Part II

The Great Smoky Mountains Study: A detailed picture of children's mental health services in western North Carolina

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Note: Most of the material in this section was taken directly or adapted from "Improving Mental Health Services for Children in North Carolina: Agenda for Action." E. Jane Costello, Adrian Angold, Barbara Burns, and the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (1998).

The Great Smoky Mountains Study

The Great Smoky Mountains Study (GSMS) is a longitudinal, population-based community survey of children and adolescents in North Carolina. It began in 1992 with funding from the National Institute of Mental Health. The study is a collaborative effort between Duke University and the North Carolina Division of MH/DD/SAS.

Nearly 1,100 children age nine through 16 enrolled in the GSMS. Participants were selected from 11 counties in western North Carolina and include both urban and rural areas. In addition, 349 children from the Eastern Band of the Cherokee Nation participated. Data were collected through annual interviews with the children, at least one interview with their parents, and follow-up telephone calls once every three months. Children's teachers also provided input. As part of the study, a comprehensive evaluation was conducted of all the mental health service providers working in schools, social services, juvenile justice, and child welfare, as well as those working in specialty mental health settings.

Among the goals of the study were to estimate:

- The number of children with emotional and behavioral disorders;
- The number of new cases of such disorders that develop in children each year;
- The persistence of emotional and behavioral disorders in children over time;
- The need for and use of services for emotional and behavioral disorders;
- The effects of family income, health insurance, and other related factors on service use;
- Which children are most at risk for emotional and behavioral disorders; and
- Which children are most at risk for later problems (such as school dropout, teen pregnancy, and encounters with the criminal justice system).

In addition, the study evaluated the children's families, including:

- Family psychiatric history;
- The extent to which a child's mental illness affected his/her family;
- The impact of family incomes on service use, including health and mental health insurance;
- Services sought and received for a child's mental illness; and
- Access and barriers to receiving child mental health services.

The GSMS is unique in that it simultaneously evaluates children's mental illnesses, need for services, receipt of services, and the effectiveness of services received. The study includes five categories of mental health services:

1. Mental health – services provided by specialized mental health by professionals, psychiatric hospitals and treatment centers, group homes, therapeutic foster care or outpatient drug/alcohol clinics;[9]
2. School-based – services provided by a school guidance counselor or school psychologist;
3. Health – services provided by a family doctor or community health center;
4. Child welfare – services provided through child welfare agencies such as child protective services; and
5. Juvenile justice – services provided through the juvenile justice system.

GSMS findings provide important information about rates of emotional and behavioral disorders in young North Carolinians and their use of mental health services.

Findings from the Great Smoky Mountains Study

The GSMS yields policy-relevant information about prevalence, need for mental health services, use of mental health services across sectors (e.g. education, juvenile justice, social services), and effectiveness of mental health care.

The Prevalence of Children's Mental Illness

Of those children participating in the GSMS, 70 percent had no diagnosable emotional or behavioral disorder. Of the other 30 percent, 25 percent had moderately severe disorders. Children with a moderate diagnosis are more likely to see a decrease in symptoms with treatment from quality mental health care. These more moderate diagnoses can become more severe in adulthood without appropriate care. The remaining five percent of children had serious emotional or behavioral disturbances that affected their ability to develop and function normally at school, at home, or with peers.

Forty-one percent of children with a SED suffered from more than one disorder. Of children with a SED, the most prevalent diagnoses included:

- Disruptive behavior disorder (70 percent);
- Anxiety disorder (27 percent);
- Depression (20 percent);
- Substance use (16 percent); and
- ADHD (13 percent).

Further study found that, compared to children with less severe or no mental disorders, approximately 22 percent of participating children with a SED are more likely to drop out of or be expelled from school, become convicted of a crime, begin using drugs or alcohol, or become pregnant during adolescence.

The GSMS also considered prevalence by race, finding that the rate of disorders for African-American and Native American children was similar to that of white children. Rural and urban children also had similar levels of need for mental health care. Serious emotional disturbances were slightly more prevalent in boys and in children over 12 years of age.

The prevalence of these findings is consistent with another North Carolina study on children's mental illness led by Dr. Costello. The Caring for Children in the Community Study (CCCS) was patterned on the GSMS and focused on comparing the prevalence of mental illness and service use of African-American to white youth. This study included 920 children from Franklin, Granville, Vance, and Warren counties. The families of almost half of the participating African-American children and 16 percent of white children were living below the federal poverty line.

Of those participating in the CCCS, approximately 20 percent had one or more diagnosis. The study also found:[10]

- The most common diagnoses were conduct disorder, anxiety disorder, and substance abuse; and
- There was little difference in prevalence by race with the exception that depression was more common among white youth.

