

Increase in Untreated Cases of Psychiatric Disorders During the Transition to Adulthood

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Objective: During the transition to adulthood, youths face challenges that may limit their likelihood of obtaining services for psychiatric problems. The goal of this analysis was to estimate changes in rates of service use and untreated psychiatric disorders during the transition from adolescence to adulthood.

Methods: In a prospective, population-based study, participants were assessed up to four times in adolescence (ages 13–16; 3,983 observations of 1,297 participants, 1993–2000) and three times in young adulthood (ages 19, 21, and 24–26; 3,215 observations of 1,273 participants, 1999–2010). Structured diagnostic interviews were used to assess service need (participants meeting *DSM-IV* diagnostic criteria for a psychiatric disorder) and use of behavioral services in 21 service settings in the past three months.

Results: During young adulthood, 28.9% of cases of psychiatric disorders were associated with some treatment,

compared with a rate of 50.9% for the same participants during adolescence. This decrease included a near-complete drop in use of educational and vocational services as well as declines in use of specialty behavioral services. Young adults most frequently accessed services in specialty behavioral or general medical settings. Males, African Americans, participants with substance dependence, and participants living independently were least likely to get treatment. For cases of psychiatric disorders among young adults, insurance and poverty status were unrelated to likelihood of service use.

Conclusions: Young adults were much less likely to receive treatment for psychiatric problems than they were as adolescents. Public policy must address gaps in service use during the transition to adulthood.

Psychiatric Services 2015; 66:397–403; doi: 10.1176/appi.ps.201300541

One goal of the President's New Freedom Commission on Mental Health was to improve access to mental health treatment for all groups (1). To do so, it is necessary to identify groups that do not use services despite being ill. Children and adolescents with a psychiatric disorder often do not receive treatment (2–6) or receive inadequate care (6,7). This level of unmet mental health service need among children, while worrisome, could rise further during the transition to adulthood, a developmental period during which vulnerability for substance use disorders, panic disorder, and other mental disorders is high (8–10) and access to mental health services typically declines.

For example, many young adults lose access to services provided through school (typically a primary portal into mental health services), and many cease to be eligible for health insurance under their parents' policies (although this may change with recent legislation). Young adults are also less likely than any other age group to have private insurance (11), and many lose eligibility for publicly funded mental health services when they turn 18 or 21.

To date, information about mental health treatment services among young adults primarily comes from cross-sectional

studies. Analyses combining the National Comorbidity Survey (NCS) and National Comorbidity Survey Replication (NCS-R) samples found that 18- to 24-year-olds had the lowest rates of any mental health service use among all age groups (12). However, an analysis of the NCS-R data, which included data for persons ages 25–29 and which were collected more recently than the NCS data, found that 18- to 29-year-olds did not have lower rates of treatment than other age groups in any service sector (13). The NCS-R found that 41.4% of adults ages 18–29 received some treatment for mental health problems in the previous 12 months. By comparison, 45.0% of adolescents (ages 13 to 17) studied in the NCS-Adolescent (NCS-A) received some treatment for mental health problems in the previous 12 months (14). A study of the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) that focused on young adults (ages 19 to 25), however, found that fewer than one in four had sought services in the prior year (15). Together, these studies imply a significant drop in service use between adolescence and young adulthood that may be erased when youths reach their late twenties. None of these samples followed the same

group of children through the transition to clarify whether observed differences were due to factors other than age, for example, cohort or other differences, and to determine the reasons for the differences.

We used data from a longitudinal study of a community-representative sample in the southeastern United States that conducted repeated assessments of children until the age of 26 in order to examine use of mental health treatment during the transition from childhood to adulthood. The prospective-longitudinal design allowed us to look at changes in service use among participants with a psychiatric disorder as well as changes in predictors of service use. This study estimated changes in rates of service use from adolescence to young adulthood among participants with a psychiatric disorder; tested associations between service use and sociodemographic characteristics (for example, sex, race-ethnicity, and poverty), insurance, and psychiatric diagnosis during this transition, and tested whether service use was associated with key developmental tasks of the transition to young adulthood, such as attending college, living independently, marriage, and parenthood.

METHODS

Sample

A representative sample of three cohorts of children, age 9, 11, and 13 at intake, was recruited from 11 counties in western North Carolina in 1993 (9,16). All children scoring above a predetermined cut point on a screener for mental health problems, plus a random sample from all children who scored below the cut point were recruited for detailed interviews. American Indian children were recruited regardless of screen score. Like the area residents, about 7% (N=88) of the sample were blacks, 4% (N=349) were American Indians, and 90% (N=983) were whites. Of all participants recruited, 80% (N=1,420) agreed to participate. The weighted sample was 49.0% female (N=630). Sampling weights were applied to adjust for differential probability of selection.

