

Transition to Adult Health Care Services for Young Adults with Chronic Medical Illness and Psychiatric Comorbidity



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KEYWORDS

• Transition to adult care • Adolescent • Young adult • Chronic conditions

KEY POINTS

- Youth with chronic medical illness are at increased risk of psychiatric illness, and those with chronic psychiatric illness are at elevated risk of medical illness.
- Most youth with chronic medical and psychiatric conditions are not receiving needed transition support from pediatric to adult medical and behavioral health care.
- Medical professional recommendations call for transition preparation to begin early in adolescence and continue through young adulthood.
- A nationally recognized transition approach, called the *Six Core Elements of Health Care Transition*, offers a tested model for broad application in pediatric and adult medical and behavioral health care.
- Practical lessons learned are offered for implementing the *Six Core Elements* and measuring transition process and impacts.

INTRODUCTION

Advances in pediatric care have resulted in dramatic increases in the number of children and adolescents with chronic conditions.^{1,2} The increasing prevalence of childhood chronic conditions has important implications for transition to adult care because well over 90% of this population will survive into adulthood.¹ In fact, an estimated one million adolescents with chronic conditions turn 18 annually and need transition support as they move from pediatric to adult health care.³

Obtaining a precise estimate of transition-aged youth with chronic medical illness and psychiatric comorbidity is currently impossible because national survey datasets

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identify youth with special health care needs (YSHCN) based on either (1) the presence of an ongoing physical, mental, behavioral and/or other health condition that results in elevated need for services and/or an activity limitation; or (2) a listing of selected chronic conditions. In the first instance, YSHCN are defined broadly and combined to include all types of chronic conditions. In the second instance, youth with selected chronic conditions are defined to include only a subset of the total childhood population with chronic conditions. Furthermore, the limited published literature on childhood comorbidities is often disease specific, dated, or based on small study samples.

Despite these limits, evidence clearly supports that children with chronic medical illness are at increased risk of impaired psychological adjustment or psychiatric illness, and those with chronic psychiatric illness are at elevated risk of medical illness.⁴⁻⁸ Considerable variation in rates of comorbidity is found by type of medical condition, with neurodevelopmental and sensory conditions having the highest rates of psychiatric illness.^{7,8} Increased risk of comorbidity is also associated with the severity or the number of chronic medical conditions.⁴ In a seminal study on adult medical and psychiatric disorders published in 2011, called the Synthesis Project, the authors found that exposure to adverse childhood experiences, chronic stress, poverty, and poor educational attainment were risk factors for comorbidity.⁹

In this article, national data on lack of transition preparation among YSHCN, including those with emotional, behavioral, and developmental conditions, are presented along with transition barriers identified by consumers and providers. These transition gaps are followed by a summary of US transition goals and US and UK health professional recommendations for transition. In addition, an in-depth examination of the nationally recognized transition approach, the *Six Core Elements of Health Care Transition*, is discussed along with a summary of practice-based lessons learned. Finally, the article concludes with a discussion of transition measurement and evaluation.

GAPS IN RECEIPT OF TRANSITION SUPPORT AND CONSUMER AND PROVIDER BARRIERS

Transition gaps are pervasive for all YSHCN, including those with medical and psychiatric comorbidities. National survey data reveal that an estimated 25% of youth between 12 and 17 have a special health care need.¹⁰ Research shows that most of these YSHCN have not received needed transition preparation. According to the 2009/2010 National Survey of Children with Special Health Care Needs, 60% of YSHCN failed to receive needed transition support.¹¹ This survey, conducted by the National Center for Health Statistics, uses a nationally representative sample of parents or legal guardians with children less than the age of 18 years who have special health needs, identified by a 5-item screener.¹² A total of 17,114 parent respondents who have YSHCN ages 12 through 17 answered 4 transition questions in this survey, from which a composite score was obtained.¹⁰ Parents or guardians were asked about discussions that YSHCN have had with health care providers (HCPs) about changing to an adult HCP, taking increased responsibility for self-care, changing health care needs, and maintaining health insurance coverage.

As shown in **Table 1**, certain health characteristics were associated with a lack of transition preparation: (1) having an emotional, behavioral, or developmental condition (EBD), and (2) having a condition that limits activities. As many as 71% of youth with EBD, with or without one or more comorbid medical conditions, did not receive needed transition preparation compared with 54% of youth with medical conditions without associated comorbid EBD conditions. Also, of note, the extent to which HCPs encourage self-care responsibility differed sharply depending on whether the

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