The Need for and Use of Children's Mental Health Services

The GSMS explored the types of mental health services used by children and how many children used those services. One critical factor in understanding children's use of mental health services is that children almost never refer themselves for mental health care. A child's parent is the central gatekeeper in determining the child's mental health care. Recognition by a parent of their child's need for mental health services doubles the rate of mental health service use for those children. Study findings indicate that many children with mental illness are not receiving treatment. Every year of the study:

- Only 20 percent of children with a diagnosable disorder saw a mental health specialist;
- Only 40 percent of SED children received care from a specialty mental health agency; and
- Fewer than ten percent of children receiving services did so for more than three months at a time.

Consistent with these GSMS findings, the Caring for Children in the Community Study found that less than 33 percent of children with a mental health need received services.

Most children who received mental health services did so while living at home. Less than two percent of children received out-of-home placements during the year data for the study was collected. Of children with a SED, 15 percent spent at least one night away from home in a treatment setting in a year, compared with 3.6 percent of children with a moderate disorder. The average annual out-of-home stay was half a day for moderate needs, compared with four days for a child with SED.

When children in the GSMS received mental health services, it was often at school, not from a mental health provider. Some children received care through the medical service sector and others from informal or non-professional sources. Only 12 percent of children received care from specialty mental health professionals. Children with the most severe problems were most likely to use the services of mental health professionals. More specifically, of the children in the GSMS that received

some type of mental health service over the course of a year:

- More than 75 percent received service from a school counselor or psychologist;
- Six percent received services from primary care physicians;
- 50 percent received mental health services from only one agency; and
- 25 percent received mental health services from two agencies.

School is where most children receive mental health services and in most cases, it is the only place they receive such services.

The GSMS concludes that schools are the most important source of children's mental health services. Across all age groups, school is where most children received mental health services and in most cases, it was the only place through which they received services.[11] Specialty mental health services were more likely to be sought for younger children with more severe mental illness. In addition, children with more highly educated parents and parents with a history of mental problems were more likely to use specialty mental health services.[12] Almost half of all children seeking and using mental health services did so from more than one sector including education, specialty mental health, primary care, child welfare, and juvenile justice.

Who Pays for Children's Mental Health Services?

In 11 counties studied by the GSMS, the average cost of mental health services per child treated was between $2,764 and $3,173 a year.[13] Children with two or more diagnoses cost twice as much as those with a single diagnosis. Juvenile justice and non-medical residential facilities accounted for more than half the total costs. Estimates show the majority of costs associated with children's mental illness fall on agencies other than those designated to provide psychiatric or psychological services. These do not include family costs – such as travel, parents' absences from work, or other indirect costs stemming from the child's mental illness.[14]

In terms of cost by diagnosis, disruptive behavior disorders (including ADHD) and substance abuse accounted for the largest proportion of costs for children with only one diagnosis. This is explained, in part, because of the higher prevalence of these disorders. Moreover it costs significantly more to provide mental health services in the juvenile justice system. Depression and disruptive behavior disorders accounted for the highest rates of service use and the highest proportion of mental health costs.

This cost analysis shows that:[15]

- Over half of all costs of mental health services are for juvenile justice services and non-medical residential treatment facilities (e.g. residential treatment centers);
- 25 percent of all costs are for specialty mental health services;
- 16 percent of all costs were paid by schools, the most frequent providers of services to adolescents in the study;
- Most of the cost for mental health services fell on agencies other than those designated to provide specialized children's mental health services; and
- The children most costly to treat are those with disruptive behavior disorders.

Consistent with the GSMS, the Caring for Children in the Community Study showed that school is where most children receive mental health treatment and in most cases it is the only place they receive services. It also found that minority and white children had equal access to services provided by the school system.

Seventy percent of children participating in GSMS were covered by private insurance, 19 percent had public insurance such as Medicaid, and 11 percent had no insurance. When considering the use of mental health services in relation to insurance status the findings were:

- 20 percent of children with SED received some specialty mental health services regardless of insurance type (the Caring for Children in the Community Study found that white children were twice as likely as African-Americans to use specialty mental health services);

- Children with Medicaid were more likely to receive services more frequently and the service usage was found to be appropriate based on the severity of the children's mental illness;

- Children with private insurance were the least likely to receive appropriate services based on the severity of their mental illness; and

- Children with Medicaid were better served than children covered by private insurance or no insurance, especially in terms of the volume of services received. The reason for the difference was not due to the high level of services provided to Medicaid patients but to the very low level of services provided to privately insured and uninsured children.

The Effectiveness of Children's Mental Health Services

The GSMS is one of few studies that has evaluated whether the treatment children with mental illness receive improves their mental health. Specifically, the GSMS evaluated the treatment received by children whose symptoms were documented as worsening over the course of the year before they entered services. The study found:

- Children who had nine or more sessions with a mental health professional had significantly fewer emotional or behavioral problems at the next evaluation, as compared with children who did not receive treatment;

- Children who received fewer than nine sessions of treatment showed no improvement;

- Above nine sessions, the more treatment sessions children had, the fewer symptoms they displayed a year later; and

- Treatment did not significantly improve the child's functioning at school or home. A possible reason for this was that a year may be too short a period of time to realize improvements at home or school for children with serious problems.