Participants were assessed annually until age 16 and again at ages 19, 21, and 24–26. The parent and child were interviewed by trained interviewers separately until the child was 16, and thereafter only the child was interviewed. Before the interviews began, all informants signed informed consent forms approved by the Duke University Medical Center Institutional Review Board.

This study focused on two age groups: adolescence (ages 13–16; 3,983 observations from 1,297 participants collected from 1993 to 2000) and young adulthood (ages 19, 21, and 24–26; 3,215 observations from 1,273 participants collected from 1999 to 2010). Participation rates in both adolescence and young adulthood were high at any given assessment (>80%). In both age groups, close to 90% of participants completed at least one assessment (adolescence, 91.3%; young adulthood, 89.9%) and attrition was unrelated to psychiatric status at intake in both adolescence and young adulthood.

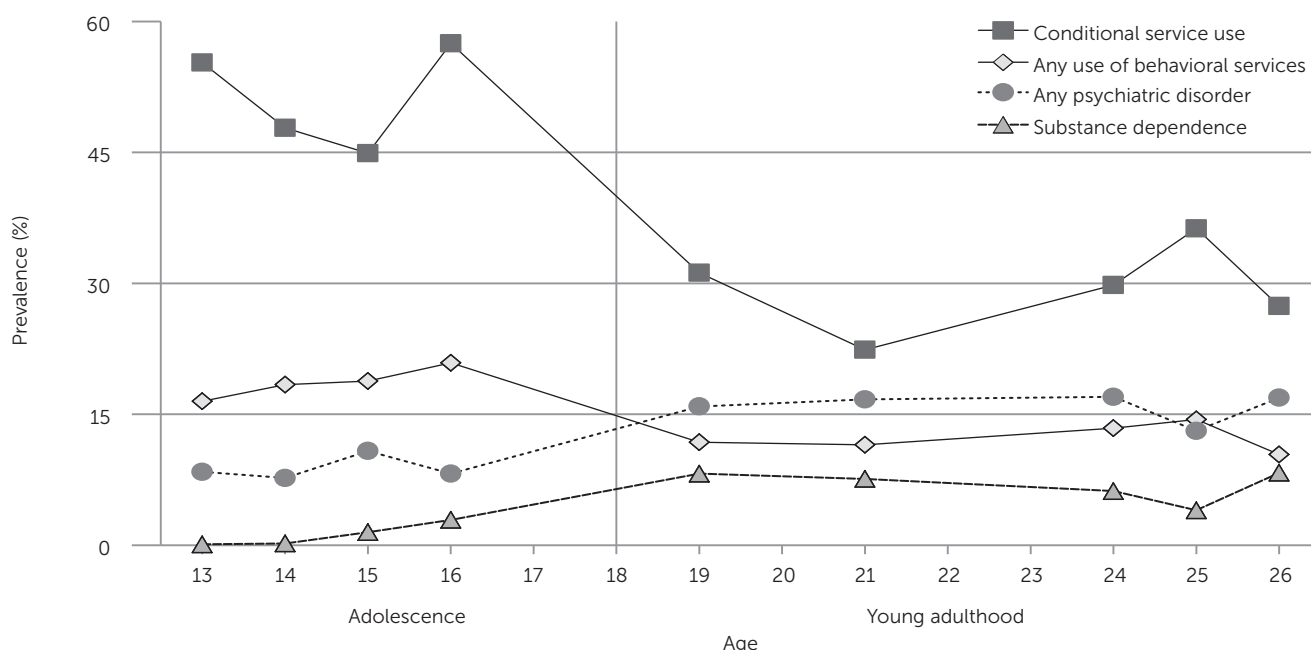
Measures

Psychiatric status. *DSM-IV* psychiatric disorders were assessed by using the Child and Adolescent Psychiatric Assessment (CAPA [17]) until age 16 and the Young Adult Psychiatric Assessment (YAPA [18]), the upward extension of the CAPA, in young adulthood. The time frame for determining the presence of psychiatric symptoms was the previous three months. In adolescence, symptoms were counted as present if reported by either parent or child or both. In young adulthood, only the participants were assessed. Two-week test-retest reliability of CAPA diagnoses of children ages ten through 18 was comparable to that of other structured child psychiatric interviews (17). Construct validity, including comparison with other interviews, was good to excellent (19,20).

