North Carolina
Family Impact
SEMINAR

# Children's Mental Health:

## Strategies for Providing High Quality and Cost-Effective Care

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**North Carolina Family Impact Seminar**

# Children's Mental Health: Strategies for providing high quality and cost-effective care

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## Purpose and Presenters

*Children's Mental Health: Strategies for providing high quality and cost-effective care* is the second North Carolina Family Impact Seminar in a series designed to connect research and state policymaking. Family Impact Seminars analyze the impact an issue, policy, or program may have on families. Family Impact Seminars started on a national level over 20 years ago. They have since transitioned into a network of state-level seminar series supported in part by the Policy Institute for Family Impact Seminars at the University of Wisconsin-Madison. The seminars and supporting materials bring together research, practice, and policy experts from a range of disciplines to share information and help bring research to policymaking. The seminars deliberately take an educational, nonadvocacy approach. They are a forum for providing objective, nonpartisan, solution-oriented research to state policymakers, including legislators, legislative and gubernatorial staff, and state agency officials.

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## Executive Summary

Policymakers and mental health professionals in North Carolina and across the nation are increasingly concerned about identifying children with mental illness and transforming the systems through which children receive mental health services. Along with efforts to increase the availability of services for all people with mental illness, there has been a particular emphasis on improving the quality of children's mental health services.

This Family Impact Seminar briefing report discusses strategies for providing high quality and cost-effective children's mental health services. A "family impact perspective" on policymaking informs this report. Just as policymakers routinely consider the environmental or economic impact of policies and programs, Family Impact Seminars help policymakers examine impact on families by providing objective, solution-oriented research to state policymakers.

This briefing report provides information and analysis of promising strategies for improving children's mental health services. The first three chapters conclude with considerations for policymakers based on lessons learned from research and practice.

This report consists of four chapters:

The first chapter provides an overview of North Carolina's mental health system with a focus on children's mental health. It offers national and state 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. It then discusses the Great Smoky Mountains Study on mental illness among children and adolescents in western North Carolina, including important findings on the effectiveness of children's mental health services.

The second chapter focuses on System of Care (SOC), the leading approach to improving the quality of mental health care for children. It describes how a data- and value-based system of care can support ongoing improvement in the quality and cost-effectiveness of children's mental health services. It defines SOC and describes its development and the critical factors for successful implementation. It also considers the use of this approach, in conjunction with best practices, to ensure coordinated child- and family-focused services.

The third chapter addresses the Ohio Mental Health Consumer Outcomes Initiative, which led to a statewide system of consumer outcomes for adults and youth in the Ohio mental health system. The initiative began in 1996 and continues to evolve. It describes the initiative's genesis, development, and its current status. In addition to the state perspective, the chapter also describes how a local provider uses outcomes to improve treatment planning, management, and outcomes for children with mental illness.

The fourth chapter shares interviews conducted by the Center for Child and Family Policy with five Local Management Entity (LME) leaders. These interviews highlight promising practices and reflections on the new structure of mental health services in NC, providing valuable lessons learned.

The briefing report concludes with additional materials for policymakers including definitions of mental health target populations, a current map of LMEs and the counties they serve, LME contact information, a glossary, a list of terms and acronyms, and additional resources.

## Four Questions to Guide Policymakers about Children's Mental Health Services in North Carolina

Policymakers routinely consider the environmental and economic impact of proposed legislation. Equally important but far less routinely considered is family impact. It is rare that legislation does not affect families in some way.

Family impact is also about how families contribute to policymaking. Incorporating family impact considerations can broaden policy deliberations, and demonstrate an appreciation of how "real people" are affected by policymakers' decisions. The questions below are intended to encourage policymakers to reflect regularly on family impact.

1. How do children's mental health services affect North Carolina families?

2. How do families contribute to the challenge of providing high quality and cost-effective children's mental health services?

3. How do families affect the quality of treatment and outcomes of children's mental health services?

4. How can North Carolina families help generate solutions to increase the quality and cost-effectiveness of children's mental health services?

## Chapter One

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

**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.[1]

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*

Nam Douglass, Lisa J. Berlin, Ph.D., Jenni Owen

*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:[2]

> *"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."

*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.[3]

### 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.[4]

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.

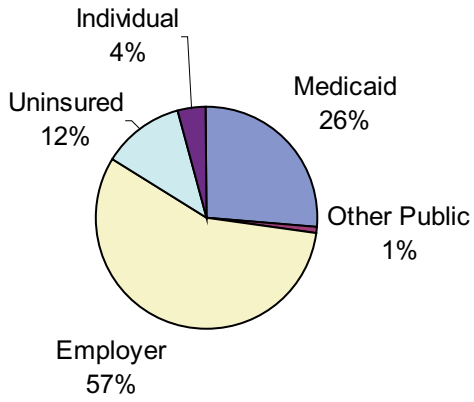
System fragmentation, availability of services, cost of treatment, and cultural and social stigmas are barriers to accessing children's mental health services and impact whether children receive care.

### 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.[5] 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.)

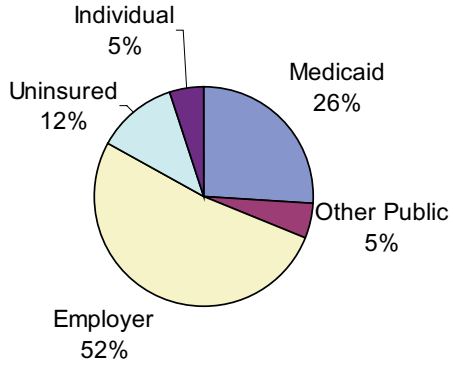
Nationally, state and local funds, including general fund revenues, grant funding, and a variety of other local sources, cover approximately 20 percent of children's mental health costs.[6] States supplement funding for children's mental health through federal grant programs that cover services such 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.*

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




*Source: Kaiser Family Foundation, 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:

- 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.

### 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.

## 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.[7]

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.**

| Services | Children Served (FYO5) |
|---|---|
| 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 |
| | |
| **Total Children Served (Duplicated)** | **165,533** |
| **Total Children Served (Unduplicated)** | **68,704** |

*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:[8]

- 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.**

| LME (counties served) | Child Population Estimates (2004) | Number of Children Served (FY 05) | Percent of Children Served (FY 05) | Children's Mental Health Services Expenditures MH/DD/SS (FY 05) | Expenditures per Child Served |
|---|---|---|---|---|---|
| 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 |
| **Total Expenditures*** | | | | **$504,644,504** | |
| **Children Served (unduplicated)** | | **68,704** | | | |

*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.*

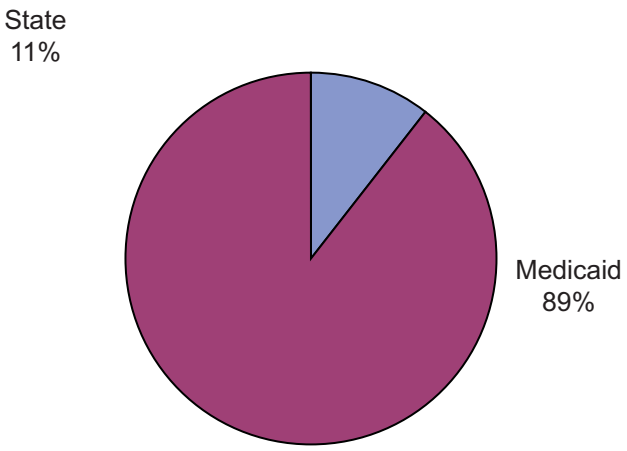
This increase is counter to the state's child mental health plan which is to provide "quality care... delivered in the home and community in the least restrictive and most consistent manner possible." As the next chapter illustrates, the System of Care approach to reform holds promise for curtailing 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.**

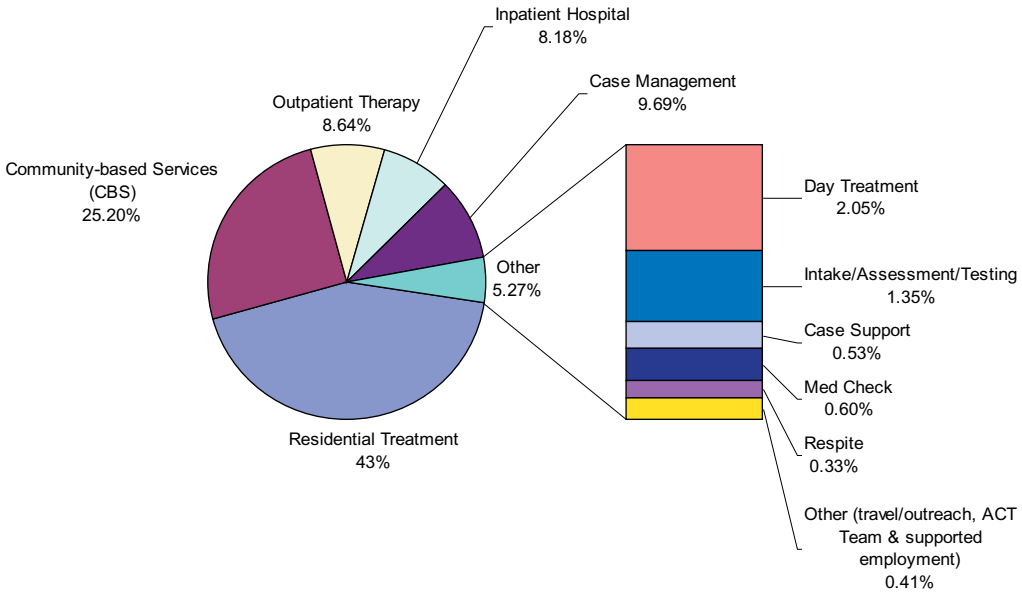
| Services | Expenditures (FY 05) | Percent of Expenditures (FY 05) | Children Served (FYO5) | Percentage of Children Served by Service (FY05) |
|---|---|---|---|---|
| Residential Treatment | $217,095,249 | 43.02% | 5,853 | 9% |
| Community-based Services | $127,193,647 | 25.20% | 10,152 | 15% |
| Outpatient 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% |
| | | | | |
| Total | **$504,644,504** | | **165,533 (Duplicated)** | |
| Total Children Served | | | **68,704 (unduplicated)** | |

*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.

