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## CHAPTER ONE

# Setting the Stage: Children's mental health services in North Carolina

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**Abstract:** Managing children's mental health services in North Carolina is an increasingly important policy issue. This chapter provides an overview of North Carolina's mental health system with a focus on children's mental health services. Part I describes children's mental health services nationally and in North Carolina. It offers national data on children's mental illness; describes mental health reform in North Carolina; discusses the need for and receipt of mental health services; and provides data on service costs. Part II discusses the Great Smoky Mountains Study, which addresses mental illness among children and adolescents in western North Carolina. It provides an in-depth look at the prevalence of children's mental illness, the need for and receipt of services, and service costs. Importantly, it also provides research findings on the effectiveness of children's mental health services. Last, the chapter offers considerations for policymakers on improving children's mental health services including: increasing coordination among providers of children's mental health services; increasing documentation of the need for, costs of, and effectiveness of children's mental health services; and supporting a System of Care approach that focuses on coordinated, child- and family-centered services.

Policymakers and mental health professionals in North Carolina and across the nation have placed increased emphasis in the last two decades on identifying children with mental illness and on transforming the systems through which children receive care. Research has made significant progress on understanding children's mental health needs and their use of mental health services. However, efforts to apply this knowledge have been modest. More research is needed on the effectiveness of mental health services on children's well-being. A better understanding of children's and families' use of mental health services is critical to ensure that mentally ill children receive the care they need. Studies of children with serious emotional disturbances (SED) indicate that children receive mental health services from a range of providers (e.g. mental health, health, education, child welfare, and juvenile justice) over a period of time. The true cost of treating child mental illness is often not fully recognized, as multiple providers and service systems share expenses for children's mental health services.<sup>1</sup>

Drawing on nationally-recognized research, the following discussion provides an overview of children's mental illness. It highlights promising strategies for improving mental health systems' infrastructure and carrying out effective treatment.

# PART I

## Children’s Mental Illness in the United States and North Carolina\*

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*Mental Health: A Report from the Surgeon General* (1999) defines mental illness as disorders that are “characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning.” Examples include: depression that results in mood alteration and attention deficit hyperactivity disorder (ADHD) that creates changes in behavior and/or the ability to concentrate.

According to the U.S. the Department of Health and Human Services, Substance Abuse, and Mental Health Services Administration, a serious emotional disturbance is:<sup>2</sup>

*“A diagnosable disorder in children and adolescents that severely disrupts their daily functioning in the home, school, or community.”*

For purposes of this brief, children are persons under the age of 18.

Children with SED are affected in their ability to develop and function normally at school, at home, or with peers, and typically require mental health and other services during childhood and in many cases throughout their lives. Children with SED suffer from a range of disorders, including, but not limited to:

- Anxiety disorders (e.g. obsessive-compulsive disorder);
- Disruptive behavior disorders (e.g. conduct disorder);
- Depression;
- Substance abuse;
- ADHD; and
- Eating disorders (including anorexia and bulimia).

### **A 2001 Surgeon General’s report estimates that nationally, fewer than half of the children suffering from mental illness receive needed treatment.**

Without treatment and support, children with SED are more likely to:

- Be expelled from school;
- Drop out of school;
- Become pregnant during adolescence;
- Commit suicide; and
- Be convicted of a crime.

A critical aspect of childhood mental illness is that, for many individuals, managing their illness becomes a lifetime battle. Mental illness is much more similar to a chronic condition, such as diabetes, than to a short-term ailment like influenza. Appropriate treatment can help control the symptoms of mental illness and improve functioning; therefore, providing high quality treatment for children with mental illness must be viewed as a long-term commitment with no definitive “finish line.”

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\*Part I is based on data from the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS) and supplemented with information from the *State Plan 2005: Blueprint for Change*, Division of MH/DD/SAS; *Child Mental Health Plan, Updated March 2004*, Division of MH/DD/SAS; and *Children’s Mental Health: An Overview and Key Considerations for Health System Stakeholders*, National Institute for Health Care Management, February 2005.

