Chapter Six

Service Access and Utilization

Pre-schoolers Using Mental Health Services: Evidence from a National Survey

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Introduction

Most of what is known about psychiatric services for youth has focused on elementary school-aged children and adolescents where reliable information about youths' clinical profiles, unmet needs, and available services has provided necessary leverage to successfully develop and test family- and community-based innovations in mental health care (Evans, Huz, McNulty, & Banks, 1996; Friedman, Katz-Leavy, Manderscheid & Sondheimer, 1998; Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 1998, Henggeler et al., 1999; Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001). Much less is known about characteristics of pre-school aged children under the age of six and their families who seek help from our mental health system. Mounting evidence from psychological research demonstrates that poverty, as well as early negative childhood experiences and traumatic life events such as exposure to violence, abuse or neglect, are associated with problems in school functioning and with difficulties in developing normal peer relationships and adult attachments (Zeanah, 2000). Despite noteworthy exceptions in recent services research by Zito et al. (2000), Lavigne et al. (1996, 1998), Leslie, Rosenheck, and Horowitz (2001), Gresenz, Liu and Sturm (1998), and dosReis, Zito, Safer and Soeken (2001), we know very little about pre-schoolers in the mental health system, and less about their national characteristics.

The comparatively small number of pre-schoolers using services may be one reason that service use among this group is not well understood, despite knowledge of the importance of early development for positive life outcomes. Specifically, children and adolescents up to age 17 represent a small proportion (24%) of the total US mental health service population, and children between 0 and 4 years of age represent a fraction (5.0%) of the youth population (Milazzo-Sayre et al., 2001). Moreover, children in general, and the very youngest children in particular, who use mental health services are infrequent users of costly inpatient care where policy makers have aimed to reduce financial burden. To better inform policy makers, administrators, and practitioners as well as families themselves, of the current status of our youngest citizens in the mental health system, and to allow for future projections of service needs, we investigate this overlooked service population. This study seeks to answer three key questions:

- How many pre-schoolers are admitted for mental health services over a year in comparison to older youth, what are their respective rates of service use per 100,000, and where do they receive services?
- What is the demographic profile of pre-schoolers, and does it vary by gender, race-ethnicity and primary source of payment?
- What kinds of mental health conditions do these youngsters have? Do these conditions vary by gender, race-ethnicity and primary source of payment?

We expect that the rate of service use in the youth population will be substantially less for the youngest aged youth (0-5 years) than for elementary school-aged youth (6-12 years) or adolescents (13-17 years). On the basis of existing research on older youth, we hypothesize that boys will display more externalizing behaviors than girls. We also hypothesize that minority youngsters, such as Blacks and Hispanics, will be more likely than White youngsters to enter the mental health service system through living situations that signal reduced resources, such as public insurance status or out-of-home placement, such as foster care or kinship arrangements. Finally, we expect that pre-schoolers who receive public money for services will be more likely than privately-insured pre-schoolers to have multiple problems due to the consequences of economic hardship experienced by their families.

Method

This study is based on the 1997 Client/Patient Sample Survey (CPSS) collected by the Center for Mental Health Services (CMHS) that provides detailed information on the status of youth and adults in mental health care; with an oversample of more than 8,000 youth, the CPSS allows reliable estimates of subgroups of the youth population (Milazzo-Sayre et al., 2001). The CMHS calculated weights to inflate sample counts to national estimates reflecting one-year totals (CMHS, 2001). Offering the most recent data available, the CPSS is exceptional in its breadth of coverage of each child's illness, family background, and living situation.

Our study selects the subsample of 339 youngsters under the age of six (weighted to a national estimate of 119,541) who received mental health services in 1997, and generates rates of service use per 100,000 from 1997 population statistics for this age group (U.S. Census Bureau, 1998, 2000). Our study describes the youngsters' primary diagnoses as based on the DSM-IV (American Psychiatric Association, 1994) or the ICDS-9 (World Health Organization, 1980) and also details their presenting problems, including abuse or neglect histories, problems with aggression and other social and interpersonal difficulties, and sociodemographic information regarding gender, race/ethnicity and primary source of payment.

To adjust for the complex sample design we use SUDAAN program software (Research Triangle Institute, 2001). We follow guidelines set by the CMHS and do not report information when the number of a sample is less than five, or when the relative standard error of the estimate is above 50% (CMHS, 2001).

Results

Overall, our data show that 1,314,938 children and adolescents under the age of 18 were admitted for mental health services in 1997—a rate of 1,889 per 100,000 youth population (see Table 1). Of these, half (50.7%) were adolescents aged 13-17; 40.3% were elementary school-aged children 6-12; and 9.1% (*n* = 119,541) were pre-schoolers aged 0-5. The rate of service use among pre-schoolers was 517 cases per 100,000; the rate of use for children aged 6-12 years was four times higher (1,943 cases per 100,000), and for 13-17 year olds the rate was 6.7 times higher (3,462 cases per 100,000). Over nine-tenths (91.9%) of the pre-school service population was admitted to outpatient care; by comparison, only a fraction were in residential treatment (1.0%) or inpatient care (7.1%) (Not tabled).