## Part II

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

E. Jane Costello, Ph.D.

*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.

## Chapter Two

# Services for Children with Mental Illness:
## The System of Care approach*

Nam Douglass

**Abstract:** Policymakers and mental health professionals face the ongoing challenge of addressing children's mental illness in a cost-effective manner while ensuring high quality care. Since the 1980s, federal and state policymakers and experts in the field have emphasized the development and implementation of holistic approaches to treating children with mental illness; approaches that are child- and family-centered and focus on the individual needs of children and their families. System of Care (SOC) is recognized as the leading approach to improving the quality of mental health care for children. This chapter describes the key factors in implementing SOC, which can be a complex and challenging process. It includes information on how a data- and value-based system of care can support ongoing improvement in the quality and cost-effectiveness of care for children. Finally, it highlights policy strategies that have helped, as well as tested collaboration among state and local stakeholders in the implementation of SOC for children with mental illness and their families.

### What is a System of Care?

A System of Care (SOC) is a comprehensive continuum of mental health and necessary services organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances (SED) and their families. SOC is based on the understanding that children with SED have many strengths and needs and that services should be individualized or tailored to those strengths and needs.

Children's mental health problems contribute to crime and delinquency, poor school performance, and teen pregnancy. It is estimated that 60 percent of adult alcohol and substance abuse problems could be solved by effectively treating children with mental health needs. SOC can also decrease the long-term negative consequences that can result from not adequately meeting these needs.

* The material in this chapter is taken directly or adapted from the following sources: "Implementing Effective Data-Based and Value-Based Systems of Care," presented by Robert M. Friedman (November 2005); "Evidence-Based Practices, Systems of Care, and Individualized Care," Robert M. Friedman and David A. Drews (2005); "Some Perspectives on Getting There," Dean L. Fixen and Karen Blasé (2005); "Findings: Examining the Impact of Policy on Collaboration in Systems of Care," presented by Mary Armstrong and Mary Evans, (March 2005); "System of Care: History of the Concept, General Implementation Issues, and Relationship to Individualized Care and Evidence-Based Practices" (February 2006); "Taking a Giant Step Forward from Good to Great Systems of Care" (March 2004); and "The Status of Children's Mental Health: A Need for Urgent Action" (July 2004).

Children with SED typically have multiple needs and are served by multiple agencies and systems (education, social services, juvenile justice, health, mental health, vocation, recreation, and substance abuse). In SOC, agencies work collaboratively to develop and deliver services and supports for children with SED and their families.

### Features of a System of Care

- Coordinated network of community-based services and supports for children with serious mental health needs and their families.
- Involves collaboration among many stakeholders and systems, including mental health, health, education, social services, and juvenile justice.
- Child- and family-centered where the family participates in decision making and services reflect what is best for the child, not what is most readily available or financially feasible.
- Uses evidence-based practices with demonstrated effectiveness.
- Uses quality information and data.
- Flexible use of dollars to access services for children with spending caps to contain costs.

SOC is widely-recognized as a promising approach. It has resulted in the improved provision of services and has decreased out-of-home and out-of-state placement of children. Evaluations suggest it can improve the effectiveness and functioning of the children's mental health system, and allow for the provision of services beyond those addressed by traditional medical and specialty care sectors.[1]

Many studies have addressed SOC effectiveness.[2]

- A 1995 evaluation of the system of care in Vermont compared outcomes of children served through SOC to data from a longitudinal study of youth receiving "traditional services." While the seriousness of diagnosis was comparable between the two groups of children, those receiving services using SOC fared better in terms of rates of reinstitutionalization after leaving a residential facility, in addition to reporting higher service satisfaction; and

- In California, a 1997 evaluation comparing counties with and without a SOC approach found a reduction in cost and restrictive placement in counties with SOC. The evaluation estimated that California could have saved $1.1 billion in group home costs had it been using a SOC approach.

Some studies have shown less favorable results in terms of clinical outcomes. These same studies did, however, show positive results in terms of treating children in less restrictive environments and in child and family satisfaction with the services received. Research continues to illustrate the challenges of implementing an effective SOC.

## System of Care in North Carolina

Numerous NC entities have supported SOC concepts and strategies and are encouraging its implementation in association with family members and LMEs. These include the NC Department of Health and Human Services Division of MH/DD/SAS Child and Family Services Section, Divisions of Medical Assistance, Public Health, and Social Services; the NC Department of Juvenile Justice and Delinquency Prevention; the NC Department of Public Instruction; and the Governor's Crime Commission.

Beginning with the Willie M. program and followed by the Fort Bragg experiment reform efforts, North Carolina is often considered the birthplace of the SOC approach. The Willie M. program resulted from a class action lawsuit on behalf of four North Carolina youth involved with the juvenile justice system who also had mental health problems. Neither the mental health nor the education systems in North Carolina were equipped to work effectively with the youth. The only options appeared to be training school especially from the perspective of available financial resources.

**Since Durham began SOC, court-ordered out-of-home treatment costs dropped from $762,000 in 2000 to $7,100 in 2004 to $0 in 2005.**

Willie M. led to new strategies for both service delivery and assessment. It resulted in a new focus on child- and family-centered services and requirements for individualized and least restrictive treatment determined by children's needs, not by available services.

The Willie M. lawsuit and the policy and program implementation that followed provided the foundation for other mental health reform initiatives. Among them was the Fort Bragg Children's Mental Health Demonstration Project, based in Fayetteville and funded by the U.S. Department of Defense. The Fort Bragg study looked at "what systemic, clinical, and functional outcomes could be achieved if a wide range of individualized and family-centered services were provided without any barriers to their availability."[3]

Grants from the National Center for Mental Health Services have supported the establishment of locally-based SOC in more than 20 counties. Durham County is implementing SOC without grant funds targeted for that purpose. Data from the national evaluation of these North Carolina communities prior to 2001 indicate:

- Improved school attendance and performance;
- Reductions in the number of hospital and out-of-home residential placements;
- Improvements in child behavior and emotional functioning;
- Reductions in violations of the law; and
- Increased services and supports to a greater proportion of the children and families.[4]

**Counties with Federal Grants to Implement System of Care**

| | |
|---|---|
| Buncombe | Macon |
| Chatham | Madison |
| Cherokee | Mitchell |
| Clay | Montgomery |
| Cleveland | Moore |
| Edgecombe | Nash |
| Graham | Orange |
| Guilford | Person |
| Haywood | Pitt |
| Henderson | Richmond |
| Halifax | Swain |
| Jackson | Yancey |

More recently, the Durham Center, Durham's LME, reported the benefits of Durham's SOC in its 2004-2005 Annual Report:

- Significant increases in the number of children and families receiving community-based services;
- Substantial reductions in expenditures for court-ordered care;
- New best practice services cross-funded among agency partners; and
- Substantial decreases in the number of children sent to out of area residential treatment facilities.

Policy and practice suggest that North Carolina recognizes the value of a SOC approach to serving the needs of children with mental illness. State policymakers, however, must ensure that the benefits to children and their families achieved to date through the SOC efforts can be sustained within the new state mental health services delivery structure. Implementation of SOC in North Carolina took place largely before the state mental health system transitioned from Area Programs to LMEs *(see Chapters one and four for more information about this transition)*. Within this new structure, perspectives differ on the extent to which policymakers and state-level administrators have reconfirmed a commitment to SOC for all children with mental health needs in North Carolina. Anecdotal evidence suggests that LMEs desire such a commitment; doing so would require ensuring that state polices are consistent with the implementation of SOC.

The new mental health system in North Carolina has created tension about whether the state or LMEs have the power to make certain decisions. Some would say this tension is one of the most significant barriers to implementing SOC.

## History and Core Elements of the System of Care Approach

Mental health professionals and decision makers across the nation agree broadly on the need to transform systems and services for children with mental health needs. Three basic issues frame the discussion:

1. Improving access to care for those in need;
2. Improving the quality and effectiveness of care; and
3. Improving the mental health status and well-being of children.

Efforts to establish and expand comprehensive, community-based care grew tremendously with the publishing of *A System of Care for Children and Youth with Serious Emotional Disturbances* in 1986 by Beth Stroul and Robert M. Friedman. This publication describes in detail the concept of SOC and provides guidance for implementing services following this approach.