## Mental Health Services for Children in the United States

### The Olmstead Decision

In 1999, the U.S. Supreme Court's Olmstead Decision stated that institutionalizing a mentally ill or disabled person when community-based treatment was available was a violation of rights. As a result of this mandate, many people previously confined to state facilities and institutions began to receive care in the community or in-home settings.

The Olmstead decision challenged states to meet the needs of mentally ill and disabled people. As a result, many states have undertaken major reforms to implement community-based care and, in many cases, deinstitutionalize mentally ill people. Aside from community-based services, the federal government has encouraged states to plan not only for health reforms but also for transportation, housing, education, and other social supports to fully integrate people with mental illness and physical disabilities into the least restrictive setting.

### The Prevalence of Children's Mental Illness in the United States

National estimates indicate that 20 to 28 percent of children in the U.S. suffer from a mild mental health disorder, and five to six percent suffer from a serious emotional disturbance.<sup>3</sup>

### The Need for Children's Mental Health Services

A 2001 Surgeon General's Office report estimates that nationally, fewer than half of the children suffering from mental illness receive needed treatment. Minority children are least likely to receive needed care. While the prevalence of mental illness between racial minorities and white children is similar, white children are more likely to use professional mental health services. Only an estimated ten percent of uninsured children's mental health needs are met, regardless of race.<sup>4</sup>

Children's mental health service provision varies greatly from state to state with responsibilities often spread across state and county government, private and public service providers, private insurers, and public insurance, such as Medicaid.

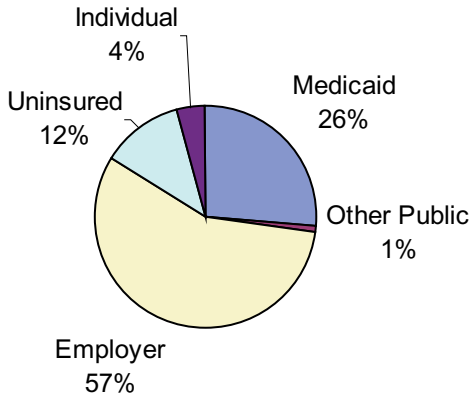
System fragmentation, availability of services, cost of treatment, and cultural and social stigmas are barriers to accessing children's mental health services and impact whether children receive care.

### Who Pays for Children's Mental Health Services?

Like service provision, financing for children's mental health also varies across and within states. Medicaid insures approximately 20 percent of children in the U.S. with a mental health problem and pays a disproportionate share of children's mental health costs (roughly 30 percent). The type of insurance coverage also varies by race. The Caring for Children in the Community Study, described in Part II of this chapter, found that approximately 33 percent of African-American and 20 percent of white children in North Carolina had public insurance such as Medicaid. Private insurance covers roughly 70 percent of children but pays only 50 percent of the cost of treatment for children's mental health. This is in part because Medicaid typically pays for more services per child than private insurance.<sup>5</sup> Children covered by public insurance programs also tend to have higher rates of mental health problems than children covered by private insurance. Medicaid coverage of specific mental health treatments varies across states. (See Fig. 1A, Insurance Coverage of U.S. Children.)

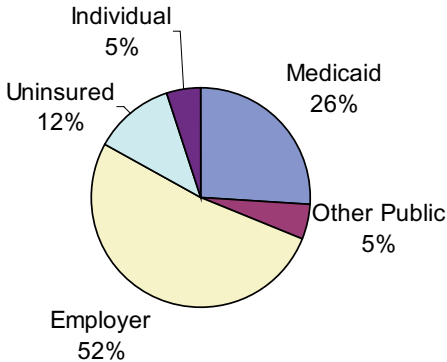
Nationally, state and local funds, including general fund revenues, grant funding, and a variety of other local sources, cover approximately 20 percent of children’s mental health costs.<sup>6</sup> States supplement funding for children’s mental health through federal grant programs that cover services such as screenings and community-based treatment options. The primary federal grant program in mental health is the Community Mental Health Services Block Grant program.

