Within-State Availability of Transition-to-Adulthood Services for Youths With Serious Mental Health Conditions

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Objective: **This study describes the existence and nature of services within state child and adult mental health systems that support the transition from adolescence to adulthood.** ***Methods:*** **State child and adult mental health administrators from all but one state were interviewed by telephone with a semistructured questionnaire regarding transition services in their state mental health system, such as supported housing, vocational support, preparation for independent living, and dual diagnosis treatment. Eight states were deemed sufficiently decentralized to render state-level administrator reports invalid. Specific service data from the remaining 41 states and the District of Columbia were analyzed with descriptive statistics.** ***Results:*** **One-quarter of child state mental health systems and one-half of adult state mental health systems offered no transition services, and few provided any kind of transition service at more than one site. Most types of transition services were available at all in less than 20 percent of the states.** ***Conclusions:*** **Across the United States transition support services are lacking. The adult system in particular will require major transformation to provide the service capacity that is needed to meet the current standards of transition service accessibility for young Americans with serious mental health conditions. (*Psychiatric Services* 57:1594–1599, 2006)**

Young adulthood, ages 16 to 30, is a critical developmental stage that bridges adolescence and mature adulthood. It is when most individuals end their formal education, which can permanently define their occupational choices. It is when most delinquent youths desist from criminal behavior and when young people are first held accountable for their actions as adults and their choices profoundly affect their lives (1). Society demands much of young adults—that they complete their education, move into stable employment, and then support a household, become citizens who contribute to society, and eventually start a family.

Current societal conditions have made young adulthood particularly difficult for vulnerable populations, which can result in a protracted immature adulthood (2). One vulnerable group is young people with serious mental health conditions. Longitudinal research on adolescents in this group demonstrates their struggle in each domain of adult functioning (3–6). For example, in one study of 292 youths with serious emotional disturbance who had been in public child mental health services or special education, approximately half completed high school, 42 percent were unemployed, and 10 percent were living in a correctional facility by ages 18 to 26. Another study of the same population of 812 found that substance abuse and dependence were the most common disorders among those aged 17 to 25 years (7,8). A study of 181 women 18 to 21 years of age found that those diagnosed as having childhood psychiatric disorder were 6.5 times more likely to become pregnant than those without the diagnosis (5). Thus the transition to adulthood for this group is particularly concerning.

Given the vulnerability of youths with serious mental health conditions, understanding service systems' capacities to support their transition needs is crucial. In keeping with the breadth and duration of functional impairment described in the longitudinal literature, the guidelines for transition systems for this population call for access to supports for all domains of transition functioning, starting in adolescence and lasting as long as services are needed (9,10). This array of services, referred to herein as transition services, includes service coordination; vocational, educational, independent living, and housing supports; and mental health and substance abuse treatment.

Numerous public systems, such as special education, vocational rehabilitation, and community colleges, can provide some transition services for

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youths with serious mental health conditions. However, there are two central reasons to examine transition service capacity within state mental health systems. First, the research literature from other systems except special education suggests that there has been little focus on transition services for this specific population (11). Within special education, the adult outcomes of students who qualify as disabled because of serious emotional disturbance include the highest dropout, course failure, and grade repetition rates and the worst employment rate compared with other disability groups (12). These findings suggest that other systems do not serve this population well. Second, it is important to examine the system that serves those with the most serious mental health conditions and intense service needs, which is the mental health system. A focus on transition service capacity in that system informs key policy makers who affect this high-risk population.

In this study state mental health systems refer specifically to state mental health authorities that have administrative oversight of child and adult mental health services, or in states with consolidated child agencies, this includes the part of those agencies that have administrative oversight of child mental health services. Service capacity refers to the number of programs available within the system and the number of individuals those programs accommodate. As used here, service capacity is independent of accessibility or appropriateness of services, although these are also critical dimensions of high-quality care. Service capacity was chosen because it captures a system's investment in a type of service and is a foundation from which changes can be made. For example, if a system has adequate transition service capacity, changing the accessibility or appropriateness of those services is a matter of refinement, whereas if capacity is low, then a basic investment needs to be made, which is a larger change.

Child mental health systems typically serve youths up to ages 18 or 21, and adult services begin at age 18 (13). Transition ages, roughly from 14 or 16 years to 25 or 30 years (2,7), span these two systems. Thus assessment of service capacity within state mental health systems requires examination of those services in both the child and adult systems.