Building a SOC is complex and challenging even when community stakeholders are committed to working together. A successful SOC not only requires services to be available, but also needs policy and administrative processes, implementation plans, performance measures, and an evaluation process focused on accountability and outcomes for children and their families.[5] In recognition of the challenges of successfully implementing a SOC, experts advocate taking a system-building approach. Such an approach engages all community stakeholders and allows for the development of a blueprint that moves the SOC concept into an accessible, child- and family-centered treatment process for children with mental health needs.

The SOC model addresses a number of conditions within a traditional mental health system:

- Inadequate range of services and supports;
- Lack of individualized services;
- Fragmented system even though children and families have multi-system needs;
- Children with special needs are in many systems;
- Lack of clear values or principles for the system;
- Lack of clarity about the population of children to be served;
- Inadequate accountability; and

- Inadequate responsiveness to cultural differences.

The SOC approach is based on a vision, a defined set of principles, and core values that include:

- A child-and family-focused approach, with the needs of the child and family dictating the types and mix of services provided;
- Cultural competence, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve;
- Individualized services determined in accordance with the unique needs of each child and guided by an individual service plan;
- Full partnership among professionals, families, and extended families of children with emotional disturbances in all aspects of the planning and delivery of services;
- Promotion of early identification and intervention to enhance the likelihood of positive outcomes;
- Collaboration among multiple agencies and service sectors; and
- Systems for ongoing evaluation and accountability.

A key element of the SOC model is that all community stakeholders develop and agree upon the goals and outcomes. The community functions as the center of services, decision making, and responsibility. As such, community-based services are planned, implemented, and sustained through the input of multiple stakeholders and are accountable to those stakeholders. State policymakers and officials can improve the likelihood of success with SOC by empowering local stakeholders to make decisions about local resources and services.

To meet the complex needs of children with mental illness, SOC strives to integrate the work of education, juvenile justice, public and mental health, child welfare, and family court leaders, and families and children. Most importantly, key stakeholders must be willing to come together to not only plan but implement. To accomplish this, local stakeholders need the authority to make decisions about the use of local resources. A shared vision and collaborative planning among key stakeholders is critical at the state and local levels. This ensures that state policies are consistent with the community implementation efforts and that the system and services are moving in the same direction.

## Putting a System of Care into Practice

As more communities undertake SOC, there has been a growing realization of the complexity and difficulty of implementing the values and principles of such a system and achieving change at both the state infrastructure and local service level. Not surprisingly, states and communities are more successful at understanding SOC theory than they are at critically and strategically evaluating their community and developing a process for successful implementation.

The National Implementation Research Network, which conducts implementation research and evaluation in relation to evidence-based programs across sectors (e.g. mental health, substance abuse, education, juvenile justice), recently completed an analysis of 45 communities that received federal grants to develop a SOC. The analysis found that grant communities were more successful in making changes at the service delivery level than at the system level. Successful implementation of a SOC requires services and systems change just as it requires a change in behaviors of service providers and families.[6] Creating an environment that can support a change in thinking from policymaker to practitioner requires patience and perseverance.

The Research and Training Center for Children's Mental Health at the University of South Florida has developed a model of implementation factors that contributes to the development of effective SOC.[7] The Center's model includes 14 implementation factors.[8] The model builds on, and is consistent with earlier SOC research, but places a greater emphasis on development and interaction of the system's components. This requires rethinking at the state and local level about the underlying assumptions that guide service delivery. These assumptions concern:[9]

- Who are the intended service recipients;
- What are the intended accomplishments; and
- What is necessary to accomplish the goals for the population of concern.

The challenge for implementing SOC is to move beyond traditional thinking and focus on the inter-relatedness of factors; considering how 1) any one area is affected by and in turn affects other areas and 2) that short- and long-term consequences of actions may often differ.

## Keys to Successful Implementation of a System of Care

Policymakers, state agency leaders, mental health professionals, families, and family advocates must all be committed to SOC for the approach to work. Collaborating to define the vision and values to guide the direction of a state mental health service system is the first step in implementing an effective SOC. Following are other key components for the development of SOC with state leaders, local involvement, and feedback:

- A statement of values and principles developed in a participatory manner with parents and professionals and with representatives from various service sectors. To have a SOC, the statement of values must show that the state and local communities are committed to cultural competence and individualized care.

- Identification of a clearly defined population of children and families the system seeks to serve and support. The process of defining this population should include an assessment of its needs and strengths as well as the organization and functioning of the existing delivery system. Special attention should be given to the racial, ethnic, and socio-economic make-up, as well as developmental stages and gender sensitive issues of the population of concern. The North Carolina *State Plan 2005* defines the target populations for public mental health services for children. Furthermore, there is value in continuously reviewing the definitions to determine their applicability and to modify them as needed. *(See Appendix for detailed descriptions of target populations.)*

- Any state or community implementing SOC must recognize that implementation includes multiple stages. A state SOC implementation plan should consider not only the process for local service delivery but the appropriate state investment in human and financial resources, technical assistance, and resource development to support the necessary capacity building and decision making. Critical components of the process include staff selection, training, coaching, and performance feedback.

- A performance measurement system that provides practical, ongoing information about the SOC performance is critical to continuous system improvements. At the state and local levels, a results-based accountability system that is part of a data-based approach is essential

for identifying improvements to SOC. The Ohio Consumer Outcomes Initiative, discussed in Chapter Three, is one example of a statewide data collection system. It allows both state and local providers to make quality improvements using performance data as the basis for identifying areas of improvement, along with improving treatment plans for individual children.

## Data-based Systems of Care

There is broad agreement at the service, system, and policy levels that there are benefits to a data-based decision-making process. While the perspective at each level differs, each recognizes the value of a data-based system in making decisions about how best to meet the needs of children with mental illness.

- The *state government perspective* emphasizes the need to stay within budgets, policy, and regulatory guidelines, maximize revenues, and provide maximum benefits to the population of children and families. The state government point of view recognizes there are limited resources and because demand for services is often insatiable, scarcity will impact decisions about who receives which service. A data-based decision support system helps inform policymakers of gaps or areas of need to allow for appropriate resource and policy decisions to meet those needs.

- The *SOC perspective* stresses long-term benefits for a range of children and families, well-coordinated services in which all agencies share responsibility for joint processes and overall outcomes, and a data-based decision support systems that helps to coordinate services and assure continuity for children and families. The SOC point of view places a high value on the expressed needs of families and children and other community members whose participation is necessary for successful outcomes.

- The *evidence-based perspective* highlights practices that produce the best results for children and families. Evidence-based programs are guided by the use of valid assessment tools and the input of experts. Effective interventions can be an important part of the individualized treatment plans for children with mental health needs. Data-based decisions assist in ensuring high accountability for processes and outcomes of these interventions.

A data-based SOC involves the routine collection of data on system performance and outcomes to improve the system. Such a system should include information on process (how services were accessed, participation, what services were used), outputs (how many children and families were served), and outcomes (how children function at home, in school and in the community). This creates an environment that promotes accountability by assessing the system's performance on a regular basis for the purposes of improvement, as documented in the next chapter. Ohio's Consumer Outcomes Initiative is one data-based effort that has allowed for the use of outcomes data in individual treatment planning and is working toward the use of aggregated outcomes data in agency quality improvement. Data-based SOCs:

- Are utilization- and improvement-focused;
- Combine in-depth and aggregate information;
- Use qualitative and quantitative information;
- Focus on a few key measures;

- Have a feedback loop for all users and participants; and
- Are themselves interventions, not just measurements.

The process of how, why, and when decisions are made at the practice, program, and policy levels are critical to successful implementation of SOC. Data-based SOCs are useful in developing a performance-based measurement system and data-based decision making. A data-based decision-making system provides a solid foundation on which to implement and integrate evidence-based programs or practices with SOC efforts. In some instances, evidence-based programs are offered by individual providers but are not integrated into the overall team-based treatment process for children with the most serious challenges. A data-based, decision-making process can assist in identifying the children that may most benefit from evidence-based treatment and allow families and children to consider these treatments as part of the larger package of SOC services and supports.

Data-based tools and processes may help SOC to: [10]

- Clarify questions related to current service configuration and access (e.g. access for specific populations, outcomes, cultural competence);
- Define the outcomes with respect to the areas of need and populations of concern;
- Determine if improving collaboration, access, integration, staff development, and accountability structures are appropriate; and
- Determine if implementing an evidence-based program or practice would increase the quality and cost-effectiveness of treatment through
    - Analyzing the fit of the values of the particular evidence-based programs with SOC values;
    - Analyzing whether there is expertise to adopt the evidence-based program;
    - Determining the infrastructure needed for high-fidelity implementation and sustainability including requirements and costs; and
    - Developing the ongoing process and performance measures to guide the evolution of the SOC and the adoption and implementation of the evidence-based programs.

For policymakers and state leaders, supporting a SOC with data-based decision making is most useful for assessing quality and outcomes that allow for system improvements when the following components are included: [11]

- Well-defined goals and strategies;
- Frequent data collection with feedback loops within and across levels (e.g. practice, program, system);
- Operationalization of "what works" - do it, write it down, follow the written guidelines, analyze results, revise it, do it again;
- Focus on innovation with consistent attention to improving benefits; and
- Elimination of harmful or ineffective practices in favor of evidence-based practices and programs.