**Figure 1A. Insurance Coverage of U.S. Children, 2003-04.**



Source: Kaiser Family Foundation, [statehealthfacts.org](http://statehealthfacts.org).

**Figure 1B. Insurance Coverage of North Carolina Children, 2003-04.**



Source: Kaiser Family Foundation, [statehealthfacts.org](http://statehealthfacts.org).

## Effectiveness of Children's Mental Health Services

With few exceptions such as the Great Smoky Mountains Study described below, the available information on the effectiveness and quality of treatments received by U.S. children with mental illness, is not widely applied. Furthermore there is not consensus among mental health professionals on how to measure the quality of care. While there is growing evidence on the effectiveness of certain treatments, such as evidence-based practices, opinions differ as to how to best define and measure successful treatment for children with mental illness.

## **Mental Health Services for Children in North Carolina**

### Recent History and Current Challenges

In 1999, the North Carolina General Assembly asked the State Auditor's office to assess the physical conditions of state mental hospitals and make recommendations for reforming the state and local mental health system. In July 2000, the General Assembly passed HB1519, which created the Joint Legislative Oversight Committee on MH/DD/SAS. The committee was charged with developing a plan to implement the recommendations made in the Auditor's report for reorganizing the public mental health system. In 2001, HB381 was enacted to establish guidelines to reform the state mental health system over a five-year period (2001-2006). The Joint Legislative Oversight Committee continues to grapple with the state's mental health reform efforts.

The North Carolina Department of Health and Human Services (NC DHHS) was charged with overseeing the reform process and developed *State Plan 2001: Blueprint for Change* that outlined guidelines for meeting the requirements of the reform legislation. Central to reform is ensuring that public funding provides consumers, families, and communities with the resources that allow people with the most severe mental disabilities to receive services in their communities.

A significant piece of the reform effort involved transferring the management and oversight of the public mental health system from Area Programs (semi-independent public agencies that provided services throughout their catchment area), to local management entities (LMEs, public agencies that manage and oversee local services purchased from a network of providers and vendors). Currently, 30 LMEs cover North Carolina's 100 counties. Some cover a single county while others cover up to eight counties. (*See Appendix C for a map of LMEs and the counties they cover.*)

Among the purposes of this system-wide change is to separate management from service provision to:

- Increase efficiency;
- Alleviate tensions stemming from the same entity serving as both the payer and payee for treatments; and
- Improve quality by creating competition among providers based on value of service instead of price.

Along with developing a network of mental health service providers, each LME is responsible for planning, budgeting, implementing, and monitoring community-based mental health, developmental disabilities, and substance abuse services in the counties it serves. Each LME is required to complete a business plan that details implementation and operating procedures. For the LME to be

operational, the business plan must be certified by NC DHHS. Certification lasts three years at which time the LME must submit a new plan.

NC DHHS and the LMEs have negotiated a statewide performance contract that includes each LME's business plan as the scope of work. The contract specifies state requirements, performance measures, and financing requirements for each LME. Modifications and additions to the contract are anticipated over time.

*State Plan 2003*, an updated version of *State Plan 2001*, outlined LMEs' responsibilities for developing a service plan to meet the health care needs of children and their families. It stressed use of best practice services, which it defined as "well-implemented, scientifically-defensible, supported by formal evaluation and research, have documented evidence of significant consensus among experts in the field, and have demonstrated effectiveness and positive outcomes for consumers and their families."

The state's *Child Mental Health Plan* (March 2004 version) identifies the array of services to be provided:

### Of the children served by the NC mental health system in 2005:

- 58 percent were ages 12 to 17;
- 33 percent were age six to 11;
- Nine percent were less than six years old;
- 50 percent were white;
- 43 percent were African-American;
- Seven percent were of an "other" race/ethnicity; and
- More than 500 were homeless.

Source: NC Division of MH/DD/SAS.

- Assessment and diagnosis;
- Community inpatient services;
- Inpatient alternatives;
- Community living services;
- School-based services; and
- Vocational services.

