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Assessing the Health, Functional Characteristics, and Health Needs of Youth Attending a Noncategorical Transition Support Program

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A B S T R A C T

Purpose: To assess the health, functional characteristics, and health care service needs of youth and young adults with special health care needs attending a comprehensive, noncategorical transition program.

Methods: A self-administered survey was developed from national health surveys and clinical experience to assess concepts identified as important for successful transition to adulthood. Surveys were mailed to 198 parents of youth and young adults with special health care needs attending the transition clinic. Parents were asked about the youth's health, functional status, and health care services needed. The clinical database provided demographic and patient health characteristics. Results were compared against the 2005–2006 National Survey of Children with Special Health Care Needs.

Results: Forty-four percent of surveys were returned. Average age of youth was 17.5 (11–22) years old and diagnoses included cerebral palsy (36%), spina bifida (10%), developmental delay or Down syndrome (17%), and autism (6%). Most youth needed assistance with personal care (69%) and routine needs (91%) and used assistive devices (59%). Compared with the 2005–2006 National Survey of Children with Special Health Care Needs, parents reported higher needs for all services except mental health care and tobacco or substance use counseling. Forty three percent reported at least one unmet health need. Few parents reported the need for counseling on substance use (1%), sexual health screening (16%), nutrition (34%), and exercise (41%).

Conclusions: Youth attending our transition program had more functional limitations, poorer reported health status, different diagnosis distribution, and higher levels of needed health services. Few parents identified needs for other recommended adolescent preventive services. Transition programs should assess patient health characteristics and service needs to design effective patient-centered services.

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**IMPLICATIONS AND
 CONTRIBUTION**

Noncategorical transition programs currently in development will need the staff and skills to address the multiple needs of a medically complex population of patients. This study describes how transition programs can use a program-specific assessment of youth's health, functional characteristics, and health needs to develop patient-centered services.

One of the six *Healthy People 2010* core outcomes identified by the Maternal and Child Health Bureau (MCHB) for children with special health care needs (CSHCN) is that all youth will receive

the services necessary to make transitions to adult life, including adult health care, work, and independence [1]. The 2002 American Academy of Pediatrics, American College of Physicians, and American Academy of Family Physicians consensus statement on health care transitions for youth and young adults with special health care needs (YSHCN) described six critical first steps for successful transition to adult-oriented care [2]. Nearly a decade later, many youth continue to face significant barriers to successful transition, and the majority of youth do not receive recom-

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mended transition services [3,4]. To measure progress in achieving the *Healthy People 2010* core outcomes, MCHB has developed a monitoring strategy that uses two national surveys conducted by the Centers for Disease Control and Prevention: the National Survey of Children with Special Health Care Needs (NS-CSHCN) [5,6] and the National Survey of Children's Health (NSCH) [7]. To satisfy the core transition outcome on the 2005–2006 NS-CSHCN, parents of youth ages 12–17 years must have reported that the child's doctors *usually or always* encouraged increased responsibility for self-care and (when needed) had discussed transitioning to adult health care, changing health needs, and how to maintain insurance coverage [6]. Results indicated that only 41% of CSHCN met the core outcome for transition [4].

Barriers to successful transition to adult health care can result in gaps in needed services, unmet health needs [8–10], and negative health outcomes [11,12]. Results from the NS-CSHCN suggest that YSHCN, compared with youth without special health care needs, generally experience greater unmet health care needs [13], including increased mental health service needs [8,14]. These health care needs and unmet health needs are associated with demographic factors such as insurance status, poverty, and race [13,15] and the youth's functional limitations [8,16]. In addition, studies suggest YSHCN have elevated rates of adolescent health-risk behaviors, such as smoking, drinking alcohol, and sexual activity [17–19], and their associated negative health outcomes [18–20]. Descriptive and qualitative studies of transition experiences of YSHCN commonly describe gaps in recommended preventive counseling for health-risk behaviors [21–23].