## Integrating Systems of Care and Evidence-based Programs

Simultaneous with SOC taking hold in more states and communities, the use of evidence-based practices is gaining emphasis to improve outcomes for children with mental illness. SOC

advocates have demonstrated an interest in evidence-based practices, although to date there has not been extensive integration between SOC and evidence-based programs. With a focus on individualized care plans and the inclusion of family choice in treatment planning and provider selection, the SOC approach would appear to be compatible with the use of evidenced-based practices in treating children with mental illness. There may be tensions, however, between evidence-based practices and what families and community partners want for a child. One mark of successful SOC implementation, therefore, would be the ability to work through such challenges.

In recent work, the Research and Training Center for Children's Mental Health sought examples of states and communities that had strategically integrated evidence-based practices with the individualized care focus of SOC. Case studies of these communities revealed information about factors that contributed to successful integration of SOC and evidence-based programs, as well as barriers to integration.[12]

## Elements of Successful Integration of SOC and Evidence-based Programs

A key factor in success was an interest by policymakers and state officials in using new strategies to improve outcomes for children and families. In several cases, outcome or performance measures revealed the need for improvement. In other instances, frustration with the lack of information about the types and impact of existing treatment led to support for and interest in evidence-based practices.

Other elements that facilitated integration between SOC and evidence-based practices included:

- A functioning SOC with strong values and principles, a clear direction and goals, and a strong performance measurement system that was practical and useful to professionals and families; and
- A data-based culture with a strong performance measurement system that allows policymakers to identify populations of children for whom positive outcomes were and were *not* being obtained, along with a process for explaining these outcomes.

## Challenges to Integration of SOC and Evidence-based Programs

Despite support by state and local policymakers and community stakeholders, barriers to effective integration included:

- Evidence-based practices may prohibit involvement of service providers who are not part of the evidence-based program once treatment begins to ensure that outcomes can be associated with the programs in question. Prohibiting provider involvement conflicts with SOC and may limit continuity of care for families.

- Evidence-based programs may provide services on a time-limited basis, while SOC proponents prefer providing services for as long as they are needed and progress is being made.

- While SOC focuses on children with serious mental health challenges and their families, programs frequently identified as being evidence-based (multi-systemic therapy and multi-

dimensional therapeutic foster care), were not initially designed to serve these populations.

- Funding evidence-based programs may require significant start-up resources and can extend long-term. The communities studied recognized the need for such resources but cited difficulty in securing them.

- Proponents of SOC or an evidence-based program tend to be passionate advocates for their approach, sometimes leading to overt criticism of other approaches.

## Examples of Effective Integration

Some states and communities have successfully integrated SOC and evidence-based approaches for children with mental illness.

- Hawaii has a comprehensive effort that incorporates evidence-based programs and other practices (social skill development, anger management) that has contributed to successful outcomes for children with varying diagnoses and needs. Hawaii's approach integrates SOC values and principles, individualized care, a performance measurement system, and strong family involvement in selecting treatments and providers. A key component is providing information to families and treatment team members about what research indicates about the effectiveness of various interventions for particular problems. Hawaii's integrated approach is based on a strong partnership between state policymakers and the University of Hawaii. Initial outcomes are promising for this statewide effort which integrates many features into a data-based and value-based SOC.[13]

- The Research and Training Institute found other positive examples of integration in communities in Nebraska, New York, Ohio, and California. These examples typically involve a single evidence-based program working within systems of care rather than the comprehensive approach taken in Hawaii. However, they serve as illustrations that while it is still the exception and not the rule, SOC and evidence-based programs can work together.

## Characteristics of Communities Integrating SOC and Evidence-based Programs

To assist policymakers interested with pursuing the integration of SOC and evidence-based practices, it is useful to keep in mind the following characteristics common among communities committed to this integrated approach:

- The existence of a strong SOC with a well-established treatment planning process that is family-driven and culturally-competent and has a practical performance measurement system that provides data on how well the system is serving children with various types of mental illness;
- The existence of one or more evidence-based programs or practices (e.g. multi-systemic therapy, therapeutic foster care) that have the potential for improving outcomes for specific populations of children most in need of improvement;
- SOC administrators and evidence-based program developers who have mutual respect for each other's efforts and are willing to work together in a flexible and collaborative manner; and

- A solid plan for implementing new interventions and for continuously assessing effectiveness. Critical elements of the plan include resources and processes for training, consultation, and coaching of personnel as well as ongoing development and testing of evidence-based programs to ensure effectiveness in real-world settings with culturally-diverse populations of children and families with a range of needs.

## Improving Collaboration within Systems of Care

A 2004 study by the Research and Training Center surveyed mental health agencies to better understand how public policy strategies facilitate or inhibit collaboration in a SOC. The study analyzed the types of policy approaches used to support or administer mental health services and how those policies affected collaboration outcomes.[14] The study evaluated policies against a series of organizational factors, behavioral factors, and attitudinal factors. Analysis of both quantitative and qualitative data revealed factors that fostered effective collaboration within a SOC. These include:

- Policies that support local and regional level autonomy and flexibility regarding financial and human resources distribution;
- The existence of a coordinating state-level entity with commissioner-level representation, legislative authority, and a mandate to promote collaboration;
- Consistent policies and initiatives that provide moderate resources for collaboration and SOC development;
- Creative use of human resources such as placement of personnel in schools, child welfare, and juvenile justice agencies to provide training and skill development;
- Trust among family members and community partners, local and state administrators, and program providers; and
- Shared data used by policymakers to guide decision making, planning, and problem solving.

Other factors hindered collaboration within SOC. These included:

- Diffuse responsibilities and accountability for the target population;
- More than one state entity with mandates for children with mental health problems;
- Financing systems with inadequate funding levels to support a comprehensive service array or flexible funds;
- Policies developed with conflicting interpretations that do not reflect core SOC values; and
- Mistrust among system partners, including family members of children with mental health needs.

Policymakers and policy strategies lead to a range of factors that have a significant impact on and can affect the effectiveness and availability of services to children and their families.

## Considerations for North Carolina Policymakers

New issues and ideas continue to emerge that stimulate further discussion, research, and policy in efforts to increase the quality and cost-effectiveness of care for children with mental illness. The recognition of serious emotional disturbances among children and the critical development that occurs during childhood continues to highlight the need for early intervention and detection. In spite of the spotlight on children with mental health needs, only one in five children with a serious mental health disorder receives services.[15] The growing resources and information available to policymakers, state mental health administrators, and mental health service providers should help improve this situation.

Stemming from the lessons of research and practice, it would be valuable if policymakers included the following when setting an action plan for high quality children's mental health services:

- **Joint state-local implementation planning.** To create an effective SOC, efforts at the state and local levels must be based on common guiding principles and goals and must work collaboratively. Policies must balance statewide standardization and efficiency with local autonomy and decision making to facilitate the collaboration critical to SOC.

- **Services for children must be child- and family-centered**. Public-private collaboration and the involvement of multiple children's service providers are critical to serving children through a coordinated and comprehensive treatment plan.

- **Human resource development to strengthen local systems of care and provider networks.** Training and technical assistance are critical components in building a state-level infrastructure to support SOC. It is challenging for new and long-time professionals to keep up with new treatments, practices, outcome measurement tools, and technology for individualized and child-centered services. State-level investment in people and providers can contribute to a richer array of services and a continuum of care in communities.

- **Wide use of accountability mechanisms and performance measurement tools.** Data collection, outcome measures, and quality improvement standards provide a foundation for making data-based decisions about improving the effectiveness of mental health systems. Performance measures allow for ongoing system evaluation that can lead to a more efficient allocation of resources and can fill service gaps for children with mental illness.

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## Chapter Three

# Mental Health Services in Ohio:
## Learning what works

## Part I

## Ohio's Mental Health Consumer Outcomes System: History and successes

Leslie Brower, Ph.D., RN

**Abstract:** Ohio has developed and successfully implemented a statewide system of consumer outcomes for adults and youth in the mental health system. The effort began in 1996 and continues to evolve. Providers, local administrators, other stakeholders, and the state point to its unprecedented training and communications effort as a key factor in the success of the Outcomes System.

Ohio's mental health system has rapidly evolved since passage of the Mental Health Act of 1988. This act required the Ohio Department of Mental Health (ODMH) to move from hospital-based to community-based services. By 1995, a basic level of community services was available in almost all communities in Ohio. The upcoming challenge would be to ensure quality.

The themes that emerged from the Department to shape policy activity and ensure quality are known collectively as the ODMH Quality Agenda, and include:

- Consistently applying evidence-based clinical practices;
- Moving from the use of quality assurance to continuous quality improvement techniques; and
- Measuring consumer outcomes and using these data for quality improvement.

Simultaneously, there was a focus on ensuring the protection of vulnerable consumers and shifting from state certification of service agencies to national accreditation. The following analysis focuses on the Ohio Consumer Outcomes Initiative. It highlights the continuing tension between the commitment to applying evidence-based practices and the respect for evidence generated at the practice level by consumers and families, clinicians, and administrators. The former provides a high standard against which practitioners may compare their performance. The latter provides

*Note: This chapter was adapted from the 2003 article, "The Ohio Mental Health Consumer Outcomes System: Reflections on a Major Policy Initiative in the U.S." by Leslie Brower, Ph.D., RN, Deputy Director for Program and Policy, Ohio Department of Mental Health.*

a check for real-world application of concepts that may have only been tested in a research setting. The continued interplay between the two provides the material for policy initiatives as well as mid-course correction of ongoing activities. At times, such interplay can result in difficult choices. However, it is worth the effort to continue seeking resolution because the mental health system, not to mention the children and families for whom it exists, benefits in the process.