While the services are clearly stated, the shift from Area Programs providing services, to LMEs overseeing a network of service providers, has vastly increased privatization of mental health services in North Carolina. Varying availability of service providers in each county as well as a shortage of mental health workers have added to the challenges of reform. According to a 2006 study by the North Carolina Area Health Education Centers Program, in 2004, 43 counties in North Carolina had no child psychiatrist. The shortage of mental health professionals is striking, especially in the context of the prevalence of children's mental illness in North Carolina.

### The Prevalence of Children's Mental Illness in North Carolina

According to *State Plan 2005*, approximately ten to 12 percent of children in North Carolina suffer from a SED. Based on the population of children age 17 and younger in 2003, between 205,137 and 246,164 North Carolina children experienced a SED.

### The Need for and Provision of Children's Mental Health Services in North Carolina

To meet the needs of North Carolina's mentally ill children, LMEs are expected to:

- Ensure access to services on a 24 hours/7 days a week/365 days a year basis;
- Create systems that ensure greater consumer input on the management of the service delivery system;

- Coordinate with public and private organizations to assess consumer needs and fill service gaps;
- Recruit and contract with service providers; and
- Approve person-centered plans for individual consumers.

To that end, the NC Division of MH/DD/SAS and LMEs use specific diagnostic criteria to prioritize service delivery for certain target populations. For example, anyone who meets the specific criteria and is publicly insured is eligible for services through the state’s mental health system. The state is required to use its resources to best meet the needs of these persons. In addition, Medicaid-eligible persons with a condition that meets “medical necessity” as defined for a particular service are also eligible to receive care. People falling outside the target populations can receive screening and triage services from the public mental health system and receive referrals to private providers and community organizations.

Following are North Carolina’s target populations for children’s mental health services:

1. Children with an early childhood disorder;
2. Children with SED who require out-of-home placement;
  - Children with three or more psychiatric hospitalizations or at least one hospitalization of 60 continuous days within the past year; or
  - Children with a DSS substantiated case of abuse, neglect, or dependency within the past year.
3. Children with SED who do not require out-of-home placement;
4. Children who are deaf or hard of hearing; and
5. Children who are homeless.

*For a full description of these target populations, see Appendix A.*

The North Carolina public mental health system served approximately 69,000 children with a mental health need in FY 2005. Given the prevalence of children with an SED, this means that about 66 percent did not receive any mental health services, or are receiving private services. The largest group of children receiving state-funded mental health services included white teenagers between the ages of 12 and 17 who lived in a private residence (their home or with extended family).

Compared to whites, African-American children who need mental health services are more likely to receive them through the juvenile justice system. According to 2003 data from the NC Department of Juvenile Justice and Delinquency Prevention (DJJDP), 50 percent of children who have been found responsible for an offense are African-American. Of children in the juvenile justice system committed to a youth development center (a secured residential facility), most have a mental health diagnosis and 50 percent have more than one diagnosis.<sup>7</sup>

Table 1 shows the categories of services provided to children with mental health needs and the number of children served by each treatment category. Children typically receive multiple services during the course of their treatments and are counted as “being served” in multiple categories. Therefore it is important to note the difference between the two “total” figures given. The “duplicated” total includes children who have received more than one service and are counted in the total more than one time. The “unduplicated” total reflects the number of distinct children who received the services.

**Table 1. Children’s Mental Health Services, FY 2005.**

<b>Services</b>	<b>Children Served (FY05)</b>
Residential Treatment	5,853
Community-based Services (CBS)	10,152
Outpatient Therapy	49,269
Inpatient Hospital	4,258
Case Management	25,116
Day Treatment	1,696
Intake/Assessment/Testing	35,281
Case Support	12,389
Med Check	18,129
Respite	479
Other (travel/outreach, ACT Team and supported employment)	2,911
<b>Total Children Served (Duplicated)</b>	<b>165,533</b>
<b>Total Children Served (Unduplicated)</b>	<b>68,704</b>

Source: NC Division of MH/DD/SAS.