To address these gaps in transition services and unmet health needs, transition programs have been developed that vary in their structure, focus, and patients served [24–26,27]. Published descriptions of various disease-specific transition programs (e.g., juvenile idiopathic arthritis, diabetes mellitus, cystic fibrosis, etc.) often describe patient characteristics, perceived patient and provider transition barriers, needs assessments, and processes for development of specific services [25–28]. In an August 2008 report of current transition programs, the MCHB Division of Services for Children with Special Healthcare Needs summarized the effective strategies and common approaches of seven different transition program models, five of which provided non-disease-specific clinical services [24]. However, these noncategorical transition support programs vary markedly in scope and staffing, and none have been described in the peer-reviewed literature. Current methods for providing transition-specific services must be evaluated and best practices established [29]. As noncategorical transition programs develop, they will need to identify the health status, functional characteristics, and health needs of their population to tailor services and staff to best address general transition care recommendations and individual needs for each youth [29]. Effective methods to assess these issues have not been well described. The aim of this study is to describe the development, implementation, and initial results of an assessment of the health status and service needs of YSHCN attending a noncategorical transition support program.

Methods

The Center for Youth and Adults with Conditions of Childhood (CYACC) in Indianapolis, IN, was one noncategorical program briefly described in the 2008 MCHB Health and Ready to Work Transition Models report [24]. CYACC is a transition support

Table 1
Demographic characteristics of youth of survey respondents and nonrespondents

	Respondents (n = 87) 17.5 years (16.9–18.0) n (%)	Nonrespondents (n = 111) 16.6 years (16.1–17.2) ^a n (%)
Mean age (95% CI)		
Male	47 (54)	65 (59)
Race		
White	66 (76)	73 (66)
Black	18 (21)	32 (29)
Other	3 (3)	6 (5)
Diagnosis		
Cerebral palsy	31 (36)	27 (24)
Spina bifida	9 (10)	9 (8)
Developmental delay/Down syndrome	15 (17)	8 (7) ^a
Autism	8 (9)	16 (14) ^a
Insurance status		
Private	9 (10)	14 (13)
Public ^b	55 (63)	77 (69)
Both	23 (27)	17 (15)
Referral source		
Subspecialty clinic	40 (46)	48 (43)
Primary care physician	19 (22)	32 (29)
Family/self	14 (16)	16 (14)
Other organization	2 (2)	3 (3)
Weight status ^c		
Obese or overweight	20 (27)	43 (43)
Underweight	12 (16)	16 (16)

^a $p < .05$.

^b Includes Medicaid, Medicare, healthy Indiana plan, county safety net insurance, state high risk pool insurance, Title V program.

^c Missing values not included in denominator.

program for youth ages 11–22 years with any chronic condition. Subspecialists, primary care physicians, community organizations, or families themselves refer patients to CYACC. The clinic provides a medical consultative visit and care coordination services that support the medical home to bridge gaps in needed services and address transition needs. CYACC's interdisciplinary team of physicians, social workers, nurses, and community partners develops a comprehensive transition plan. The team emphasizes self-management, community inclusion, and optimal access to services and health outcomes. Services are designed to address the recommendations within the 2002 American Academy of Pediatrics consensus statement [2]. Anticipatory guidance addresses anxiety about new providers, self-advocacy skills, differences in the organization of the pediatric and adult care system, health insurance changes, care coordination resources, and gaps in preventive and primary health care services [22,30,31].

Recognizing the importance of an ongoing assessment of patient health care needs and outcomes, CYACC initiated a study to develop a patient database, including a yearly patient questionnaire, to collect longitudinal patient and family-reported outcomes. All youth presenting to CYACC's clinic are recruited to participate in the study. Informed consent is obtained from either the young adult or parents at the time of the initial clinic visit. If possible, assent is obtained from youth. Demographic characteristics including age, gender, ethnicity, primary diagnoses, type of health insurance, referral source, and body mass index are examples of data included in the CYACC clinical database (Table 1).

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