This analysis included participants meeting criteria for the following psychiatric disorders: anxiety disorders (panic disorder, social phobia, generalized anxiety disorder, and agoraphobia), mood disorders (major depression, dysthymia, mania, and hypomania), behavioral disorders (conduct disorder, oppositional defiant disorder, attention-deficit hyperactivity disorder, and antisocial personality disorder), and substance dependence. Substance abuse was not included because the diagnosis requires only one symptom and thus criteria are commonly met in young adulthood. The focus on substance dependence is consistent with the more stringent *DSM-5* standard for diagnosis of substance use disorders (21).

Service use was identified by using the Child and Adolescent Services Assessment (CASA) (22). This interview was administered immediately after the CAPA or YAPA and mirrored the three-month time frame. As was the case for psychiatric diagnosis, service use was coded as positive if use was reported by either parent or informant up to age 16 and by older youths thereafter. This reflects standard assessment procedures in each age group. Twenty-one types of service covered by the CASA were categorized into five domains: specialty behavioral (psychiatric hospital, general hospital psychiatry unit, residential treatment facility, community outpatient center, private professional, and outpatient drug and alcohol treatment), general medical (hospital medical inpatient, community health center, physician visit, and emergency room visit), educational or vocational (boarding school, counselor or social worker, special classes for emotional or behavioral problems, and vocational support), informal (religious counselor, crisis hotline, self-help group, and friends), and justice system (detention center, probation officer, and corrective counsel). Specialty behavioral and general medical services are typically insurance-related. To ensure that services are related to mental illness or substance dependence, the CASA begins by reviewing all concerns identified during the CAPA or YAPA, which was administered immediately prior to the CASA. It qualifies all questions about service use with the phrase “for any of the kinds of problems that you told me about.” Service use was coded for services related to psychiatric disorders only. The CASA also assesses insurance coverage (public, private, both, or neither).

FIGURE 1. Three-month prevalence rates for a psychiatric disorder, substance dependence, conditional service use, and any behavioral service use during adolescence and young adulthood (ages 13–26)^a



^a Age period effects were significant ($p < .001$) for all measures. Diagnoses of psychiatric disorders and use of behavioral services were assessed at ages 13–16, 19, 21, and 24–26. Conditional service use measures use of behavioral services in the previous three months among individuals who met full diagnostic criteria for a *DSM-IV* disorder at the same follow-up.

Test-retest reliability of the CASA (intraclass correlation coefficient: .74, self-report; .76, parent report) and concurrent validity with official service center records was good (22,23).

Predictors of service use and young adult milestones. Socio-demographic variables included sex, age group (adolescence or young adulthood), race-ethnicity (white, American Indian, and African American), and poverty status on the basis of the federal definition (24). To address young adult milestones, the study asked participants about educational attainment, marital status, living situation, and parenthood. All variables were assessed by using the CAPA, YAPA, and CASA interviews.

Analytic Framework

Sampling weights were applied in all analyses to ensure that results represented unbiased estimates for the original sample population. In addition, sandwich-type variance corrections were applied to adjust the standard errors for the sampling stratification and repeated assessments of the same participants over time (25). Weighted logistic regression analyses were used to study the effect of age group, demographic factors, insurance status, diagnostic status, and young adult milestones on service use. All models were implemented in SAS PROC GENMOD by using the REPEATED statement (26).

RESULTS

Rates of Three-Month Service Use

The rate of psychiatric disorders during the three months prior to assessment increased from 8.9% in adolescence

(ages 13–16) to 15.9% in young adulthood (ages 19, 21, and 24–26; $p < .001$), whereas the rate of service use for participants with psychiatric disorders—referred to as conditional service use for the remainder of this article—declined steeply (50.9% to 28.9%, $p < .001$; Figure 1). A portion of the increase in the three-month rate of psychiatric disorders is accounted for by participants with substance dependence (1.3% in adolescence versus 7.3% in young adulthood, $p < .001$).

The observed decline in conditional service use could be an artifact of shifting from two informants in adolescence (parent report and self-report) to a single informant in young adulthood (self-report). When parents' reports of service use by adolescents were removed from the data, the rate of conditional service use in adolescence was lower (38.3%), but it was still significantly higher than the rate of conditional service use among young adults ($p < .002$). Furthermore, rates of participants with psychiatric disorders rose significantly from adolescence to young adulthood, despite the shift to a single informant. Thus the loss of parents as informants during young adulthood did not account for the significant declines in conditional service use.