Of the 119,541 pre-schoolers in services, boys outnumbered girls (about 60% vs. 40%), and the rate of service use per 100,000 population was greater for boys than for girls (591 vs. 439, respectively). Although there were proportionately more Whites (60.6%) than Blacks (22.9%) and Hispanics (15.3%) receiving mental health services, the population-based rates show much higher service utilization for Blacks (829) than for Whites (493) and Hispanics (457). The majority of pre-schoolers admitted for mental health services lived with at least one biological parent (64.9%), and 16.4% lived in kinship care arrangements (e.g., living with aunts and uncles, grandparents). Fully 15% of pre-schoolers lived in custodial arrangements (foster care or group homes). Almost three-quarters of the preschool service population received some type of public money to pay for services (73.2%), while a comparatively small proportion paid with private insurance (18.0%) or personal resources (6.9%).

Almost three-fourths of the youth had one of three diagnoses: disruptive behavior (34.4%), adjustment disorders (25.7%), or developmental or pervasive disorder (13.2%; see Table 2). Nearly 10% had diagnoses of social conditions, and almost 6% were not assigned a psychiatric diagnosis, suggesting that these youngsters may need other community services in addition to mental health care.

Other analyses suggest that children entered services with a variety of presenting problems, including aggression (45%), family/parent-child problems (44.6%), problems coping with developmentally appropriate activities (32.5%), or experiences of being a victim of abuse or neglect (25.3%).

Table 1
Sociodemographic Characteristics of Pre-Schoolers Admitted for Mental Health Services in the United States, and Rates in the Population

	Admissions		
	National Estimates of Youth	*%*	*Cases per 100,000 Youth*
I. Youth Mental Health Population	*N* = 1,314,938	100.0%	1,889
Age Groups			
0-5 years	119,541	9.1	517
6-12 years	529,364	40.3	1,943
13-17 years	666,033	50.7	3,462
II. Pre-schooler Mental Health Population	*N* = 119,541	100.0%	517
Gender			
Male	69,905	58.5	591
Female	49,636	41.5	439
Race-Ethnicity			
Whites	72,377	60.6	493
Blacks	27,374	22.9	829
Hispanics	18,289	15.3	457
All others	1,501	1.3	128
Living Arrangement			
Biological parent(s)	77,610	64.9	---
Kinship care	19,594	16.4	---
Foster care	3,575	13.4	---
Group home	1,851	1.6	---
Step/adoptive parent(s)	1,336	1.1	---
Other/unknown	3,186	2.3	---
Primary Payment Source			
Medicaid	72,951	61.0	---
Other public insurance	10,080	8.4	---
Charity care	4,544	3.8	---
Private insurance	21,557	18.0	---
Personal resources	8,202	6.9	---
Unknown	2,207	1.9	---

Note. Youth population includes all children and adolescents under age 18. Part I of this table represents 4,014 (Weighted *N* = 1,314, 938) observations of youth 0-17 years of age and part II of this table represents 339 (Weighted *N* = 119,541) observations of youth 0-5 years of age from the 1997 Client Patient Sample Survey. US territories of Puerto Rico, Guam, and the US Virgin Islands were excluded (21 observations). Dashes indicate that rates were not calculated.

Rates calculated from July 1997 census statistics.
(http://www.census.gov/population/estimates/state/stats/st-99-12.txt;
http://www.census.gov/prod/3/98pubs/98statab/sacec1.pdf).

Table 3 summarizes how the sociodemographic and illness characteristics of pre-schoolers vary by gender, race-ethnicity, and primary payment source. We conducted chi-squared analyses, and set statistical significance at probabilities of ≤ .05. Cross-tabular analysis of such a small sample may result in an underestimation of group differences, so observed differences are likely to be real and strong. Variables are coded as they are displayed in Tables 1 and 2. There were no race/ethnicity (χ^2=2.5, df = 3, p = .48), living arrangement (χ^2=3.5, df = 6, p = .74), or source of payment differences (χ^2=3.3, df = 5, p = .65), among boys and girls. There were no differences in living arrangement (χ^2=21.6, df = 17, p = .20), or source of payment (χ^2=17.9, df = 15, p = .27), among the

Table 2
Number and Type of Diagnoses, Severity of Illness, and Presenting Problems of Pre-schoolers (ages 0-5; *N* = 119,541) Admitted for Mental Health Services in the United States: 1997 National Estimates

	National Estimate of Youth	*%*	*Standard Error*	*Sample N*
Number of Diagnoses				
Two diagnoses	36,520	30.6	4.2	217
One diagnosis only	76,339	63.9	4.1	101
No diagnosis[a]	6,676	5.6	1.6	21
Primary Diagnosis				
Disruptive behavior disorder	41,162	34.4	4.0	101
Adjustment disorder	30,690	25.7	3.1	93
Developmental or pervasive disorder	15,732	13.2	2.8	43
Anxiety disorder	11,456	9.6	2.4	33
Social conditions	10,290	8.6	2.1	37
Mood disorder	1,829	1.5	0.7	6
Personality disorder	950*	0.8	0.6	2
Alcohol or drug use disorder	246*	0.2	0.2	2
Psychotic disorder	---	---	---	---
Other disorders[b]	510*	0.4	0.4	1
Presenting Problems				
Family problems	53,207	44.6	3.7	148
Depressed or anxious mood	30,590	25.6	3.4	82
Coping with activities	38,775	32.5	3.5	120
Aggression	53,778	45.0	4.2	152
Suicidal thoughts or behaviors	3,099	2.6	1.1	10
Abuse or neglect victim	30,186	25.3	3.2	94
Alcohol or drug use	---	---	---	---
Interpersonal skill deficits	21,221	17.8	2.8	67
Social withdrawal	11,189	9.4	2.2	34
Delinquent behavior	4,216	3.5	1.1	16
Other	23,383	19.6	2.8	62

