



Implementation of a Transdisciplinary Team for the Transition Support of Medically and Socially Complex Youth

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Purpose This article reports the ongoing work of a statewide transition support program which serves youth ages 11 to 22 with medically complex conditions and socially complex lives.

Methods: Seven years of transition support services have led to program evolution demonstrated via a descriptive summary of the patients along with both families' and primary care providers' responses to satisfaction surveys. An illustrative case is used to highlight the types of expertise needed in specialized transition service delivery for patients with significant complexity. The team's analysis of their transdisciplinary work processes further explains the work.

Results: Nearly three hundred youth with complex needs are served yearly. Families and primary care providers express high satisfaction with the support of the services. The case example shows the broad array of transition-specific services engaged beyond the usual skill set of pediatric or adult care coordination teams. Transdisciplinary team uses skills in collaboration, support, learning, and compromise within a trusting and respectful environment. They describe the shared responsibility and continuous learning of the whole team.

Conclusions: Youth with complex medical conditions and complex social situations are at higher risk for problems during transition. Serving this population with a transdisciplinary model is time consuming and requires advanced expertise but, with those investments, we can meet the expectations of the youth, their families and primary care providers. Successful transdisciplinary teamwork requires sustained and focused investment. Further work is needed to describe the complexity of this service delivery along with distinct transition outcomes and costs comparisons.

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Background

AGING YOUTH TRANSITION from a pediatric to an adult-centered model of healthcare. In parallel, they develop from a role as dependent children to that of self-managing adults. Health care providers in both the pediatric and adult arenas are urged to specifically support this transition process so that it progresses in a seamless and continuous manner. To assist providers in facilitating a successful transition, the Got Transition/Center for

Health Care Transition recommends core elements for all providers: 1) a transition policy, 2) a tracking and monitoring registry, 3) a readiness assessment method, 4) a plan of care, 5) the actual transfer of care, and 6) confirmation of the completed process (Got Transition/National Center for Health Care Transition, 2014).

The 2009–2010 National Survey of Children with Special Health Care Needs (NS CSHCN) measured randomly selected families' reported rates of transition services at a performance level of 40% out of a desired 100% (U.S. Department of Health and Human Services, Health

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Resources and Services Administration, & Maternal and Child Health Bureau, 2013).

The Maternal and Child Health Bureau has funded pilot programs to demonstrate methods and promote improvements in transition measures. Despite a federal focus on improving transition, community providers continue to be slow in their adoption of these recommendations. Few pediatricians (6% for children without special needs) reported that they have staff responsible for coordinating transition planning (American Academy of Pediatrics, 2009). Learning collaboratives, electronic health record supports, and enhanced payment methods have been applied in demonstration projects to facilitate further progress in primary care settings (Clemmons, Friedrich, Segar, & Sprangers, 2013).

More functional limitations, the presence of emotional, behavioral, or developmental conditions, lack of a medical home or absence of private health care financing are factors that have been associated with lower rates of transition preparedness among youth ages 12–17 with existing health conditions (McManus et al., 2013). In a literature review, Bloom et al. (2012) report that transition has been shown to proceed smoothly for many youth with chronic conditions, even when compared to peers without special health care needs. However, some youth with more medically complex needs experience transition to adult care with poorer quality health services and poorer health outcomes.

While transition should be incorporated into health care processes for all youth, a focus on the transition for youth with more complex needs is worthy of specific attention. Medically fragile children may be defined as those with complex chronic conditions that involve several organ systems and require multiple specialists, technological supports, and community services (Gordon et al., 2007). In the analysis of the 2005–06 NS CSHCN, participating children reported to have limitations in their activities and participation were noted to have statistically higher needs for services. These include prescription medication, specialty care, mental health services, therapy services, medical supplies, durable medical equipment, and communication aids. In addition, they have increased unmet needs (22.8%) and more problems with behavior and mental health (Houtrow, Okumura, Hilton, & Rehm, 2011). Youth with disabilities generate significantly higher health care costs per capita than their peers without disabilities and are described as particularly challenging to primary care providers (Bramlett, Read, Bethell, & Blumberg, 2009; Rich, Lipson, Libersky, Peikes, & Parchman, 2012). These patients with more complex conditions do present opportunities for their medical homes to more readily demonstrate improved outcomes, by lowering costs, and providing higher-quality care and better care experiences through the application of interventions. For example, only 48.8% of the families described by Houtrow et al. (2011) reported adequate care coordination.

In considering how to provide appropriate coordination of the care needs of youth with disabilities and complex medical needs, literature has applied the medical home concept, the primary care chronic disease management model and the disease-specific, multidisciplinary, specialty clinic. Rich et al. (2012) recommend

integration of care coordinators into primary care teams with enhanced practice reimbursement for care coordination as two crucial supports to aid PCP's in the care of medically complex patients. However, the PCP is less likely to have significant experience in treating patients with the broad array of rare conditions. The Cystic Fibrosis Center and Hemophilia Treatment Centers propose use of the disease-specific multidisciplinary specialty clinic to improve care. They have established patient registries to monitor outcomes and evaluate their specialized centers (Grosse et al., 2009). Programs for children with complex needs which utilize care coordinators have shown decreased inpatient and emergency utilization and costs, with high family satisfaction (Gordon et al., 2007; Petitgout, Pelzer, McConkey, & Hanrahan, 2013).

However, the question remains as to how transition-specific interventions would fit into these recommendations for care coordination and multidisciplinary clinics. Though existing evidence is limited, interventions with direct contact with adult health providers before leaving the pediatric system may enhance transition, as measured by follow-up, stability of metabolic markers, and satisfaction. At least one study suggests that a transition coordinator may also help reduce unnecessary hospital admissions, thereby reducing costs (Bloom et al., 2012).

Bent studied young people with complex neurological disabilities who received services during transition from a team-based multidisciplinary specialty teams. Those youths receiving team care compared to ad hoc care were noted to incur no increased cost while also reported to be less limited by their conditions and more likely to participate in society (Bent et al., 2002). This study's positive gains in both health care and community has particular value when considering the comprehensive transition needs of youth with disabilities across healthcare, education/employment, and community living.

To better understand the transition-specific interventions needed by children with chronic health conditions who are preparing for exit from continuous, longitudinal services received in a children's hospital and/or its surrounding medical homes, we used implementation science to launch and analyze a statewide transition support program (Ciccarelli, Brown, Gladstone, Woodward, & Swigonski, 2014). As we further observed the program's evolution, we proceeded from the initial question "What is transition planning and preparation?" to "How do we teach and support other providers in this work?" In this article, we look at the ongoing value of a specialized transition team as support for other providers in caring for youth and families with complex needs. We describe the operations during year seven of implementation where the focus is on solving problems related to medical and social complexities, lessons learned and next steps for further evolution.

Methods

With funding from the state department of health, a statewide transition support program was opened in 2007. Referrals were accepted from subspecialists, primary care physicians, community organizations or families for youth ages 11–22 with any

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