## Ohio's Mental Health System

To fully appreciate the factors involved in developing and implementing Ohio's Outcomes System, it is important to understand the structure of the state's mental health system and the political context in which the Outcomes System evolved. Like North Carolina, Ohio's mental health system is highly decentralized. It consists of:

- ODMH, the state agency vested with the authority and responsibility for overall financing and regulation of the system and for operation of a network of psychiatric hospitals. *(Note: In North Carolina this responsibility is split between the Division of Medical Assistance, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services.)*;
- 50 county and multi-county community mental health boards, most of which manage local alcohol and drug treatment services, in addition to mental health services;
- Nearly 400 service agencies with which the 50 health boards contract;
- A highly variable set of consumer and family advocacy organizations; and
- Statewide professional associations that represent local constituents and work at the state level to ensure effective communication of their concerns.

Local mental health boards have the authority and responsibility for financing, managing, and ensuring quality in the county-based system. They do not provide services except under certain urgent circumstances. This is also the direction of North Carolina's mental health reform efforts. Private and not-for-profit agencies contract with boards to provide publicly-funded services. Many of these agencies also have contracts with other public and non-public payers such as employer-financed employee assistance plans.

By the mid-1990s, the mental health system was influenced by the trend of devolution from the federal government to the states. In Ohio, devolution was overlaid with a long tradition of "home rule," in which county authority is vested with and exercises significant political influence. A similar context exists for North Carolina counties.

Devolution in Ohio spawned an increased emphasis on the state's consultation and collaboration with the core mental health system constituencies: consumers and families, providers of services, and county authorities. By 2000, virtually every important state-level policy activity was developed and implemented in concert with an advisory group which included a mix of these constituents. This general trend energized the state agency's predisposition to co-manage issues with constituents, to encourage system learning, and to bring more people, especially consumers and families, into the policymaking process. While this movement curtailed ODMH's ability to impose mandates on local government and private agencies, this limitation was outweighed by the advantages of partnership, collaboration, and consensus.

## Other Key Contextual Factors

In partnership with the state's alcohol and drug agency, ODMH had already developed the Multi-Agency Community Service Information System (MACSIS) information system. The Outcomes System's technology environment was built on the MACSIS system and used the main MACSIS function of enrolling "members" and processing claims.

Even in the midst of an unprecedented economic boom nationally and in Ohio, mental health services financing was decreasing. The joint federal/state Medicaid program had reached its apex by the mid-1990s and was receiving public criticism for double-digit annual cost increases.[1] Limitations in the growth of Medicaid were required and efficiencies would need to be achieved. At the same time, other competing state funding priorities had emerged, particularly the priority of achieving funding parity between the hundreds of local school districts in Ohio (another similarity with North Carolina) and a growing prison system. The road ahead would require fiscal discipline, strategic thinking and documented evidence for the economic value of mental health services.[2]

There was also ambiguity about whether ODMH would mandate the use of the Outcomes System. This was unclear even to ODMH when the Outcomes Task Force (OTF) convened. Ultimately, ODMH decided to require use of the Outcomes System through the Department's regulations affecting provider agencies. (Local boards could opt to use a different system as long as it met OTF criteria.) Coincidentally, the Legislature required review of the Department's administrative rules oon after the implementation process began, meaning that consideration of a new Consumer Outcomes rule was included in the review process. The strategic approach was simple: a new, integrated package of standards would be developed that would trade reduced regulatory burden for new or additional requirements for consumer outcomes measurement, quality improvement, and core consumer protections.[3]

On the Department's second attempt, the legislature approved the standards in September 2003. The final rules required providers to demonstrate how they use data for treatment planning and performance improvement. These rules, however, were fairly permissive with regard to how providers met the requirements. One of the original administrative rules required agencies to utilize evidence-based practices. This requirement was ultimately removed from the regulatory framework and incentivized through seven Coordinating Centers of Excellence (CCOEs) based in local systems in partnership with university or other research organizations.

## A Mental Health Consumer Outcomes System: Foundations of success

In September 1996, ODMH Director Michael Hogan convened the OTF and charged it with recommending an approach to measuring mental health consumer outcomes. The OTF defines consumer outcomes as "indicators of health or well-being for an individual or family, as measured by statements or characteristics of the consumer/family, not the service system."[4]

This group took the charge seriously, committing two consecutive days each month for 16 months to build consensus around a comprehensive and integrated set of recommendations. *(The recommendations are in Vital Signs, Revised- 2001, accessible at www.mh.state.oh.us/initiatives/outcomes/outcomes.html.*) Of vital importance are the preliminary sections reflecting the values and principles the group adopted. These served as the screen for every recommendation that was considered. A subsequent group guided the process of pilot testing the instruments in three local systems and produced recommendations for enhancements and changes.

While it will always face challenges, the Outcomes System has been successful and continues to add to its achievements. First, the sheer quantity of data in the system removes potential concerns about sample size and other limitations that might otherwise exist. The statewide database now includes over 1.2 million approved records, representing nearly 350,000 individual consumers, up from 161,000 and 65,000, respectively in 2003. The state produces reports that local boards and providers use for outcomes measurement, policymaking, county-to-county comparisons, and other purposes.

Leading up to implementation, ODMH and a core of local "champions" worked closely to develop the policy infrastructure that would support the vision of the OTF. The recommendations published in *Vital Signs* continue to be the marker against which the state tests new policies and procedures. Broad consensus now exists on the critical importance of using Outcomes System data:

- To inform clinical decision making;
- For program evaluation and planning at all levels of the system; and
- For administrative oversight and planning.

## A Clear Vision and Shared Values

Perhaps the single most important decision of the OTF was made in the early stages. Before examining available measurement instruments, the group was guided through a series of consensus-building processes to produce statements of vision, mission, values, and assumptions. Being clear about values at the start not only helped overcome decision "gridlock" but also advanced reforming of the mental health services system for both adults and children. Hundreds of decisions followed the OTF, most of which held some element of controversy. The vision and mission statements helped subsequent workgroups stay on course by providing a credible, consensus-based framework for action. The values and assumptions provided guidance for selecting among policy options while eliminating others that were inconsistent with the recommendations of the OTF.

A good example is the value that has come to be described as "consumer-driven." It suggests that the most critical litmus test for any clinical activity is the opinion and perspective of the consumer, and in the case of children, the family. This is not to exclude clinicians but to achieve a balanced collaboration between consumer and clinician. "Consumer-driven" guided future decisions, including about which instruments and items the OTF included in the final recommendations. Other considerations guided by this value included:

- The key role of consumers and families in all subsequent workgroups - one aspect of the emerging notion of consumer "recovery";
- Surveys of consumers and families who participated in the pilot of instruments;
- Development of tailored consumer and family training packages after the pilot;
- Development of data reports for consumers that offer an opportunity to prioritize their problems and strengths; and
- Development of a clinician training program with step-by-step guidance for using Consumer Outcomes data collaboratively with consumers in treatment and recovery planning.

At the outset OTF adopted the philosophy of "recovery" for adult consumers. The initiative has continued to use this as a major filter for developing and evaluating policy options. Similarly, the philosophy that has come to be called "resiliency" for children and their families has guided decisions affecting design and implementation of outcomes measurement in the child-serving community.

## Design of the Consumer Outcomes Initiative

By the time the OTF completed its work, the plan for statewide implementation had begun to take shape. The Outcomes Implementation Planning Group was a statewide taskforce that planned and developed documents for implementation of the Outcomes System. Although none of the principals could have anticipated the volume of work and the challenges ahead, it was obvious it would involve a multi-faceted, multi-year strategy. It was not enough to simply disseminate the Outcomes instruments, with or without a government mandate. A key element would be integrating the outcomes instruments into the daily operations of the provider agency, and particularly into the activity of treatment planning. This involved gaining the voluntary participation of staff at nearly 300 community agencies and 50 boards and ensuring they appreciated both the intent and the operational requirements of the Outcomes System. The overall program to accomplish this goal became known as the Outcomes Initiative.

By the conclusion of the OTF there were hints that the design of the system would need to evolve and there was commitment to continually improving and modifying the system. A good example was the decision during the pilot to abandon the package of instruments for youth in favor of a more user-friendly package that better fit the values and outcomes articulated by the OTF. This kind of flexibility and responsiveness to user concerns has characterized the Initiative and has contributed significantly to the productive collaboration with community partners.

Finally, measurement of consumer outcomes was subsequently included in the department's Quality Agenda. The notion of the Quality Agenda was developed as a way to focus attention on three critical aspects of improving the mental health system:

- Mechanisms to improve clinical quality;
- Measurement and use of consumer outcomes data; and
- Increased use of evidence-based or other demonstrated best practices.

Like the OTF recommendations, the focus on these aspects of the mental health system has shaped policies and priorities at the Department in recent years and has been used as a platform for conversations with local systems about other policies and priorities.

## The Right Resources at the Right Time

Applying several kinds of resources at critical points has contributed significantly to the success of the Outcomes Initiative. These include:

- State and local staff time;
- Infusions of cash;
- Technology to ease the burden of implementation;
- Effective process facilitation;
- Political will; and
- Technical assistance and training for local systems.