Note. Youth population includes all children and adolescents under age 18. This table represents 339 observations of youth 0-5 years of age from the 1997 Client Patient Sample Survey. US territories of Puerto Rico, Guam, and the US Virgin Islands were excluded (21 observations). Dashes represent zero cases in the sample; asterisks represent unreliable estimates due to 5 or fewer sample cases.

[a] No diagnosis includes: diagnosis deferred, no mental disorder, other non-psychiatric diagnosis and medical diagnosis.

[b] Other diagnosis includes: other mental disorder, somatoform, and sexual disorder.

racial/ethnic groups. There were significant differences in the living situations of publicly and privately insured pre-schoolers (χ^2=48.2, *df* = 23, *p* < .001). Pre-schoolers covered by Medicaid (55.5%) were significantly less likely to live with biological parents than those who were privately insured (91.6%).

There were no statistically significant gender, racial/ethnic and source of payment differences in diagnosis, but there were important differences in presenting problems. Boys and girls were about equally likely to be assigned each of the diagnoses identified in Table 2 (χ^2 = 17.1, *df* = 10, *p* = .07) . The diagnostic patterns of non-Hispanic Blacks, Hispanics, non-Hispanic Whites and other ethnic groups also were similar (χ^2 = 11.5, *df* = 16, *p* =.78), as were the patterns of youth with different sources of payment (χ^2 = 47.3, *df* = 35, *p* = .08).

Table 3
Characteristics of Preschoolers:
Gender, Race-ethnicity, and Primary Source of Payment

Boys versus Girls	Black vs. Hispanic vs. White	Public vs. Private Source of Payment
No Differences	*No Differences*	*No Differences*
Race-ethnicity Living arrangement Source of payment Diagnosis	Gender Living arrangement Source of payment Abuse or neglect Diagnosis	Gender Race-ethnicity Diagnosis
Differences	*Differences*	*Differences*
Abuse or neglect	—	Abuse or neglect Aggression Living arrangement

Note: χ^2 analyses were conducted for all comparisons: probability of <.05 indicates significant differences.

Girls were more likely to have been a victim of abuse or neglect than boys (36.5% vs. 17.3% respectively; $\chi^2 = 6.4$, $df = 1$, $p < .01$), but there were no other significant gender differences in presenting problems. Rates of presenting problems were no different for the racial/ethnic groups. With regard to payment source, pre-schoolers whose care was paid by Medicaid compared to private insurance were more likely to have presenting problems of aggression (50.5% vs. 39.1% respectively; $\chi^2 = 14.6$, $df = 5$, $p < .01$), and to have been victims of abuse or neglect (30.6% vs. 8.3% respectively; $\chi^2 = 11.4$, $df = 5$, $p < .04$).

Discussion

These findings from the nationally representative survey of mental health facilities reliably identify how many 0-5 year olds are in mental health care, and their rates of use. These early results reveal a vulnerable service population with multiple problems. Many of the young children are living in circumstances that are unsafe and unstable. There is an urgent need to develop age-appropriate and individualized services to effectively limit future mental health problems, and increase the possibilities of success in school and at home.

References

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders.* (4th revised ed.). Washington, DC: American Psychiatric Association.

Center for Mental Health Services (2001). Manderscheid, R. W., and Henderson, M. J. (Eds.) *Mental Health, United States, 2000.* (DHHS Pub. No. (SMA) 01-3537). Washington, DC: U.S. Government Printing Office.

dosReis, S., Zito, J. M., Safer, D. J., & Soeken, K. L. (2001). Mental health services for youths in foster care and disabled youths. *American Journal of Public Health, 91*, 1094-1099.

Evans M. E., Huz, S., McNulty, T., & Banks, S. M. (1996) Child, family, and system outcomes of intensive case management in New York State. *Psychiatric Quarterly, 67*,273-86.

Friedman, R. M., Katz-Leavy, J. W., Manderscheid, R.W., & Sondheimer, D. L. (1998). Manderscheid, R.W. & Henderson, M.J. (Eds.). Prevalence of serious emotional disturbance: An update. *Mental Health, United States, 1998.* (DHHS Publication No. (SMA) 99-3285). Washington, DC: U.S. Government Printing Office.

Gresenz C. R., Liu, X., & Sturm, R. (1998). Managed behavioral health service for children under carve-out contracts. *Psychiatric Services, 49*, 1054-1059.