Few studies shed light on transition service capacities of state mental health systems. One national study examined transition service capacities of state child mental health systems and found them to be sparse, although frequently the focus of discussion (13,14). There are no other published studies of transition service capacities of child mental health systems. Assessment of statewide adult mental health services is limited to an indirect assessment of young adult services in New York's mental health system (15). Historically, there was a focus on "young adult chronic" patients (16–19), who composed the first cohort of adults with serious mental illness who had not experienced long years of institutionalization. These studies described their service utilization patterns, service discontinuity, and the nature of the population (20–24). Focus on this specific population has ended, and no further study of system capacity for young adults has been reported. No study has assessed transition service capacity across child and adult mental health systems, although expert panels have acknowledged that responsibility for the population needs to be shared equally across child and adult mental health systems and that increased funding is needed to ensure that services are available and accessible (25).

Assessment of service capacity often occurs through an interview or survey of those who are knowledgeable about services (26–28). An alternative approach is to examine existing administrative databases, such as the State Mental Health Authority Profiling System of the National Association of State Mental Health Program Directors (NASMHPD) Research Institute. There are no national administrative databases that record the existence of transition services; therefore, this study focused on obtaining information from knowledgeable informants. For an initial examination of transition service capacity, we selected state-level child and adult administrators as knowledgeable informants about their state's systems for this study.

The objective of this study was to describe how many transition service programs were available in child and adult state mental health systems across the United States.

Methods

Participants

The University of Massachusetts Medical School's Office of Human Subjects approved this study as exempted from review as specified by Federal Regulation 45 CFR 46.101(b).

Participants were members of NASMHPD, a professional organization of state mental health administrators. Each state's Adult Services member and Child, Youth and Families Division member, or their designees, participated in interviews concerning transition services offered in adult and child systems, respectively. The only exception was that no Adult Services member for Michigan was successfully engaged. Administrators included in this analysis were from 41 states and the District of Columbia, collectively referred to herein as states, that provided detailed information about both child and adult system services. In some states, administrators of child services reported an inability to provide accurate information about local services because the system was so decentralized. Consequently, interviews of administrators for adult systems, conducted two years later, specifically queried about decentralization. Administrators for adult systems from eight states reported decentralization that hindered reporting capacities (California, Florida, Nebraska, New York, Pennsylvania, Utah, Washington, and West Virginia). Results from the remaining states, minus Michigan, were used. Administrators also reported large Medicaid-funded mental health systems operating through private managed behavioral health care organizations (BHOs), for which the mental health agency had little administrative responsibility or information, in eight of the 42 states and in four of the decentralized states. Transition services in BHOs were not assessed.

Procedures

Detailed interview methodology for child system administrators is reported elsewhere (13). Interview methodology for administrators for adult systems was the same, with exceptions noted below. Briefly, administrators received a cover letter introducing the study's purpose, a supportive statement from NASMHPD, and the questionnaire. Transition services were defined as services that focus on assisting young people to complete the tasks of adolescence and take on the mantle of adulthood. Typical transition programs were described as offering supports in the following areas: completing high school or earning a graduate-equivalent diploma (GED), entering and completing postsecondary education or training, obtaining and maintaining employment, preparing for and achieving independent living, developing and maintaining adult social support networks, obtaining age-appropriate mental health services and supports, and participating in transition planning and coordination of transition services and supports (14,29).

Interviews of child services administrators were conducted between March and June 2001, and interviews of adult services administrators were conducted between July and October 2003. Interviews lasted from 15 to 90 minutes. All interviews were conducted by the first author. Administrators were read the questions from the interview instrument, which had been mailed in advance. Answers were recorded in writing during the interviews, and responses to open-ended questions were paraphrased. Unclear responses were queried during the interview to ensure accuracy. Questions analyzed in this study are listed below. A count was made of the number of states providing each type of service and the number of sites at which the service type was available within the state (one site, multiple sites, or statewide). Administrators were not asked to describe how many clients each program served.