LME-specific data from MH/DD/SAS allow for a more detailed understanding of the number of children served (see Table 2). As expected, the LMEs representing the urban areas of the state treat the greatest number of children. They do not, however, treat the highest percentage of children. Based on data from MH/DD/SAS and child population estimates by county from census data, the information in Table 2 shows that several rural LMEs served a greater percentage of the children in their catchment area in FY 2005 than some LMEs serving urban areas.

While most children receive mental health services in a private residence (e.g. their home, a relative’s home), a significant number of children receive services in out-of-home settings, including community residential homes, foster homes, correctional facilities (e.g. training schools), reeducation programs (e.g. Whitaker School), and state psychiatric hospitals. While the percentage of children being treated in out-of-home residential treatment facilities has fallen nationally, a recent report suggests North Carolina’s children are not experiencing the same trend. A June 2005 North Carolina Psychiatric Association report, *The Clinical Impact of North Carolina’s Reform*, found there is still work to be done to reduce the use of state hospitals for children with mental illness. Based on data provided by MH/DD/SAS on state hospital admissions for the period July 1999 through April 2005:<sup>8</sup>

- From April 2000 until September 2003, there was a steady decline of adolescent state hospital admissions; and
- Between August 2003 and December 2004, the trend reversed, with the number of admissions almost doubling.



**Table 2. Population Estimates, Children Served, and Children’s Mental Health Service Expenditures by LME, FY2005.**

<b>LME (counties served)</b>	<b>Child Population Estimates (2004)</b>	<b>Number of Children Served (FY 05)</b>	<b>Percent of Children Served (FY 05)</b>	<b>Children's Mental Health Services Expenditures MH/DD/SS (FY 05)</b>	<b>Expenditures per Child Served</b>
Alamance-Caswell-Rockingham	59,197	1,782	3%	\$13,049,438	\$7,323
Albemarle	19,435	1,085	6%	\$13,873,996	\$12,787
Catawba	36,155	1,242	3%	\$5,615,699	\$4,521
CenterPoint	60,312	2,916	5%	\$19,888,107	\$6,820
Crossroads	60,312	1,706	3%	\$9,641,271	\$5,651
Cumberland	84,562	3,305	4%	\$11,321,713	\$3,426
Durham	57,441	2,220	4%	\$22,847,997	\$10,292
EastPointe	72,806	3,174	4%	\$13,736,964	\$4,328
Edgecombe-Nash	36,075	1,232	3%	\$5,083,322	\$4,126
Five County	55,473	2,180	4%	\$13,094,195	\$6,007
Foothills	56,626	1,786	3%	\$13,343,550	\$7,471
Guilford	104,608	3,013	3%	\$14,660,080	\$4,866
Johnston	37,508	1,321	4%	\$6,347,208	\$4,805
Mecklenburg	199,186	3,719	2%	\$22,712,028	\$6,107
Neuse	26,686	1,046	4%	\$6,710,140	\$6,415
New River	31,611	1,304	4%	\$5,188,443	\$3,979
O-P-C	45,531	1,633	4%	\$12,788,351	\$7,831
Onslow	51,794	1,582	3%	\$8,611,659	\$5,444
Pathways	86,530	4,485	5%	\$57,457,256	\$12,811
Piedmont	164,901	2,604	2%	\$17,008,596	\$6,532
Pitt	33,322	1,571	5%	\$10,671,205	\$6,793
Roanoke Chowan	17,475	1,185	7%	\$5,093,825	\$4,299
Sandhills	125,198	5,084	4%	\$39,638,467	\$7,797
Smoky Mountain	42,528	2,062	5%	\$10,866,896	\$5,270
Southeastern	63,038	3,253	5%	\$22,270,841	\$6,846
Southeastern Regional	66,468	2,976	4%	\$20,936,068	\$7,035
Tideland	21,069	1,183	6%	\$10,278,610	\$8,689
Wake	188,056	4,360	2%	\$47,388,533	\$10,869
Western Highlands	100,986	4,856	5%	\$40,104,055	\$8,259
Wilson-Greene	23,897	912	4%	\$4,366,317	\$4,788
<b>Total Expenditures*</b>				<b>\$504,644,504</b>	
<b>Children Served (unduplicated)</b>		<b>68,704</b>			