Regarding technology to ease the burden of implementation, technologies to facilitate data entry and data flow have proven to be a double-edged sword: where they have worked, the data flow is voluminous and of good quality; where there have been technological problems, the volume has been

**The most critical point throughout the process has been political will at all levels of the mental health system to develop an outcomes system.**

low. Recognizing the decentralized mental health system in Ohio, local systems were allowed to choose which technology to use for collection and transport of Outcomes data. Some technologies did not function as expected, which led to problems, some of which remain. In addition, discretionary dollars to invest in technology/support have largely evaporated.

The most critical point throughout the process has been political will at all levels of the mental health system to develop an outcomes system. Not only has ODMH been willing to support the Initiative with available resources, but constituents have had to work with the Outcomes System and find ways to integrate it with their core mission. This has required significant effort, particularly from providers, and consistent support from their statewide trade association. It has required consumer and family organizations to create strategies for communicating with their constituents and encouraging the use of data in treatment planning and advocacy. It has required local boards and their statewide trade association to commit resources for contributing and using data to improve local system quality, even in an ambiguous financial and policy environment.

A critical resource was the distribution of incentive funds to local systems. A year after the mental health system moved into the implementation phase of the Outcomes System following the findings of the pilot, it became clear that implementation had reached the limits of voluntary, unfunded participation. The Initiative had achieved significant voluntary adoption by the county board representing the largest percentage of consumers, as well as some smaller areas. However, financial limitations constrained the depth and scope of implementation. Investments were required, especially in the area of data processing technology, that the chronically under-funded community mental health system was simply unable to support. In response, ODMH allocated nearly $3 million of federal block grant dollars by formula as an incentive to local systems to implement the Outcomes System, with dollars focused especially on assisting provider agencies to offset their costs. Allowable costs included data processing hardware and software, consultation, training, and communications. This infusion of cash contributed greatly to improving the level of local participation.

In addition to the formula funding, the grant dollars included a parallel marketing and training effort in response to frequent comments that local staff needed help translating the Outcomes System into action. ODMH developed and disseminated a toolkit of training and technical assistance in collaboration with local constituents. This included:

- Consumer and family training packages (manuals and training videos);
- An orientation video for consumers, families, and staff -- suitable for continuous play in waiting rooms or more specialized settings;
- An orientation pamphlet for consumers and families entitled, *Are You Getting Results?*;
- A re-engineering manual to help providers reorganize around measurement of Consumer Outcomes; and
- A set of cultural competence studies to support the introduction of the Outcomes instruments to diverse cultural groups.

These were distributed free of charge to participating local systems in hard copy and on CDs, and are available on the Outcomes web site *(www.mh.state.oh.us/oper/outcomes/training.toolkit.html)*. Subsequently, regional trainings were offered in which local clinicians tutored other direct care staff in the use of Outcomes data in treatment and recovery planning.

Process and People

Even the best idea will only take hold if it is well-understood and valued by users. Users in this context meant consumers and advocates as well as mental health professionals, state agency leaders, legislators, and other stakeholders and decision makers. This belief was at the heart of a commitment ODMH made at the outset of the Initiative: to develop and implement the Outcomes System in full partnership with local constituents. To this end, the OTF included all core constituents: consumers and families, provider and board staff, and evaluators and researchers. All subsequent work groups have included a mix of these constituents as appropriate. One effect of this decision has been the emergence of a core group of champions at each stage who work alongside the Department in developing policy and implementation procedures. This could not have occurred without the strong foundation in mutual trust and respect that was developed and nurtured from the OTF. Several factors supported the development of trust and respect, including commitment to frequent and candid communication, mutual planning, and timely responsiveness to constituent concerns.

It should be unnecessary to emphasize that these processes must be sincere and used actively to shape the processes and products of the Initiative. No significant decision about the Outcomes System has been made without consultation and partnership among constituents. In addition, all technical assistance products and communication vehicles have been designed in partnership with and focused on the needs of each constituency group with competing priorities. Continued focus on communications helps keep users focused on the Initiative.

## Use of Data

Although the usefulness of the consumer outcomes database was questioned at the outset, it has proven valuable. The OTF did not start with a specific vision of data use but developed a framework on which future policy was built. With the framework, the OTF:

- Included notions that the data would need to be useful and available to all constituents, at a level of detail appropriate to the need, with protections for consumer confidentiality and privacy and with safeguards against misuse of the data;
- Advised against premature use of the data for anything other than system quality improvement, warned potential users away from any use of the data for financial purposes before the Outcomes System had an opportunity to prove itself; and
- Correctly identified fear as an implementation risk at all levels of the system, and sought to provide guidance that would prevent fear from becoming resistance.

The implementation pilot group used this data use framework to develop a matrix for each level of the system. This was distributed widely during implementation and has formed the basis for consensus around the activities needed to support responsible use of the data. Considering the cost involved in implementing a system such as Consumer Outcomes, consensus exists to ensure that the data are not left "on the shelf" for lack of insight, training, or data support resources but used to support decisions at all levels of the system. Broad consensus exists on the critical importance

of using the data to inform clinical decision making. Two years ago, the Department launched a training effort for clinicians to support this goal. It parallels the consumer-training program, *Climbing into the Driver's Seat,* which is designed to prompt and inform consumers about how they can work with providers to use the data in treatment and recovery planning and to monitor their progress. Similarly, there is broad consensus about the use of data for program evaluation and planning at all levels of the system, as well as using aggregate data at the board and Departmental levels for administrative oversight and planning.

The Outcomes System has made it possible to track and evaluate the effectiveness of other initiative, such as FAST$05, a children's mental health service provision program. Data from the system supported the FAST$05 outcomes data report by Ohio State University. *(http://medicine.osu.edu/sitetool/sites/pdfs/familyresearchpublic/outcomes05a.pdf)*

## Lessons Learned

Among the most significant lessons learned was to pay attention to the education of ODMH staff and leadership. One cannot assume that all staff will automatically embrace an initiative, even one endorsed by leadership as a priority of the organization. Nor can one assume that staff will recognize the policy implications of an initiative or the imperative to think carefully about the integration of new and existing initiatives. Failure to attend to these organizational learning needs can cause confusion and frustration at best, and potential failure of the initiative at worst. It is important to maintain open channels of communication with leadership, work closely in collegial settings to integrate activities appropriately, and monitor communications and initiatives to ensure consistency and clarity.

These lessons learned concern both the importance of data use and the process of implementing an outcomes initiative:

1. Build consensus with constituents on vision, mission, values, and principles, especially from the perspective of consumers;
2. Design the implementation to include constituent representation, to be evolutionary, to support the philosophy of care ("recovery" for adults and "resiliency" for youth), to integrate with other quality activities, and to support use of data at the direct care level;
3. Apply the appropriate resources (staff time, expertise, cash) at the appropriate stage of the initiative;
4. Build partnerships among constituents based on mutual trust and respect and use these relationships to support decision making;
5. Specify a framework for the use of data early in the process in order to focus users on their expected roles and responsibilities;
6. Use data for its numerous benefits, including
    a. To inform clinical decision making;
    b. For program evaluation and planning at all levels of the system; and
    c. For administrative oversight and planning; and
7. Develop a marketing and training program for state agency staff to ensure policy integration and clear, consistent communication with the field.

## Recognizing Success While Looking Ahead

Both the utility of the Outcomes System and the political will of participants have been tested since the system's inception. Its success has stemmed from ongoing investments in training, technical assistance, and technology. The closer the system gets to full integration of outcomes data in service agency operations, the more it will be able to focus on outcomes monitoring. The system has achieved more robust use of outcomes data in treatment planning with individual consumers than in the use of aggregated outcomes data in agency quality improvement. The latter has been the focus of ODMH's most recent training with related training scheduled in the future. Even with a highly-technical endeavor such as the Outcomes System, the most challenging task remains a fundamentally human activity: changing attitudes and behaviors. Ohio has found that the most effective strategies are those that are "high touch," with a healthy dose of interpersonal contact, dialogue, and personal communication. While ODMH and its partners continue to develop policies and products that demonstrate the value of the system and model best practices, there is no substitute for the personal contacts that build trust, enable learning, and reinforce important values.

## ENDNOTES

[1] Shortly after implementation of the Outcomes Initiative, Ohio's budget was dramatically affected by the downturn of the U.S. economy. Revenues fell even as the cost of quality increased, and local providers, boards and ODMH faced difficult choices. While some partners appreciated the even greater need to inform policy with outcomes data, the costs involved were significant, especially to support technology solutions, and were sometimes viewed as prohibitive in light of reduced consumer access to services. While this has been addressed for the vast majority of agencies it is still a concern for the smallest providers.

[2] ODMH convened a statewide mental health commission (1999-2000) to develop an overall agenda for the mental health system, including financing, clinical quality, administrative management, services to populations with special needs, and accountability. ODMH Director Hogan was asked to chair the President's New Freedom Commission on Mental Health (2002-03), which issued its final report to the President in July, 2003.

[3] The CCOEs provide policy leadership, consultation and training to other local systems regarding particular best practices such as multi-systemic therapy for youth, Cluster Analytic Planning and Evaluation (CAPE), and the Dartmouth University model of Substance Abuse/Mental Health services.

[4] The Ohio Mental Health Consumer Outcomes System Procedural Manual, Seventh Edition (Revised), May, 2005, page 14.