Table 1 shows a downward shift in service use from adolescence to young adulthood across service sectors. Use of educational or vocational services became rare among all young adults. Among participants with psychiatric disorders, there were also significant declines in the use of specialty behavioral and informal services. Given the increases in rates of substance dependence in young adulthood, it is reasonable to suggest that the lower conditional service use rates were

TABLE 1. Three-month rates in weighted percentages of behavioral service use during adolescence (ages 13–16) and young adulthood (19–26), for the overall sample and for participants with psychiatric disorders, by service sector

Sector	Psychiatric disorders														
	Overall sample					Participants with substance dependence included					Participants with substance dependence not included				
	13–16		19–26		p	13–16		19–26		p	13–16		19–26		p
	%	SE	%	SE		%	SE	%	SE		%	SE	%	SE	
Any service	18.7	.01	12.2	.01	<.001	50.9	.04	28.9	.03	<.001	52.2	.04	35.3	.04	.01
Specialty behavioral	6.9	.01	4.8	.01	.06	22.8	.03	11.6	.02	.005	22.9	.03	15.9	.03	.12
General medical	2.9	.01	2.7	.01	.81	12.6	.03	9.8	.02	.47	12.1	.03	12.6	.03	.87
Education ^a	6.9	.01	.3	.01	<.001	17.3	.03	.3	.01	<.001	17.8	.03	.4	.01	<.001
Informal	6.9	.01	4.1	.01	.003	20.0	.03	9.1	.02	.002	20.9	.03	11.1	.03	.01
Justice system	2.7	.01	2.5	.01	.89	8.3	.02	6.6	.01	.71	8.4	.02	6.5	.02	.59

^a Includes vocational services in adulthood

related to lower service use by young adults with substance dependence. Service rates for cases of psychiatric disorders were generally higher when they did not involve substance dependence. However, even after removing cases of substance dependence, the use of any services, educational and vocational services, and informal services for psychiatric disorders was significantly lower among young adults compared with adolescents. Rates of use of specialty behavioral services for psychiatric disorders were also somewhat lower among young adults versus adolescents after removal of cases of substance dependence.

Sociodemographic, Insurance, and Diagnostic Predictors of Service Use

Table 2 shows demographic, insurance, and diagnostic covariates of service use for participants with a psychiatric disorder during adolescence and young adulthood. An interaction term with the age group variable tested whether these associations changed significantly from adolescence to young adulthood. Education and vocational services were excluded from the analyses because of their low rates in adulthood. Results for justice system services were similar to correlates for any criminal justice system involvement and are not included in Table 2 (data available on request from first author).

Sociodemographic predictors. Cases of psychiatric disorders involving females were significantly more likely than cases involving males to be associated with use of specialty behavioral and informal services during young adulthood versus adolescence. Among young adult participants with a psychiatric disorder, blacks generally had lower rates of service use compared with whites. There was significant drop in use of any services and specialty services among blacks versus whites during young adulthood compared with adolescence, when rates for blacks and whites were similar. Poverty status was not associated with service use in either age group.

Insurance. In adolescence, 75.5% of participants had some form of private insurance, 14.7% had public insurance only, and 9.8% were uninsured. In young adulthood, these rates shifted

to 68.4%, 10.3%, and 21.3%, respectively. The likelihood of being uninsured peaked at ages 19 and 21 (27.0%) but dropped to adolescent levels (10.5%) by the mid-twenties. This shift was limited to young adult whites and blacks; very few young adult blacks were uninsured (3.5%). Nevertheless, the shifts in insurance status had little effect on service use in young adulthood.

Diagnosis. Type of diagnosis affected use of service by young adults in all sectors: Anxiety was associated with use of higher levels of insurance-based services, whereas substance dependence was associated with lower levels of use of any services and specialty services and a trend toward lower use of services in other sectors. Both patterns represented a shift from adolescence, when the likelihood of receiving services (other than informal services) was greater among cases of substance dependence versus other psychiatric disorders. A diagnosis of depression was associated with use of significantly lower levels of insurance-based services among young adults versus adolescents.

