visit along. I provide requested prescriptions for current medications, and ask about his most recent hemoglobin a1c, ophthalmologic exam, and endocrine care. His mother replies they were just told they need to find an adult endocrinologist to take over his care by his 18th birthday.

Does it have to be like this? No.

I have a better-case scenario: Our office was contacted at hospital discharge to book a follow-up appointment for JD. The nurse noted he was enrolled in our practice with an upcoming visit, but had not yet been seen. The needed post-discharge visit was scheduled for end-of-session, and with the visit-reminder call, his mother was asked to bring his immunization record. Prompted at morning huddle, our nurse called the pediatric office and had the record of a recent visit faxed to our office.

In meeting with JD and his mother, I note our office policy that anyone age 11 and up has time with the doctor on their own as a part of each visit. The policy preserves confidentiality, often improves the history, and offers an every-visit opportunity for an emerging-adult to develop skills in conveying their own needs and concerns when interacting with health care professionals. JD, on his own, is able to relay information regarding insulin dosing and his annoyance at how his diabetes care disrupts his school and social activities. He endorsed smoking cigarettes, but denies alcohol, illicit drugs and sex.

When his mother re-joins us, she pauses more to listen for JD's responses. But at the conclusion of the visit, she repeats her frustration about his not monitoring blood sugars, connecting this behavior to the DKA admissions. JD is again silent. I ask: "Wow, you really stepped out of the conversation when we came to that – what happened?" JD and his mother acknowledge they fight almost daily about whether he is "responsible enough." She says, "I wish he'd take care of it, but if he doesn't, I have to!" He wants "to do it my way and

not be hassled.” I ask for a compromise: “How can we allow some level of responsibility and risk, but avoid the extremes you find scary or frustrating?” We set up a plan to trial JD being responsible to check his sugars, without nagging. They agree to review his meter together nightly, and if there is at least one check, no comments are allowed. If there are no checks, he has to check immediately, without argument. The plan stays in place until he goes a full week with at least one daily check. Neither get exactly what they want, but it’s framed as: “What could you each live with in exchange for not having the daily fights?” I acknowledge limits; “this is the small step we can take in today’s allotted time,” but plan for the next step. We book a longer physical slot for JD’s next visit, and I ask them to complete an online transition screening to give us all a better idea of how the process is going and what next-steps are needed, and give them information about a peer-based transition program for RI adolescents.

The transition process can be overwhelming to a patient and family, but also to us as physicians. There are long-standing dynamics within families, and the issues of the medical condition are superimposed on the age-appropriate adolescent struggle for independence. See **Table 1** for helpful resources, which can be used to inform, engage and guide families in their efforts. I continually remind families, and myself, that transition is a process and won’t be accomplished in one over-long visit. Ultimately, transition is intended to help someone realize their potential and can be incredibly rewarding for patients and providers.

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As a hospital-based social worker, I sometimes meet with a patient as a consultant during an admission, or make an arrangement to see them at the time of a primary care or specialty visit if these are at Hasbro Children’s Hospital (HCH). This case is typical in that our service is often asked by a physician, family or patient to enter the picture after things are well off-track.

Chronic medical illness often co-exists with mental health issues, like depression and anxiety. I’ll focus on framing JD’s experience. He is resentful of his diabetic regimen interfering with his life. Part of his frustration is that even when he follows his insulin regimen, that doesn’t always keep his blood sugar in range. As a result, he may not fully trust his care team. Irritability, sleep disruption and poor concentration may be symptoms of uncontrolled depression. Chronic illness can be an isolating experience for adolescents and contribute to depression and anxiety. Untreated, depression can interfere with his judgment and motivation. Striving for more independence is a normal adolescent behavior and brain capacity for logical reasoning and future thinking is still developing through early adulthood. All of these factors help us understand why he is upset and non-adherent.

It’s also important to consider the perspective of JD’s mother. She has spent years managing his diabetes. It is difficult for her to relinquish the role of caretaker and entrust him with self-care, but equally concerning if he does not move into this role.

Our service’s approach incorporates both the patient and parent. I try to identify past issues, without laying blame, and help the patient to develop a plan. Plans must incorporate patient suggestions, and should use a stepwise approach, allowing the patient some autonomy as an opportunity to build trust. The graduated independence, and hopefully success, will build confidence for later tasks. I encourage parents to share their concerns with their child in a non-accusatory way and to understand their developing role as