Coding. In response to the child services question, administrators described service types—supported housing or vocational counseling, for example—and their availability. These answers were then coded into ten broad categories of service types (13) and four geographic distributions (one site, multiple sites but not statewide, statewide, or unknown). Administrators of adult services were asked about the existence and distribution of a list of specific services. Two additional categories, psychosocial rehabilitation and residential treatment, emerged from these questions. Responses from administrators of child services were then recoded with each of the categories from the adult services interview, plus psychosocial rehabilitation. Age-specialized residential treatment was unusual in adult services, but adolescent residential treatment in child systems is common and would not have been reported as a transition program. All coding was done by the first author.

When service types were available, they were rarely available at more than one site in the state; less than 8 percent of adult systems and 22 percent of child systems offered any single type of transition service in more than one geographic site.

Instrument. We interviewed administrators by using a semistructured questionnaire. For administrators of adult and child services, questionnaires were identical, with two exceptions. First, in the interviews of child services administrators, transition service availability was an open-ended interview question, whereas in the interviews of adult services administrators the respondents were queried about a list of specific transition services. Second, the adult services administrators were queried about decentralization and BHOs. Interview questions were developed from research literature topics about the transition to adulthood. These included the evaluation of elements from current guidelines for transition systems: access to supports for all domains of transition functioning, such as independent living, school, and vocational and career supports; transition planning; and developmentally appropriate supports (10).

Specific services. Child services administrators were asked, "Are there any specific adolescent programs focused on preparation for adult functioning (either vocational, educational or housing and independent living)?" Adult services administrators were asked, "Do you offer categorical programs that serve only a younger adult age group or have tailored services for younger adults in the following areas: a) educational support (high school, GED, or postsecondary education), b) vocational counseling, c) vocational preparation, d) vocational support, e) independent living preparation, f) supported housing, g) supervised housing, h) other housing supports, i) homeless mentally ill programs, j) treatment for comorbid substance abuse, k) mental health treatment, l) social skills or social support, m) specialized transition planning and service coordination (i.e., PACT or ACT teams, wrap-around services)?"

Both child and adult administrators were also asked whether there were any other efforts to support the transition to adulthood. Administrators were asked to report only on services that their mental health system funded (partially or fully). Services funded only by other systems were not recorded even if they were provided to state mental health service users. Adult services formally limited to or tailored for young adults, such as a day program only for younger adults,

Table 1

Availability of transition services offered by state adult and child mental health systems in 41 states and the District of Columbia

	Any site[a]				1 site only				More than 1 site				Statewide				Unknown			
	Adult		Child		Adult		Child		Adult		Child		Adult		Child		Adult		Child	
Type of service	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Special comprehensive services[b]	8	19	16	38	4	10	7	17	3	7	7	17	0	—	2	5	1	2	0	—
Supported or supervised housing or group homes	10	24	13	31	6	14	5	12	2	5	7	17	0	—	1	2	2	5	0	—
Vocational support, counseling, or preparation	5	12	8	19	2	5	2	5	2	5	6	14	1	2	0	—	0	—	0	—
Specialized case management[c]	5	12	3	7	1	2	0	—	1	2	2	5	1	2	1	2	2	5	0	—
Other	2	5	7	17	1	2	1	2	1	2	5	12	0	—	0	—	0	—	1	2
Educational support	1	2	5	12	0	—	3	7	1	2	2	5	0	—	0	—	0	—	0	—
Independent living preparation	0	—	5	12	0	—	1	2	0	—	1	2	0	—	3	7	0	—	0	—
Mental health treatment	2	5	2	5	1	2	2	5	0	—	0	—	1	2	0	—	0	—	0	—
Psychosocial rehabilitation	3	7	0	—	0	—	0	—	2	5	0	—	0	—	0	—	1	2	0	—
Residential treatment	3	7	na		2	5	na		0	—	na		0	—	na		1	2	na	
Social skills	2	5	1	2	0	—	0	—	2	5	1	2	0	—	0	—	0	—	0	—
Dual diagnosis treatment	1	2	1	2	0	—	1	2	0	—	0	—	1	2	0	—	0	—	0	—
Homeless with mental illness	1	2	0	—	0	—	0	—	1	2	0	—	0	—	0	—	0	—	0	—

[a] Sum of the remaining columns
[b] Services that offer or coordinate an extended array of specialized services, such as wraparound services or assertive community treatment
[c] Services in which case managers only or primarily worked with that age group or specifically focused on providing transition support

were considered transition services. Interviews about children's services asked about only the programs that addressed specific transition-related tasks (14).