*Source: North Carolina Division of MH/DD/SAS. (See Appendix B for counties served by each LME.)*

*\* Totaling the individual LME expenditures would result in a discrepancy of approximately \$69,000 due to expenditures of that amount for which no county was assigned.*

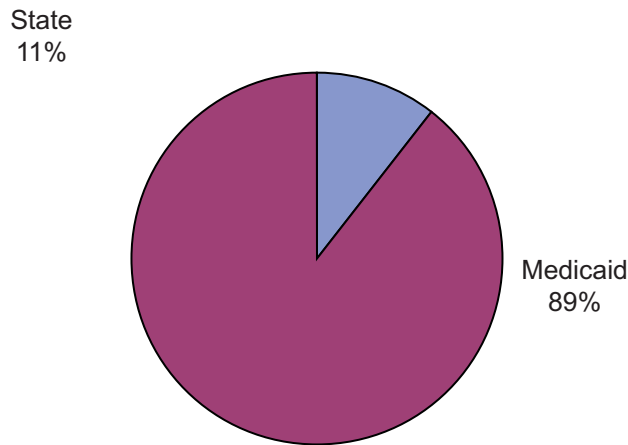
This increase is counter to the state’s child mental health plan which is to provide “quality care... delivered in the home and community in the least restrictive and most consistent manner possible.” As the next chapter illustrates, the System of Care approach to reform holds promise for curtailing out-of-home placements for children with mental illness.

## Who Pays for North Carolina Children’s Mental Health Services?

North Carolina spends more than \$2 billion annually on the public mental health system which includes mental health, developmental disabilities, and substance abuse services. Funding for the state public mental health system comes from Medicaid, state appropriations, county general funds, and other receipts. Of the \$2 billion, in FY 2005 North Carolina spent approximately \$504 million of federal and state funds on children’s mental health services and served roughly 69,000 children.

In FY 2005, Medicaid covered approximately 89 percent of those expenditures; the state covered approximately 11 percent (see Fig. 2). This does not include county funds. This data reflects expenditures through MH/DD/SAS but does not include funding by the NC Department of Public Instruction, the NC Department of Juvenile Justice and Delinquency Prevention, the NC Division of Social Services, NC Health Choice, county funds, or grants received by the LMEs.

**Figure 2. Children’s Mental Health Public Expenditures FY 2005 by Source of Funds.**



*Source: North Carolina Division of MH/DD/SAS.*

In 2003-2004, the Kaiser Family Foundation reported that 57 percent of NC children ages 0-18 were covered by employer insurance. Twenty-six percent were covered by Medicaid, five percent by other public insurance (e.g. military coverage), and 12 percent were uninsured. This is similar to national insurance coverage rates. (See Figures 1A and 1B.)

Table 3 looks more closely at North Carolina’s expenditures for children’s mental health. The largest category of expenditures is for residential treatment. Figure 2 illustrates that in FY 2005 more than 40 percent of the state’s expenditures on children’s mental health services was for residential treatment. Community-based services represent the next largest category with 25 percent of total expenditures.