Table 1. Transition resources for practices and providers

<p>GotTransition.org is a national clearinghouse, run by the National Alliance to Advance Adolescent Health. Their nationally recognized transition model is aligned with professional organization recommendations and includes 6 core elements of health care transition support: policy, tracking and monitoring, readiness assessment, transition planning, transfer of care and transfer completion.</p> <ul style="list-style-type: none"> • A tip sheet to start the transition process: www.gottransition.org/resourceGet.cfm?id=331 • A validated tool providing a framework for conversation about transition: www.gottransition.org/resourceGet.cfm?id=126 • Information regarding Billing and Coding for Transition¹: www.gottransition.org/resourceGet.cfm?id=353 • The QuickGuide Transition Tool with guidance on health insurance and career goals: www.gottransition.org/resourceGet.cfm?id=372
<p>New guidelines and tools for transition for internists, from the American College of Physicians’ Pediatric to Adult Care Transition Initiative:</p> <ul style="list-style-type: none"> • https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative.
<p>Local resources for transition services are listed at the bottom of the Rhode Island Department of Health’s Pediatric to Adult Healthcare Transition Guidance, along with a checklist for families and patients to plan and track progress:</p> <ul style="list-style-type: none"> • http://health.ri.gov/programs/detail.php?pgm_id=89 • http://www.health.ri.gov/publications/brochures/specialneedschildhoodtransition/Ready.pdf
<p>RI Department of Education, Office of Student, Community and Academic Supports has 4 Regional Transition Centers:</p> <ul style="list-style-type: none"> • http://www.ride.ri.gov/StudentsFamilies/SpecialEducation/SpecialEducationProgramming.aspx#1239631-secondary-transition-services.
<p>A community-based organization, the Rhode Island Parent Information Network (RIPIN), has a Transition Coordinator who can help families start the process.</p> <ul style="list-style-type: none"> • Phone: (401)270-0101, or on-line: www.RIPIN.org or http://www.startingpointsforparents.org/content/transition-school-adult-life.

an advisor in their child's care. This can open up new ways to communicate around transition issues.

Sometimes a single visit or a series of visits during an admission are sufficient, and JD and his family may be ready to move forward on their own. For more support, I'd encourage JD and his mother to participate in our transition program. The Adolescent Leadership Council (TALC) is a transition program offered at Hasbro Children's Hospital for youth age 13–18 with chronic medical illness (www.TALCProgram.org). College-age mentors with chronic illness and Hasbro staff lead monthly meetings. There is a concurrent parent group. JD and his mother would have peer support and opportunities to address transition issues on an ongoing basis.

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JD and his case highlight challenges faced by adolescents as they transition care in Rhode Island. Our office supports a wide variety of programs to help. JD and his family can learn more about our programs on our website. See **Table 1** for links to on-line RIDOH materials including: youth-friendly patient handouts with prompts for transition geared towards different levels of readiness, a youth transition workbook, and transition checklists for providers.

We'd encourage JD to sign up for our Dare to Dream Conference, where he'd have the option to train as a peer teacher. These programs can help adolescents realize real growth and achievement. Our perspective is that health affects all aspects of life. School, community, and job success are all associated with health. We emphasize ensuring inclusion and full participation of individuals with disabilities and chronic health conditions in education, meaningful employment, and community living. Our positive youth development interventions include the Dare to Dream Conference, Healthy Lifestyle Classes, and a Youth Internship Program especially geared to supporting an activated patient. The programs cover a wide range of special needs, including those of patients with cognitive disabilities and disabilities that may qualify for SSDI and other programs.

We'd also ask JD and his mother if they had explored any of the resources available through the RI Department of Education. Their Office of Student, Community and Academic Supports ensures children with diverse learning needs and children requiring special education services are provided equal access to a public education, and that schools develop effective strategies for meeting the needs of these unique learners. There is programming focused on transition; **Table 1** includes links to their 4 Regional Transition Centers.

Early contact with a community support, such as the Transition Coordinator at RI Parent Information Network (RIPIN), can help families start the process. **Table 1** includes a link to the Rhode Island Parent Information Network.

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Almost 1 in 5 US youth ages 12–18 have a special health-care need. Their health care transition has become a focus

of professional organizations, insurers, policy makers and providers over the past decade. Despite these efforts, the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) demonstrated no significant improvement in transition preparation nationwide versus a 2005 survey.¹ Four transition goals were measured, asking parents if their child's doctor had discussed a shift to an adult provider, future health care needs, future insurance needs or if their child was encouraged to take increasing responsibility for their own health care needs. Fewer than half (40%) met the 4 national transition outcomes. Rhode Island performed slightly better, reaching 44% overall (a 6% increase over the state's 2005–2006 result). A local survey identified specific areas in need of improvement: only 13% of providers had written practice policies on transition.² Consistent with the national trends, 97% of providers reported that health care plans and insurers did not help in the transition process.

Rhode Island has committed to focus on transition objectives and strategies in their Title V State Action Plans for fiscal year 2016.³ There are many resources for providers and practices to improve transition; **Table 1** highlights links to several useful options.

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