Results

Almost twice as many administrators of adult services (N=21) as administrators of child services (N=11) reported no transition services anywhere in their state (50 percent versus 26 percent, respectively). Table 1 summarizes the distribution of each type of transition service that was reported. Each service type was available in less than 20 percent of states with the exceptions of special comprehensive services, which were offered by 38 percent of state child systems, and housing services, which were offered by 24 percent of state adult and 31 percent of state child systems. Special comprehensive services were services such as assertive community treatment or wraparound approaches in which a single entity provided or brokered a full array of needed services. When service types were available, they were rarely available at more than one site in the state; less than 8 percent of adult systems and 22 percent of child systems offered any single type of transition service in more than one geographic site. Special comprehensive services could provide an array of transition services to many if offered statewide. Statewide comprehensive services were offered only within the child system, only for wraparound services, and only in two states.

Discussion

These findings demonstrate that state mental health systems' transitional service capacities are minimal. No research has established how much transition service capacity is adequate within state mental health systems. However, the standard for transition support systems is for youths to have widespread access to comprehensive transition services throughout the transition period (9,10). To meet this standard, service capacity would, minimally, need to have the most common transition supports, such as vocational supports, offered statewide, and in both the child and adult systems. These findings suggest that mental health system capacities are a significant barrier to achieving this standard. The extent of the limitation is reflected in the finding that transition services were absent from half of the state adult systems and from one-quarter of the state child systems. Gaps in transition service offerings were apparent from the finding, with rare exception, that each type of transition service was available in fewer than ten states. The findings of this inventory corroborate the testimonials and reports by youths and parents that describe the paucity of helpful supports (30–35).

Despite sparse transition services, several states have made significant strides in increasing transition service capacity. Some examples include Maryland's systematic attempts to fund at least one transition program of varying types (for ages 16–25) in each area of the state and Vermont's systematic attempt to spread statewide its wraparound-influenced, vocationally focused program, called Jump On Board for Success, for young adults aged 16 to 21. These efforts may be informative about processes leading to increased service capacity. The latter program has also yielded some encouraging, though not rigorously tested, outcomes (36). However, it is clear from the literature that much about transition services and service systems has not been researched. Important future research questions in-

clude, How much transition service capacity—and of what types of services offered and by which systems—is sufficient? Related research questions include, What services are effective, and what factors influence accessibility and engagement in those services?

Administrators likely prepared for interviews by including only additional and more informed administrators in the interview. Therefore, answers largely reflect their working knowledge, which may have distorted actual service density. Differences in the wording of the service questions and timing of interviews between child system and adult system administrators may have contributed to the general report of fewer adult transition services, although these factors unlikely fully account for reports of fewer adult services. The overall conclusion remains that transition supports within state mental health systems are sparse.

Validity of the semistructured interview questions and reliability of the coding scheme are unknown. There were no reliability checks on the coding. Although encoding was fairly simple, validity and reliability of categories would have been strengthened by using multiple individuals to develop categories and coding.

Finally, this study shed no light on transition service capacities in highly decentralized mental health systems or in private Medicaid BHOs in 13 states.

Conclusions

The findings from this study indicate that state mental health systems provide few transition services. The likely reasons for this omission are myriad. Studies of the transition into adulthood in the general population since the 1960s found that current policies are obsolete (2). Thus mental health systems may simply reflect society's outmoded approach to transition. In addition, typical federal mechanisms to encourage change in the mental health system—such as establishing young adults as a priority population or identifying transition services as a priority or developing a large, sustained grant program to address the needs—have not been implemented. Federal programs that can fund relevant transition services are greatly fragmented, confusing, and frequently limited to either child or adult age groups (37). Finally, child and adult mental health systems are separate in many ways, including funding and eligibility (37,38), which require explicit bridges to overcome fragmentation.

The agenda for the Center for Mental Health Services, reflecting recommendations by the President's New Freedom Commission on Mental Health, is "transformation" (39). A top candidate for each state's transformation list is transition services. Leaders of child and adult mental health systems need to jointly assess the need for transition services for the young adults they serve, measure that need against the services that are provided, and find ways to fill the gaps that, according to our findings, will be revealed. At a minimum, each site will likely need services that support completion of high school and postsecondary education, entry and stability of work life, skills and resources to live independently, and mental health and dual diagnosis (substance abuse) services and coordination of these services—with enough capacity to minimize any wait lists.

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