Henggeler, S. W., Rowland, M. D., Randall, J., Ward, D. M., Pickrel, S. G., Cunningham, P. B., Miller, S. L., Edwards, J., Zealberg, J. J., & Hand, L. D. (1999). Home-based multisystemic therapy as an alternative to the hospitalization of youths in psychiatric crisis: Clinical outcomes. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*,1331-9.

Henggeler, S. W., Schoenwald, S. K., Borduin, C. M., Rowland, M.D., & Cunningham, P. B. (1998). *Multisystemic treatment of antisocial behavior in children and adolescents.* New York: Guilford Press.

Hoagwood,K., Burns B. J., Kiser, L., Ringeisen, H., & Schoenwald, S. K. (2001). Evidence-based practice in child and adolescent mental health services. *Psychiatric Services, 52*, 1179-89.

Lavigne, J. V., Gibbons, R. D., Christoffel, K. K., R., A., Rosenbaum, D., Binns, H., Dawson, N., Soble, H., & Issacs, C. (1996). Prevalence rates and correlates of psychiatric disorders among preschool children. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 204-214.

Lavigne J. V., Binns, H. J., Arend, R. Rosenbaum, D., Christoffel, K. K., Hayford, J. R., & Gibbons, R. D. (1998). Psychopathology and health care use among preschool children: A retrospective analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 262-70.

Leslie, D., Rosenheck, R. A., & Horwitz, S. M. (2001). Patterns of mental health utilization and costs among children in privately insured population. *Health Service Research, 36*, 113-127.

Milazzo-Sayre, L. J., Henderson, M. J., Manderscheid, R. W., Bokossa, M. C., Evans, C. & Male, A. A. (2001). Manderscheid, R.W. & Henderson, M.J. (Eds.). Persons treated in specialty mental health care programs, United States, 1997. *Mental Health, United States, 2000*, Center for Mental Health Services. (DHHS Publication No. (SMA) 01-3537). Washington, DC: U.S. Government Printing Office.

Research Triangle Institute (2001). *SUDAAN: Software for the Statistical Analysis of Correlated Data.* Release 8.0. Research Triangle Park, NC: Author.

U.S. Census Bureau, the Official Statistics (1998). Resident population, by race, Hispanic origin, and single years of age: 1997 (No. 22). *Statistical Abstract of the United States: 1998*, September 29, 1998. Retrieved from: http://www.census.gov/prod/3/98pubs/98statab/sasec1.pdf

U.S. Census Bureau (2000). *Population estimates for the U.S. and states by single year of age and sex: July 1, 1997.* Washington, DC: Population Estimates Program, Population Division, U.S. Census Bureau. Retrieved from: http://www.census.gov/population/estimates/state/stats/st-99-12.txt

World Health Organization. (1980). *International classification of diseases.* (9th revision.) Geneva: World Health Organization.

Zeanah, C. H., Jr. (2000). *Handbook of infant mental health* (second edition). New York: The Guilford Press.

Zito, J. M., Safer, D. J., dosReis, S., Gardner, J. F., Boles, M., & Lynch, F. (2000). Trends in the prescribing of psychotropic medications to pre-schoolers. *Journal of the American Medical Association*, *23*, 1025-1030.

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The Transition Years: Mental Health Service Utilization in Late Adolescence

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Introduction

The transition from adolescence to adulthood is associated with profound institutional and developmental changes (Clark & Davis, 2000; Koroloff, 1990). Challenges of late adolescence include graduating from high school, finding employment and housing, going to college and/or starting a family and raising children. For adolescent children suffering from emotional and behavioral disorders (EBD), however, achieving these social, educational, and vocational goals can be particularly difficult (Armstrong, 1985; Stroul & Friedman, 1986). For example, compared with children without EBD, children with EBD are more likely to drop out of school (Friedman, Duchnowski, Kutash, et al., 1996), enter the juvenile justice system (Atkins et al., 1999), and experience work-related difficulties later in life (Weissman et al., 1999). Despite having a variety of functional impairments, children with EBD, particularly those in late adolescence, are unlikely to receive mental health services (Cohen & Hesselbart, 1993). The purpose of the current study was (a) to examine mental health service utilization rates among children with EBD in late and middle adolescence and (b) to identify variables that may be preventing these children from receiving mental health services.

Method

Participants. All participants were residents of Hillsborough or Duval County, Florida. Utilizing mail survey techniques, caregivers raising children on Medicaid were asked to complete and return the Florida Health Services Survey (Boothroyd & Shern, 1998). Inclusion criteria required that: (a) the child was between 14 and 19 years old, and (b) the child was exhibiting significant emotional or behavioral symptomatology as defined by Pediatric Symptom Checklist (PSC; Jellinek, Murphy, & Burns, 1986) scores above a clinical cutoff score of 27. This yielded 195 children in the middle adolescent age group (14-16 years old) and 111 children in the late adolescent age group (17-19 years old). The characteristics of the children in this study are summarized in Table 1. Given that only children scoring above the criterion score on the PSC were included in this study, older adolescent children (i.e., ages 17-19) did not differ from younger adolescent children (i.e., ages 14-16) on mental health symptom severity, $t(1,304) = .14$, p = ns. Additionally, no differences were found between the two age cohorts on gender, $\chi^2(306) = .01$, p = ns, perceived need for mental health treatment, $\chi^2(306) = .01$, p = ns, satisfaction with finances, $t(1,304) = .52$, p = ns, or type of health plan, $\chi^2(306) = .42$, p = ns; however, significantly fewer ethnic minority children were in the late adolescent age group (47%) compared to the younger cohort (61%), $\chi^2(306) = 5.40$, $p < .05$. Not surprisingly, 32% of the older adolescents were no longer in school compared to only 4% of the younger adolescents. This difference is statistically significant, $\chi^2(306) = 43.9$, $p < .01$.