Young adult milestones and service use. Young adulthood commonly involves moving out of one's parents' home, going to college, and, in some cases, getting married and having children. At age 19, most youths (74.1%) lived with a parent, but this rate dropped to 17.9% by their mid-twenties. Rates of some postsecondary education increased from 50.9% at age 19% to 66.7% by the mid-twenties. Marriage and parenthood were less common, rising from 5.9% and 11.2%, respectively, at age 19 to 43.2% and 37.6% by the mid-twenties. None of these milestones significantly predicted psychiatric status in young adulthood (results available from first author). However, living away from the parental home was associated with lower levels of any service use (odds ratio [OR]=.4, 95% confidence interval [CI]=.2–.8), especially insurance-based services (specialty behavioral, OR=.4, CI=.2–1.0; general medical, OR=.4, CI=.2–.8).

DISCUSSION

Neuropsychiatric disorders are the leading cause of disease burden among youths ages 10 to 24 (27). During this period,

youths are faced with a series of educational, family, and social transitions. In this sample, the rates of untreated cases of psychiatric disorders increased sharply from adolescence to young adulthood: less than one in three young adults who met criteria for a psychiatric diagnosis reported use of services in any sector. Part of this drop was accounted for by loss of secondary education services, but young adult participants with psychiatric disorders were less likely to use specialty behavioral and informal services. Increased rates of substance dependence coupled with decreased use of services put young adults at high risk of unmet need for psychiatric services.

This sample came from a relatively rural area in the southeastern United States, and, although the sample was representative of that area, blacks and Latinos were underrepresented and American Indians were overrepresented compared with the U.S. population. The racial make-up of the sample raises the question of how informative the sample can be about patterns and predictors of conditional service use. Rates of psychiatric illness in this sample were very similar to those found in other national and international population samples (28,29), and the proportion of children receiving needed care for psychiatric disorders was similar to rates in other areas of the United States (3,6,30–32). Among adolescents, the three-month rate of conditional service use (50.9%) compared closely with the 12-month rate in the NCS-A (45.0%) (14); among young adults, the three-month rate of conditional service use (28.9%) compared closely to NESARC reports of “fewer than 25% of individuals with a mental disorder in the prior year” (15). The service use rates in this study were very similar to those from nationally representative cross-sectional surveys. Service use was not assessed with administrative records, because many affected individuals never access any services and not all services for psychiatric disorders are recorded in accessible databases. However, self- and parent-reported service use typically converged with data from institutional records (22,33,34). Finally, a longitudinal design may be susceptible to historical confounds. In this study, this risk was minimized by use of multiple cohorts at intake.

The three-month rate of conditional service use for psychiatric disorders among young adults (28.9%) was much lower than the rate among adolescents (50.9%) and also much lower than the rate reported for young adults by prior cross-sectional studies (13,35). Young adulthood seems to be a distinctive period of unmet need compared with adolescence and also later adulthood (41.1% of adult cases of psychiatric disorders in NCS-R [13]). One obvious reason is that public, tuition-free schooling ends in late adolescence, taking away youths' primary entry point to the service system for psychiatric disorders (7). College-based services failed to fill this gap in this study. College students may not always be aware of the services available to them. Surveys of active college students showed that students at private colleges with lower enrollments had higher service use rates (36), but a majority of young adults is not enrolled in such colleges. Young adults also were less likely than adolescents to access

TABLE 2. Associations between characteristics of participants and conditional use of behavioral services among adolescents (ages 13–16) and young adults (ages 19–26)^a