**Table 3. Expenditures for Children’s Mental Health Services.**

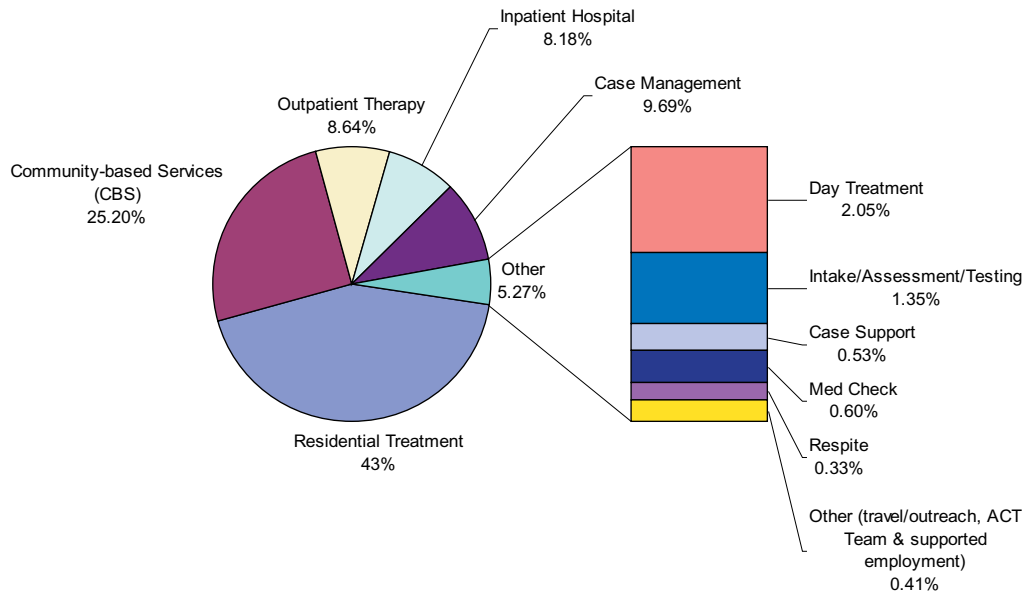
Services	Expenditures (FY 05)	Percent of Expenditures (FY 05)	Children Served (FY05)	Percentage of Children Served by Service (FY05)
Residential Treatment	\$217,095,249	43.02%	5,853	9%
Community-based Services	\$127,193,647	25.20%	10,152	15%
Outpatient Therapy	\$43,587,508	8.64%	49,269	72%
Inpatient Hospital	\$41,254,908	8.18%	4,258	6%
Case Management	\$48,895,111	9.69%	25,116	37%
Day Treatment	\$10,352,103	2.05%	1,696	2%
Intake/Assessment/Testing	\$6,796,439	1.35%	35,281	51%
Case Support	\$2,685,544	0.53%	12,389	18%
Med Check	\$3,049,208	0.60%	18,129	26%
Respite	\$1,641,749	0.33%	479	1%
Other (travel/outreach, ACT Team & supported employment)	\$2,093,038	0.41%	2,760	4%
<b>Total</b>	<b>\$504,644,504</b>		<b>165,533 (Duplicated)</b>	
<b>Total Children Served</b>			<b>68,704 (unduplicated)</b>	

Source: North Carolina Division of MH/DD/SAS.

Upon receiving approval from the National Centers for Medicare and Medicaid Services, in March 2006, North Carolina implemented new service definitions which expanded the range of community-based mental health services eligible for Medicaid reimbursement. Future information on expenditures may reflect this expansion.

MH/DD/SAS data also provides information on state expenditures for children’s mental health by LME. As shown in Table 2, the expenditures per child vary widely across the state from a high of \$12,811 for Pathways LME (Gaston, Lincoln, and Cleveland counties) to a low of \$3,979 for New River LME (Alleghany, Ashe, Avery, Watauga, and Wilkes counties). The average state expenditure per child was over \$7,000. Costs vary based on the severity of diagnosis, type, and number of treatments, and whether a child has more than one diagnosis. Data tracking the treatment of each child and that treatment’s effectiveness would be of great value to North Carolina policymakers, LME administrators, and service providers.

**Figure 3: Children’s Mental Health Services for FY 2005 Expenditure by Treatment Type.**



Source: North Carolina Division of MH/DD/SAS.

### Effectiveness of Children’s Mental Health Services in North Carolina

There is little state level data on the effectiveness of mental health treatment for North Carolina children. The increasing use of community-based services and evidence-based practices, however, is generating greater understanding of how North Carolina fares in its treatment of mentally ill children. Important work is under way in North Carolina to provide policymakers and mental health professionals with information on treatment that appears to have positive outcomes for children. Research by Dr. Barbara J. Burns of the Duke Services Effectiveness Research Program suggests significant growth in the evidence documenting positive outcomes for community-based interventions. The Great Smoky Mountains Study, led by Dr. E. Jane Costello, further contributes to understanding the effectiveness of children’s mental health services.