Table 1
Child Demographics

	Age Cohort		
Variable	*Ages 14-16*	*Ages 17-19*	*t or* χ^2
Gender			
Male	67%	67%	*n.s.*
Female	33%	33%	
Ethnicity			
White	39%	53%	5.4*
Minority	61%	47%	
Child in School			
Yes	4%	32%	43.9**
No	96%	68%	
Health Plan			
Managed Care	33%	30%	*n.s.*
Non-Managed Care	67%	70%	
Symptom Severity			
PSC Total: (Mean/*SD*)	39.6 (8.8)	39.4 (8.8)	*n.s.*
Perceived Need			
Yes	63%	63%	*n.s.*
No	37%	37%	

$^*p < .05$; $^{**}p < .01$

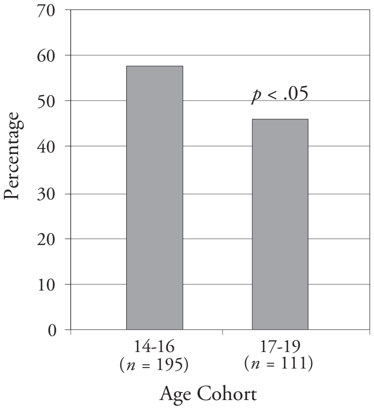
Measures. The Florida Health Services Survey was used to measure the child's utilization of mental health services in the past month (1 = *no*; 2 = *yes*), ethnicity (1 = *White;* 2 = *minority*), age, transportation problems, satisfaction with finances (1 = *very satisfied;* 4 = *not at all satisfied*), and health plan group (managed care/non-managed care). In addition, the caregiver's perception about whether their child needed mental health services in the past six months (1 = *no*; 2 = *yes*) was also measured. The PSC was used to measure emotional and behavioral symptom severity.

Results

The results are summarized below by the major research questions.

Are there differences between younger and older adolescents in their use of mental health services? As expected, late adolescent children were less likely to utilize mental health services than younger children, $\chi^2(306) = 4.10, p < .05$, and were less likely to be enrolled in school, $\chi^2(306) = 49.3, p < .01$. Figure 1 shows that 46 % of 17-19 year-old adolescents received mental health services compared with 58 % of the 14-16 year-old youth.

Figure 1
Mental Health Service Utilization X Age Cohort



What factors are predictive of mental health utilization? A logistic regression analysis was conducted to identify predictors of mental health service utilization. Hypothesized predictor variables were entered in the following order: 1) transportation problems, 2) PSC symptom severity, 3) ethnicity, 4) finance satisfaction, 5) perceived need for mental health services, 6) child enrollment in school, and 7) age cohort. These variables explained 36% of the variance in mental health service utilization ($R^2 = .36, p < .001$), with age cohort ($p < .05$), child enrollment in school ($p < .05$), and the caregiver's belief about whether their child needed mental health treatment ($p < .001$) accounting for the majority of variance (see Table 2). Results revealed that children were less likely to receive mental health services if they were older (age 17-19), were not enrolled in school, or were living with caregivers who did not believe their children needed mental health services.

Table 2
Logistic Regression Analysis for Variables Predicting Mental Health Service Utilization (*n* = 230)

Variable	*ß*	*SEß*	*Odds Ratios*	*p*
Transportation Problems	-.25	.45	.78	*n.s.*
Symptom Severity	-.02	.02	.98	*n.s.*
Ethnicity	.27	.27	1.31	*n.s.*
Satisfaction with Finances	-.23	.21	.79	*n.s.*
Perceived Mental Health Need	3.35	.43	28.44	<.001
Child Enrolled in School	.98	.49	2.65	<.05
Age	-.79	.39	.45	<.05

Implications

Regression analyses revealed that three variables were significantly predictive of mental health service utilization in adolescent children. Consistent with previous research, the current results indicate that EBD children in late adolescence are significantly less likely to utilize mental health services than younger adolescent children (Cohen & Hesselbart, 1993). The strongest predictor of mental health utilization was the caregiver's belief about whether their child needed mental health services. More specifically, adolescent children with EBD were unlikely to receive mental health services unless the caregiver believed their child needed them. In addition, the current results also support the importance of the school system in the provision of behavioral health services to adolescent children (Evans, 1999). It should be noted, however, that the results revealed that older adolescent children were less likely to utilize mental health services independent of the influence of school enrollment.