Characteristic	Any service						Specialty behavioral						General medical						Informal					
	13–16			19–26			13–16			19–26			13–16			19–26			13–16			19–26		
	OR	95%CI	p	OR	95%CI	p	OR	95%CI	p	OR	95%CI	p	OR	95%CI	p	OR	95%CI	p	OR	95%CI	p	OR	95%CI	p
Female (reference: male)	1.3	.7–2.5	.13	.7–2.5			1.4	.7–2.9	.32	1.2–8.1	<.05	3.2	1.2–9.2	1.3	.5–3.4				1.1	.5–2.5	3.3	1.3–8.5	<.05	
Race (reference: white)																								
American Indian	1.5	.9–2.5	.13	.8–2.2			1.1	.6–2.1	1.0	.5–2.2		.7	.3–1.7	1.8	.9–3.7				1.1	.6–2.1	.6	.2–1.7		
Black	2.1	.6–7.5	.3	1–1.7	<.001		1.1	.4–3.2	.1	.0–.7	<.001	.2	.0–.9	.2	.0–.8				.5	.2–1.7	.2	.0–.8		
Poverty (reference: no)	1.1	.5–2.3	.11	.6–2.3			1.2	.5–2.6	.9	.4–2.4		.7	.3–2.0	.7	.2–2.2				1.3	.5–3.2	.7	.3–1.8		
Insurance (reference: none)																								
Private	1.0	.4–2.2	.18	.9–3.8			2.3	.5–9.7	1.3	.5–3.3		2.7	.5–13.4	1.2	.3–4.4				.4	.2–1.0	1.9	.7–5.5	<.001	
Public	1.6	.6–4.4	.18	.8–4.1			5.4	1.2–24.0	2.3	.8–6.8	<.05	2.3	.3–20.4	1.5	.5–4.9				.5	.2–1.2	.8	.2–2.3		
Diagnosis (reference: all other diagnoses)																								
Depression	1.4	.7–2.7	.7	.4–1.2			2.1	1.0–4.5	.5	.2–1.2	<.05	2.7	.9–8.1	.9	.3–2.3	<.05			1.1	.5–2.4	.7	.3–1.7		
Anxiety	.8	.3–1.7	.17	1.0–3.2			.5	.3–1.0	2.3	1.0–5.5	<.05	1.1	.3–3.8	2.7	1.1–6.8				1.1	.5–2.4	2.2	.8–6.0		
Substance dependence	1.8	.7–4.7	.5	.3–.9	<.05		2.0	.7–5.9	.3	.1–.8	<.05	1.4	.4–5.5	.4	.2–1.2	<.05			.8	.3–2.2	.6	.2–1.6		
Behavioral disorder	1.5	.8–2.9	.11	.5–2.4			1.2	.6–2.5	.5	.2–1.5		.8	.3–2.3	.2	.0–.8				1.3	.7–2.6	.2	.1–.7	<.05	

^a Conditional service use measures use of services in the previous 3 months among individuals who met full diagnostic criteria for a DSM-IV disorder at the same follow-up.

^b The interaction term (IT) is a measure of the statistical interaction of the characteristic (predictor) and age group.

either insurance- and non-insurance-based services. This pattern implicates referral behavior as a reason for unmet service need. Adolescents are typically referred for services by parents (7), but for many young adults, particularly those living independently, service use is dependent on self-referral. This finding, therefore, raises questions about young adults' beliefs about service need, stigma, or effectiveness as well as motivation in the face of other distractions and symptoms of their illness. Finally, the rise of substance use disorders during young adulthood may lead youths who misuse substances to believe that their dependence behavior is normative, reducing the perceived need for help. Alternatively, it could be that fewer services are available for substance problems compared with general mental health issues.

Some young adults with psychiatric disorders did receive services. Among young adults, the likelihood of receiving services was not related to either insurance status or poverty, two variables that are often assumed to be barriers to receipt of services. Young adults who received either specialty behavioral or general medical services tended to be white and American Indian youths who lived at home, had a diagnosis of anxiety, or both. Living with one's parents in young adulthood is on the rise in the United States (37) and abroad (38). This trend has been bemoaned in the popular press (39,40), where such children have been described as "boomerang kids." Although aspects of this arrangement may be problematic, our study showed that young adults coping with mental illness experienced advantages from living at home compared with living independently or with a romantic partner or spouse.

Racial-ethnic disparities in use of services are common (13,35), but the lower rates of any service use and use of specialty behavioral services in particular among African-American versus white young adults were a sharp departure from the pattern in adolescence. These disparities were not accounted for by poverty, insurance status, or living situation. The period of young adulthood should be a priority of studies of barriers to use of mental health services by African-American youths.

CONCLUSIONS

This study paints a dire picture of service use during the transition to adulthood. Use of services for psychiatric disorders should be contingent on need—not age, race, or living situation. Institutional barriers, such as the discontinuity of education-based services, lack of continuity between childhood and adult service systems, and loss of insurance for many young adults, need to be addressed (41,42). This study suggests, however, that even if these barriers were addressed, untreated cases would persist. Young adult service use was not contingent on insurance status, infrastructure, or funding. The only young adults whose use of specialty and general medical services was similar to that of adolescents were those who still lived with a parent. This suggests that policy efforts must focus as much on young adults' beliefs and knowledge

about mental illness and service use as on ensuring broad access to care.

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The work presented here was supported by the National Institute of Mental Health (MH63970, MH63671, and MH48085), the National Institute on Drug Abuse (DA/MH11301, DA023026, and DA036523), the Brain and Behavior Research Foundation (Early Career Award to Dr. Copeland), and the William T. Grant Foundation.

The authors report no financial relationships with commercial interests.

Received December 5, 2013; revision received August 12, 2014; accepted September 26, 2014.

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