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## Part II

# The Children's Resource Center: Using outcomes in practice

William O. Donnelly, Ph.D.

### The Children's Resource Center: An early player in community-based care

The Children's Resource Center (CRC) has provided mental health services to children, adolescents, and their families in Wood County, Ohio for 30 years. Founded in 1976, the Center's original board had a vision of community-based care. It was a pioneering approach for the time and the board pushed to convince the state legislature to shift funding toward community mental health for children. The prevention of hospitalization for children was among CRC's initial goals, and one that lasts to this day.

Reflecting many of the principles previously highlighted, CRC focuses on evidence-based practices and the use of outcomes in conjunction with the Ohio Mental Health Consumer Outcomes System. Family involvement in decision making is a key tenet of the organization's philosophy. Thus, impact on the family is an upfront consideration when it comes to assessment, treatment, and evaluation of the treatment.

While CRC and ODMH have a collaborative and mutually respectful relationship, this required work and commitment from both given that CRC has frequently forged new ground ahead of the rest of the state. State and local policymakers have learned from CRC's efforts and experience and have considered those lessons as they make mental health policy and funding decisions. An example of this stemmed from a low-cost yet significant research project concerning assessment. ODMH funded research of CRC's structured assessment of family aggression during client intake assessments. This had implications for practice and led to new aspects of coordination across CRC, Bowling Green State University (BGSU), and ODMH. At the same time, the focus of Ohio's policymakers on the importance of research evidence and outcomes has contributed to CRC's refinement and improvement of its practices. North Carolina policymakers at the state and local level can learn from CRC's work with state and university partners.

### The Children's Resource Center

<u>Mission and services</u>

CRC is a private, not-for-profit agency with a behavioral health focus. Staff members provide evaluation, treatment and guidance to families of children with behavioral and emotional problems, including children with SED. The range of services include outpatient therapy, psychiatric services, intensive home-based services, residential services, partial hospitalization, treatment foster care, parenting education, school-based, early child, and prevention services. CRC is a leader in the region in raising public awareness of and advocating for the broad range of health, social, and psychological problems of children and adolescents.

The CRC's mission is to provide child-centered, family-focused mental health services to families in Wood County and nearby communities. In pursuing this goal, CRC is guided by the philosophy that:

- Mental health needs of children cannot be isolated or treated apart from other needs or problems of a child, such as educational or language challenges;
- The recognition that agencies addressing children's varying problems must unify their efforts into a coordinated, multi-disciplinary team to effectively serve the child and the family; and
- Children's problems must be recognized and addressed as early in life as possible to prevent minor problems from becoming major in later years.

CRC's funding comes from state and local sources, individuals, and other interested parties. It is increasingly seeking funding and developing partnerships with other children's mental health stakeholders.

## Meaningful Partnerships

CRC partnerships with local stakeholders include:

*Wood County Family and Children First Council (WCFandCFC)*
The WCFandCFC brings together local leaders in political and administrative positions who value families and are committed to community services that raise the general health and well-being of children. The Council includes key decision makers and constituents whose collective action sets community policy for multi-agency youth. Membership includes representatives from public agencies, including mental health, health, human services, education, substance abuse and juvenile justice; early childhood representatives; county and city elected officials; consumers, family members; relevant state agency regional office representatives; medical providers and child abuse prevention representatives. The WCFandCFC model is in place across Ohio's local mental health systems.

*Strategic Alliance Partnership*
This community-wide collaborative planning process was developed within the Family and Children First Council structure to improve the lives of children and families in Wood County. The effort was recently funded by a community foundation to assist the partners with their efforts at collaboration and joint problem solving. Partners cover the range of potential stakeholders and include the local United Way, after-school programs, non-profits that address child abuse prevention and substance abuse prevention, the CRC, and BGSU. A primary focus of the partnership is to figure out how best to improve data collection and pool data for collaborative needs assessment and monitoring. Partners intend to use the data to assess and address child health and mental health needs, child abuse rates, education challenges, and other aspects of child and family well-being. BGSU's role is significant, with faculty and students focusing on research and analysis and incorporating the university's commitment to service learning for students. Another promising aspect of the Strategic Alliance Partnership is its potential for positioning the partners for future state and federal grant opportunities.

*Wood County Cluster*
The Wood County Cluster's mission is to assure that multi-need youth receive the services necessary to meet their needs. Over the years, the Cluster has provided multi-disciplinary planning on behalf of children with extensive needs. For the great majority of these children, out-of-home placements were avoided. Two core values support the Cluster's mission:

- Community-based, with the focus of services, as well as management of these services and decision-making responsibilities, resting at the community level; and
- Child-centered, with children's and families' needs dictating the types and mix of services provided.

These and other local and state partnerships contribute significantly to CRC's ability to stay on the cutting edge of research and services related to children's mental health. Data use is another means by which the agency continuously seeks to enhance and improve its work.

## Using Data and Outcomes in Practice

The ODMH surveys mental health service providers across the state as part of a recertification process required for providers to be eligible for Medicaid reimbursement. One component of the questionnaire addresses consumer outcomes. Among other purposes, ODMH uses the responses to monitor providers' use of outcomes and to identify opportunities for improvement in the state's Consumer Outcomes System. The CRC's responses to the December 2005 survey reflect its continuous use of data to guide its work. CRC reports that 83.7 percent of its clients are included in the Outcomes System. Some providers in the state boast an even higher percentage. This demonstrates the extent to which the Outcomes System captures information about children and families across the state who receive mental health services.

A further example of data use involves the Ohio Scales instrument, a component of the Outcomes System, which measures four domains: problem severity, functioning, hopefulness, and satisfaction. Importantly, youth, parents, and agency workers all complete the Ohio Scales forms as part of the measurement effort. CRC was instrumental in encouraging ODMH to allow child agencies to collect not only one parent's report but to collect as many forms as possible from parents and extended family members. CRC advocated for this enhanced data collection in part to promote parental and family involvement. In proposing that more parent forms be completed, CRC also worked with ODMH to ensure that the electronic forms were easy to track, otherwise even the initial level of data collection would have seen far less use for policy and practice. CRC found ODMH responsive and understanding of the importance of the increased parental and family involvement through data collection.

The outcomes efforts through Scales is also critical for the CRC because of the Center's conviction that outcomes data helps identify issues for treatment planning. As it collects Ohio Scales at various intervals, CRC encourages clinicians to look at patterns of change to assess progress toward client goals and to assist with ongoing treatment planning. Consistent with a System of Care approach, CRC involves family members in all aspects of treatment. CRC encourages clinicians to discuss the results of ratings with family members, and to consider whether specific items should be included as part of treatment plans. As this demonstrates, CRC stresses meaningful integration of the Ohio Scales for performance improvement, with implications for:

- Incorporating outcome measures into clinical practice;
- Assessment, treatment planning, and treatment review activities;
- Utilization and level of care decisions;
- Combining Ohio Scales data with other data, such as individual provider data and type of service; and
- Comparing client treatment plan goals and objectives with findings from Ohio Scales.

Using the data in conjunction with performance improvement efforts led CRC to:

- Identify needs for additional staff training about use of Ohio Scales and for greater and broader involvement of clinical leaders in Ohio Scales performance improvement activities;
- Encourage increased discussion of Ohio Scales results as part of clinical supervision, including discussion of whether level of care is consistent with client need as measured on Ohio Scales;
- Add an item about Ohio Scales to the annual staff performance appraisal process;
- Begin more frequent presentations about Ohio Scale results and issues to staff; and
- Become one of the first providers to conduct aggregate data analysis about client change over time.

The attention given to performance improvement with regard to the role of data by the Ohio mental health system goes beyond CRC. An example is the Southern Consortium for Children's development of a 2004 training video conference on the use and relevance of Scales and the data it generates. The conference was broadcast live to training sites around the state, providing an opportunity to use collaborative training to generate partnerships between the developers of Scales, policymakers, and practitioners.

CRC has been deliberate about sharing data analysis results with policymakers not only for the sake of information sharing but to demonstrate how providers use data. CRC is also willing to point out limitations of the system. For example, it is not possible to link individual client outcomes data with other client-level demographic or service history data reported to the state through the MACSIS system. While this is deliberate and with consumer protection in mind, it limits how confidently and with what level of specificity the state or providers can draw conclusions from data analysis and program evaluation. The reality that clients simultaneously may receive multiple services from multiple programs makes it virtually impossible to isolate the effects of one program from another without much more data sharing across and among service domains.

Finally, how CRC uses data and incorporates it into decision-making processes is closely linked to its emphasis on evidence-based practices.

## A Key Ingredient: Evidence-based practices

The CRC uses evidence-based practice for both assessment and treatment. Evidence-based programs or practices have consistent scientific evidence showing improved outcomes for clients, participants, or communities.

For assessment, CRC uses a multi-informant, multi-measure protocol for diagnostic assessment intake that integrates the use of semi-structured clinical interviews and structured questionnaires that assess child behavior problems and functioning, family relationships, family physical and verbal conflict. This approach was initially developed at CRC as part of a CRC-BGSU clinical and research collaboration, was evaluated with the support of an ODMH grant, and was recognized by ODMH in its *Top Ten Mental Health Research Findings, Volume 3, 1999-2000*. This approach has been modified to incorporate the Ohio Mental Health Outcomes System.