It is believed that mental health policy changes can facilitate the provision of services for children with emotional and behavioral disorders, particularly those transitioning into adulthood. Our study revealed that less than half of older adolescent children receive mental health services, despite having significant emotional and behavioral disturbances. According to Koroloff (1990), effective transition policy for youth with emotional and behavioral disorders must include a process that is automatically initiated when a child reaches a certain age or stage of development. Finally, the current results support the importance of applying programs that target, and are inclusive of, both families and educational systems (Clark & Davis, 2000; Koroloff & Friesen, 1997).

References

Armstrong, L. K. (1995). Transitional case management. In B. J. Fries & J. Poertner, (Eds.). *From case management to service coordination for children with emotional, behavioral, or mental disorders*. Baltimore: Paul H. Brookes Publishing.

Atkins, D. L., Pumariega, A. J., Rogers, K., Montgomery, L., Nybro, C., Jeffers, G., & Sease, F. (1999). Mental health and incarcerated youth: I. Prevalence and nature of psychopathology. *Journal of Child and Family Studies, 8*(2), 193-204.

Boothroyd, R. A., & Shern, D. L. (1998, January). *Assessing the feasibility of using mail survey methodology with Medicaid enrollees: A summary of a pilot study for the member survey*. Tampa, FL: Louis de la Parte Mental Health Institute, University of South Florida.

Clark, H. B., & Davis, M. (Eds.). (2000). *Transition of youth and young adults with emotional or behavioral difficulties into adulthood: Handbook for practitioners, educators, parents, and administrators*. Baltimore: Paul H. Brookes, Company.

Cohen, P., & Hesselbart, C. S. (1993). Demographic factors in the use of children's mental health services. *American Journal of Public Health, 83*(1), 49-52.

Evans, S. W. (1999). Mental health services in schools: Utilization, effectiveness, and consent. *Clinical Psychology Review, 19*(2), 165-178.

Friedman, R.M., Kutash, K., & Duchnowski, A.J. (1996). The population of concern: Defining the issues. In B.A. Stroul (Ed.), *Children's mental health: Creating systems of care in a changing society* (pp. 69-96). Baltimore: Paul H. Brookes.

Koroloff, N. M. (1990). Moving out: Transition policies for youth with serious emotional disabilities. *The Journal of Mental Health Administration, 17*, 78-86.

Koroloff, N. M. & Friesen, B. J. (1997). Challenges in conducting family-centered mental services research. *Journal of Emotional and Behavioral Disorders. 5*(3), 130-137.

Jellinek, M. S., Murphy, J. M., & Burns, B. J. (1986). Brief psychosocial screening in outpatient pediatric practice. *The Journal of Pediatrics, 109*, 371-378.

Stroul, B. A., & Friedman, R. M. (1986). *A system of care for children and youth with severe emotional disturbances. (Revised ed.)*. Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.

Weissman, M., Wolk, S., Goldstein, R. B., Moreau, D., Adams, P., Greenwald, S., Klier, C. M., Ryan, N. D., Dahl, R. E., & Wickramaratne, P. (1999). *Journal of the American Medical Association, 281*(18), 1707-1713.

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Topical Discussion Overview

Children with Mental Health Problems Stuck In All the Wrong Places

Susan P. Leviton

Introduction

There are many laws throughout this country intended to ensure that children with mental health needs will be able to successfully attend school, receive necessary medical care, and continue to live with their families. Despite the tremendous gains that have been made in learning about healthy development and best practices, the traditional mental health system often fails in its mission to care for these children. While there are now laws in place that are designed to assist children with mental health needs, stakeholders, policymakers, and the child's community-at-large must demonstrate the political will necessary to guarantee that financial commitments and infrastructures are in place so that these children can receive the services they so desperately need. This Topical Discussion generated ideas about some of the factors that impede children and families from receiving the services they need. Those ideas are provided here, along with vignettes chosen to illustrate the difficulties that children and their families face in their attempts to receive services. The failure of the traditional mental health service system can be attributed to a number of factors, but there are three that seem particularly relevant: (a) the system is neither family centered nor easily accessible; (b) the range of services needed, including their range of funding and reimbursement, are not provided in a timely and integrated way so that children and their families can avoid relying on inappropriate institutional care; and (c) the system is neither fair nor just.

The System is neither Family Centered nor Easily Accessible

Conflicting Categorical Educational/Medical Eligibility Requirements

Children with mental health problems are particularly vulnerable to label manipulation. Accordingly, many experts call for de-emphasis of labeling with respect to such conditions and for a focus on strengths/weaknesses and treatment and services based on need. But many children remain victims of labeling.