These findings on treatment effectiveness suggest that while treatment improved the children's symptoms, it did not improve their overall ability to function at home or school. The seriousness of the problems may require a greater period of time to see improvement in functioning or more serious interventions may be needed.

Considerations for North Carolina Policymakers

An understanding of North Carolina's mental health service delivery system - specifically children's mental health services - can help policymakers consider specific steps to ensure that children with mental illness receive high quality and cost-effective treatment. The Great Smoky Mountains and Caring for Children in the Community studies illuminate potential policy considerations for enhancing North Carolina's mental health system for children.

Many factors must work together to increase the quality and cost-effectiveness of care. Research shows that mental health treatment for children occurs across service sectors and is impacted by family decision making. Many factors impact children's use of mental health services, such as age, gender, race, family income, and parent education.[16] The GSMS and related research have sought to more fully understand who, how, and what mental health services are accessed by children with mental illness and their families. The studies' findings contribute to the following strategies and options for consideration by policymakers. As part of the decision-making process, it is important to consider the range of impacts these policies have on children with mental illness and their families.

- **Establish and implement an ongoing process to document the need for children's mental health services.** Many questions remain about the prevalence of children's mental illness, the need for mental health services, the extent to which services meet needs, and the effectiveness of treatment.

- **Adopt strategies that better integrate schools into children's mental health services delivery.** Schools play a critical role in providing mental health services for children. Policy options that strategically engage school and mental health professionals may enhance communication and coordination among child-serving agencies. School-based mental health programs under way in North Carolina include a collaboration between East Carolina University and Eastern AHEC (Area Health Education Center). With funding from the Duke Endowment, Eastern AHEC has created a school mental health training curriculum to train school nurses and other school staff to provide mental health services in school settings. ECU provides the school nurses and school staff with enhanced mental health training.

- **Pursue policies that increase coordination among providers of children's mental health services.** Collaboration across agencies (mental health, education, juvenile justice) facilitates the provision of high quality services to children with mental illness. This is necessary since children often use specialized services from mental health professionals in conjunction with services from other agencies.

- **Adopt data collection practices and procedures that allow for a full assessment of the costs of and outcomes associated with children's mental health services.** Several systems including mental health, juvenile justice, and education, absorb costs of children's mental health services. With a better understanding of the cost burden, policymakers would be better equipped to assess both quality and cost-effectiveness of care.

- **Document the effectiveness of children's mental health services** to facilitate data-driven quality improvement.

- **Target services to vulnerable populations**. Children exposed to domestic violence and other crimes, children in the child welfare and criminal justice systems, and those exposed to medical trauma are especially vulnerable. Policymakers could support efforts to identify and meet the needs of those children early.

- **Support a Systems of Care approach** to children's mental health services.

ENDNOTES

[1] *Service Costs of Caring for Adolescents with Mental Illness in a Rural Community, 1993-2000.* E. Jane Costello, William Copeland, Alexander Cowell, Gordon Keeler, Adrian Angold. Submitted for publication.

[2] *U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration* glossary.

[3] *Child Mental Health Plan*. North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. Updated March, 2004.

[4] *Children's Mental Health: An Overview and Key Considerations for Health System Stakeholders*, National Institute for Health Care Management, Issue Paper, 2005.

[5] *Mental Health Care for Youth: Who Gets it? How Much Does it Cost? Who Pays? Where does the Money Go?* Rand 2001.

[6] *Children's Mental Health: An Overview and Key Considerations for Health System Stakeholders*, National Institute for Health Care Management, Issue Paper 2005.

[7] *Portrait of Youth: 2003 Annual Report. North Carolina.* NC Department of Juvenile Justice and Delinquency Prevention.

[8] *Report Card on the Clinical Impact of North Carolina's Mental Health Reform*, North Carolina Psychiatric Association, June, 2005.

[9] Use of the phrase "specialty mental health services" throughout this section refers to the mental health services category described in this report.

[10] *Psychiatric Disorder, Impairment and Service Use in Rural African-American and White Youth.* Adrian Angold, Al Erkanli, Elizabeth Farmer, John Fairbank, Barbara J. Burns, Gordon Keeler, and E. Jane Costello. Arch Gen Psychiatry, Vol. 59, October, 2002.

[11] *Pathways Into and Through Mental Health Services for Children and Adolescents.* Elizabeth Farmer, Barbara J. Burns, Susan Phillips, Adrian Angold, and E. Jane Costello. Psychiatric Services, Vol. 54, January, 2003.

[12] *Use, Persistence, and Intensity: Patterns of Care for Children's Mental Health Across One Year.* Elizabeth Farmer, Dalene Stangl, Barbara J. Burns, E. Jane Costello, Adrian Angold. Community Mental Health Journal, Vol. 35, February 1999.

[13-15] *Service Costs of Caring for Adolescents with Mental Illness in a Rural Community, 1993-2000*. E. Jane Costello, William Copeland, Alexander Cowell, Gordon Keeler, Adrian Angold. Submitted for publication.