For example, according to mental health classification systems, children with conduct disorders are eligible for needed services. However, when education agencies see this diagnosis, they maintain that the child is not "seriously emotionally disturbed," but "socially maladjusted." The relevant federal laws mandate special educational services for children in the former category while they refuse them to youngsters in the latter. By not defining the difference between emotional disturbance and social maladjustment, these laws make it easy for the Department of Education to avoid its responsibility to provide services for children with SED. For example, consider Bianca (pseudonym):

> *Bianca was a twelve-year-old youth with a serious emotional disturbance (SED) who was not receiving the mental health and educational services she needed. Bianca had difficulty concentrating in class and consequently would leave class and run through the hallways of her school. One day, the school handled the problem by suspending her. However, Bianca feared walking home alone and rather than leave school premises, she hid for the remainder of the day in an upstairs empty classroom. When school officials found her, they contacted the police and had her removed in handcuffs and placed in a detention facility. Due to the humiliation she felt at having been handcuffed in front of her peers, Bianca refused to return to school. This resulted in a longer-term suspension.*

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Conversely, some diagnoses that enable children to receive education services prevent them from getting needed mental health care. Traditional systems of classification have often been used both to stigmatize and to limit eligibility or access to services. For example, children with autism may benefit greatly from the mental health services offered by health care plans, especially since many of their behaviors require the support of mental health providers. Mental health services, which enhance the treatment of a child with autism, may include initial evaluations, medication management, and/or wraparound services including behavioral aides that are provided both in the home and at school. Unfortunately, despite this need, the disorder of autism has been specifically excluded as a covered diagnosis under most mental health insurance plans. Consequently, mental health professionals will often label a child like Jasmine as depressed in order to receive reimbursement for services. This, however, adversely affects her ability to receive appropriate educational services.

> *Jasmine is a fifteen-year-old girl in the tenth grade. Jasmine has been diagnosed by one of the leading medical centers in her state as having both autism and depression. She regularly sees a social worker and a psychologist at the Center. In order to receive payment for the medical services given to Jasmine, her therapist emphasizes depression as the purpose of her therapy as opposed to emphasizing autism. This is because the diagnosis of autism excludes Jasmine from being able to access mental health services under her state Medicaid health plan.*
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> *At school, Jasmine is a bright girl who can sometimes function academically on or above her grade level. Her social skills, however, leave her isolated from her peers and often unable to attend to what takes place in the classroom. After reviewing the reports from the medical institution, school administrators determined that she had an emotional disturbance and placed her in a small classroom for children with serious emotional and behavioral problems. However, Jasmine is extremely sensitive to disturbances in that classroom. When the outbreak of behavioral problems in her classroom becomes too overwhelming, she covers her head and withdraws.*

Services Are Not Provided, Funded, or Reimbursed in a Timely, Integrated Fashion

Difficulty of Accessing In-Home Health Services Under Medicaid

The Supreme Court has held that unnecessary segregation and institutionalization of people with disabilities who could be treated just as well in their home and community is a form of discrimination and violates the Americans with Disabilities Act (Olmstead v. L. C., 1999).

The Medicaid Act requires states to provide comprehensive Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services to eligible children under age 21 (Perkins & Boyle, 2001). Therefore, in the vignette that follows, Jeremy's in-home behavioral aide should have been provided by the state. Often states do not specifically deny the in-home behavioral aide but make it so difficult to access the services that many children do not receive them. This difficulty results because: (a) the state does not advise people that they have this right, (b) the rates the state pays are so low that it is very difficult to find a provider, (c) states do not have enough providers with the requisite expertise, (d) the state does not inform parents which agency is responsible for securing the aides, or (e) the state does not provide services in a timely fashion.

Because of the difficulty of getting in-home behavioral aides and other services, advocacy groups throughout the country have filed numerous lawsuits using the EPSDT provisions to obtain mandated services. Advocates for children with emotional disturbances in Maine used the EPSDT provisions to successfully attack long waits for needed services. As part of the settlement agreement, Maine agreed to change many of its procedures and to hire additional staff so that parents could be informed and receive needed in-home health services in a much more timely fashion (French v. Concannon, 1998).

> *Jeremy is a 10-year-old boy who has been diagnosed with autism. He can be charming at times but has many troubling behaviors such as hitting, spitting and throwing furniture whenever he transitions from one activity to another. Because of these problem behaviors, it is very difficult for him to remain at home with his family. His mother has sought an in-home behavioral aide to help, so that he can remain in their home. Jeremy is eligible for medical assistance. Under federal and state law, he is entitled to receive a behavioral aide. However, securing this aide has been a virtually impossible task. Because his mother was unable to get the help he needed, Jeremy has been placed in a mental hospital away from his family, school, and community.*

The Failure to Reimburse Community-Based Providers Adequately

Inadequate pay given to community service providers and the failure to structure an adequate fee reimbursement schedule for providers of care discourages qualified direct support personnel from working with children with mental health problems. Hospital emergency rooms, where many of these children and their families consequently turn, can not handle the increased number of children and often have nowhere to refer them.

The Inadequate Funding of Community Support Workers

Community support workers are often the backbone of service provision. However, the rate at which support service providers are paid fails to compensate these workers adequately for the valuable services they provide. In most states, there is a huge difference between the wages paid to staff in public residential programs as compared to staff in community programs[1]. Although states claim to support individuals with disabilities living in integrated community-based settings, their finance systems do not support this goal.

There is also a serious problem with turnover in support staff. Some agencies and families report vacant staff positions for extended periods of time due to lack of qualified applicants willing to work for the wages offered. Program stability is at risk as tenured staff leave and positions remain vacant.

> *Adam is a fourteen-year-old boy with mental health problems, pervasive developmental disorder and mental retardation. After the death of his father, his mother was unable to care for him and abandoned him at a hospital. Since he was placed in the custody of the Department of Social Services he has been shuffled between four different group homes because the group homes cannot maintain adequate direct support staff to care for him. Because of this unstable and inconsistent living arrangement Adam has begun to act out at the private special education day school which he attends. The people who work with him currently believe that he now needs an institutional placement.*

The Failure to Reimburse Pediatric Care Adequately

Low reimbursement rates for pediatricians, whether in the fee-for-service system or as part of a Managed Care Organization, have a severe impact on children with mental health problems, since the majority of these children are seen by their pediatricians (see Report of the Surgeon General's Conference on Children's Mental Health, U.S. Public Health Service, 2000). If pediatricians are unable to provide adequate time for a visit, the child's treatment suffers. For children with mental health problems such as Attention Deficit Hyperactivity Disorder (ADHD), primary care practitioners prescribe the majority of psychotropic drugs. According to recent studies, the best results are achieved for children with ADHD when primary care physicians can spend more time with their patients (i.e., 30 minute visits), have more frequent visits (once a month), have increased contact with the child's teacher to make adjustments in the medication dosage, and the dosage prescribed is higher and more frequently administered. In actual practice, because of the constraints of the managed care system and the low reimbursement rates, this rarely occurs.

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[1] *From The Campaign to Increase Direct Support Wages in community programs funded by DDA: Justifying Increased Reimbursement Rates for Community Programs Supporting People with Developmental Disabilities; available from author.*

The System is Neither Fair nor Just

The Need to Relinquish Custody to Get Necessary Services

Children with mental health problems often fall between the cracks of the different providing agencies, as each agency disclaims responsibility for providing care. This is especially true for children with mental health problems who need residential care. Departments of Education will often argue that residential placement is not needed for educational reasons, but because of medical, home or environmental factors should be segregated from educational needs.

Children with mental health needs who are not eligible for residential services provided by the Department of Education face other hurdles. For children needing in-patient hospital care, insurance will only pay for very brief hospitalization and will not pay for longer-term community-based residential care. Parents are not told that their child may be entitled to in-home behavioral aides to help the family keep the child at home. Yet children eligible for Medicaid have the right to virtually any home or community-based mental health service that a practitioner determines is medically necessary. Not aware that they can get help, and fearing for their own wellbeing, families often are told that the only way their child can receive needed services is by relinquishing custody.

> *When Rebecca's husband got a job, the family's income rose above the limit for Medicaid. For her daughter Ginny to continue receiving the mental health services she needed, Rebecca was forced to hand over custody of Ginny to the child welfare system—an agency accustomed to cases where children are neglected or abused. Rebecca was treated as an abusive mother and subjected to standard agency procedures, such as home visits by a caseworker. Although the child welfare agency confirmed that she was not an abusive parent and that Ginny merely had a disability that needed treatment, Rebecca had no say about Ginny's placement in a foster care home. The foster mother—who received the help that was denied Rebecca—had values different from those of Rebecca and her husband. Rebecca found it especially painful that she could not take Ginny to church on Sundays.*

Conclusion

In order to create an accessible, family centered system of care that has the range of needed services and is fair and just in its delivery of services, a number of changes to the system are needed. Parents should not have to give up custody or navigate numerous and conflicting agency eligibility requirements in order to get services for their children. The state should blend their funds and set up a system where parents, through a single point of entry, can receive case management services. These case management services should arrange for assessments, if needed, and plan with the child and family for appropriate services. The case manager should have access to flexible funds to purchase needed care and can also monitor and advocate on behalf of the child and their family. In order to be able to provide care for their children and families, states must be willing to provide a much greater range of services to help families keep children at home. Also, states must look at each agency's ability to access increased federal funds through Medicaid and title IV-E funds (Social Services).

Finally, in the last twenty-five years there has been a tremendous increase in laws to support children with mental health problems. However, without the political will to ensure that the financial commitment and infrastructure is in place, many children will continue to fall through the cracks. As we know, what really makes a child special, unique and valuable is that she or he is somebody's child. Perhaps the best way to promote the wellbeing of other people's children is to think of them as your own. Then parents, advocates, government and professionals can join together to ensure that all children with mental health problems will have appropriate health care, education and a place to call home.

References

French v. Concannon, Order of dismissal and agreement, No. 97-CV-24-B-C (D. Maine, July, 1998)

Leviton, S. & Shuger, N. (1983). Maryland's exchangeable children: A critique of Maryland's system of providing services to mentally handicapped children. *Maryland Law Review, 42*, 823.

Olmstead v. L.C., 119 S. Ct. 2176 (1999).

Perkins, J. & Boyle, R. (2001). Addressing long waits for home & community-based care through Medicaid & the ADA. *St. Louis University Law Journal, 45*, 117, 124.

U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

U.S. Public Health Service. (2000). *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*. Washington, DC: Department of Health and Human Services, pp. 20-24, 40. Retrieved from the Office of the Surgeon General, http://www.surgeongeneral.gov/topics/cmh/childreport.htm.

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