With regard to treatment, CRC promotes the use of best practice, research-supported interventions in its clinical service delivery to youth and families. Three broad examples of empirically-supported approaches in use at CRC are:

- Behaviorally-oriented treatment programs for families of children with disruptive behavior disorders. The key component of this model is training parents in specialized behavioral interventions so they can help their children.

- Cognitive behavior therapy (CBT) for children and adolescents suffering from internalizing disorders such as anxiety and depression. CBT helps clients learn to identify and assess the negative and self-defeating thinking patterns associated with their emotional distress and replace those with more realistic and adaptive thoughts. Additionally, clients learn to use healthy problem-solving and coping strategies that help them manage emotional distress.

- Social and emotional competence development for children whose emotional disturbance interferes with the development of appropriate and positive relationships with peers. Using a mixture of behavioral and cognitive-behavioral approaches, therapists help children learn and practice social skills in a peer group context. Typical skills taught include identification and communication of feelings, learning to understand and respect others, social problem solving, and self-regulation in a group setting.

These approaches have accompanying treatment manuals which identify principles, strategies, and sequences for intervention, and are supported as evidence-based practices by scientific professional literature.

The challenge for clinical practice settings such as CRC is to apply evidence-based programs developed in narrower research settings to the more complex environments that clinical practitioners face. That requires a commitment to training, as well as to ongoing monitoring and supervision of implementation. CRC sponsors an annual conference, the Douglas G. Ullman Conference on Children's Mental Health, which hosts national speakers on evidence-based practices who train CRC staff, supervisors, and practitioners in Ohio. Additionally, CRC has partnered with The Cullen Center, a Toledo, Ohio site of the National Child Traumatic Stress Network (NCTSN), for networking and training designed to support evidence-based practice in child traumatic stress. Such partnerships often lead to other benefits. In the past two years the Cullen Center has linked with ODMH in a statewide initiative to help providers improve their recognition of trauma on youth, including youth in juvenile justice and educational settings. The Cullen Center has sponsored learning communities to help Ohio mental health providers learn and implement an empirically-supported model of trauma-focused treatment. This development is applicable to North Carolina, whose Duke University's NCTSN program is one of the flagship sites of the national network.

Two additional illustrations of CRC's evidence-based program implementation are related to ODMH initiatives. CRC is a member of the ODMH-promoted Ohio Mental Health Network for School Success, a statewide group that promotes the use of empirically-supported mental health programs in schools. CRC has received staff training and program financial support, provided through ODMH, to help deliver *The Incredible Years* program, an evidence-based program that includes behaviorally-based parent training and child social skills training.

The CRC provides many examples of how and why mental health providers would use data in practice. A close look at the Outcomes Initiative and CRC identify implications for policy that are relevant for North Carolina.

## Considerations for North Carolina Policymakers

Creating a way to measure outcomes was an essential element of Ohio's mental health reform efforts. Developing a set of common outcomes has allowed Ohio to establish a continuous improvement process to ensure that the system meets the needs of consumers and providers. By providing timely and meaningful information, policymakers in Ohio can use this system to reallocate resources, respond quickly to problems and effectively guide decisions about the use of scarce resources.

Like North Carolina, mental health reform in Ohio involved moving from hospital-based to community- based services, encouraging the use of evidence-based practices and increasing consumer satisfaction. Ohio began its reform efforts in 1988. By 1995, a basic level of community services had been established in nearly every county. The next challenge was to ensure the quality of those services. Key to Ohio's success was the understanding that a successful system required an accountability plan that could measure the quality of services and provide timely feedback to policymakers, practitioners, and consumers. This was especially important if Ohio was going to encourage the use of evidence-based practices. Getting practitioners to use new therapies, getting consumers to accept new treatments, and making sure program developers knew what was and was not working involved providing information about how programs worked in real-world settings.

Generating meaningful information that is useful for local and state planning is challenging. Ohio recognized that if this information was going to be useful it would have to meet the needs of a broad cross section of constituents. It had to be a collaborative process involving representatives from the state's community mental health boards, service agencies, advocacy organizations, and professional associations.

While a challenging process, convening stakeholders to reach consensus about how to measure the system's work created a strong foundation for interagency collaboration, which is essential. This also helped develop a policy infrastructure to support OTF.

Defining goals is an important first step to creating an information system. These goals should guide the selection of the indicators to be monitored. In creating the new information system Ohio decision makers had to agree on concepts that would be used to develop and evaluate policy options. Ohio chose "recovery" for adults and "resilience" for youth and families as the organizing principles for its accountability system.

The new accountability system has helped shape policies and priorities at the department and local service provider levels. Following are ways that the Outcomes Initiative and the work of the CRC have had relevance for policymaking:

- Ohio's Quality Agenda helped shaped policy activity through its focus on consistently applying evidence-based clinical practices, moving from quality assurance to continuous quality improvement techniques, and measuring consumer outcomes for quality improvement;
- State-level policy development and implementation consistently stem from a broad cross section of constituents;
- ODMH's predisposition is now to bring more people, especially consumers and families, into the policymaking process;
- The existence of a policy infrastructure affected the success of the OTF;
- Determining values and assumptions up front provided guidance for selecting among policy

options;

- The Outcomes Initiative identified filters for developing and evaluating policy options - "recovery" for adults and "resiliency" for children;
- The OTF's recommendations regarding data use affected future policy development; and
- The focus of Ohio's policymakers on the importance of evidence and outcomes has contributed to providers' ability to refine and improve their practices.

For several years, North Carolina has been in the midst of long-term significant changes to its mental health system. Ohio, too, has taken on major changes in this area. The reforms were not immediate nor were they immediately successful. Both the ODMH and local providers, such as the CRC, highlight the importance of identifying clear values and goals at the outset and involving a wide range of stakeholders throughout the change period. Moreover, funding concerns notwithstanding, it is important to recognize that aspects of Ohio's Outcomes Initiative involve new ways of thinking as well as new and different approaches to funding. Neither Ohio's nor North Carolina's work is done. In terms of using data to learn about and assess mental health outcomes for children, however, Ohio has much to offer policymakers in North Carolina and beyond.

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## Chapter Four

# Best Practices and Lessons Learned from North Carolina's Local Management Entities

Nam Douglass

In the past several decades there has been increasing attention paid to children's mental health services in North Carolina. In many cases, this attention has arisen from inadequacies in the system and the services provided. Significant efforts have been made to develop and implement a new approach that is based on a System of Care (SOC), within which:

- Children and families are involved and valued;
- Individualized treatment plans meet the unique needs of each child and family; and
- Services are coordinated among multiple providers that coordinate services.

This approach, along with the adoption of best practices and innovative strategies, are becoming more widely available and accessible to children in North Carolina. Local Management Entities (LMEs) have made strides in meeting the needs of children with mental illness and their families but not without setbacks along the way. Mental health reform has been a challenge and opportunity for LMEs. From acclimating new service providers to a SOC philosophy to leveraging the new service definitions to allowing for new community-based treatment, all are striving to achieve excellence in children's mental health services.

Staff of the Center for Child and Family Policy at Duke University interviewed five LME leaders to learn about their experiences with new models for organizing services and treating children. Two of the participating LMEs serve a single county area and three serve a multi-county area. Collectively, they represent urban and rural areas, as well as communities in the east, west, and piedmont regions of North Carolina. This firsthand information illustrates the range of children's mental health needs, the challenges of serving this population, and concrete examples of promising strategies.

### Meeting the Needs of Children

There are similarities across LMEs in terms of the average profile of the children they serve. Children served are likely to be between the ages of ten and 17, and more likely to be boys than girls. The most prevalent diagnoses are ADHD, conduct disorders, and detachment disorders.

Of particular concern to LMEs are the children they are not serving. There is unanimous agreement that Hispanic children are not well-served. In addition to the language barrier are cultural issues. A general distrust of government, issues of documentation, and the cultural sigma associated with mental illness present unique challenges. Cultural barriers also exist for other minority groups, including African-Americans, and cultural norms in certain areas of the state at times conflict with best recommended treatments whether in or out of the home.

**Table 1. Overview of LMEs interviewed.**

| Characteristic | LME1 | LME2 | LME3 | LME4 | LME5 |
|---|---|---|---|---|---|
| **Catchment Area** | 4 counties | 3 counties | 1 county | 8 counties | 1 county |
| **Estimated # of Active Child Cases** | 2,100 | 1,095 *(includes mental health and substance abuse)* | 7,500 | 2,600 | 1,500 |
| **General Assessment of Prevalent Diagnoses** | • ADHD<br>• Conduct disorders<br>• Children of abuse | • ADHD<br>• Mood disorders<br>• Post traumatic stress | • Conduct disorder<br>• Detachment disorder | • ADHD<br>• Anxiety disorder<br>• Depression | • ADHD<br>• Conduct disorder<br>• Depression |
| **General Characteristics of Children Served** | • Tri-racial service area<br>• Growing gangs are adding to conduct disorders | • More boys than girls<br>• More white than African-American | • More boys than girls<br>• More African-American than white | • More boys than girls<br>• American-Indian population largest minority | • More boys than girls<br>• More African-American than white<br>• 90 percent on Medicaid |

Other groups of children mentioned as needing additional attention include:

- Juvenile offenders;
- Older youth ages 16-18, in need of independent living skills and with mental health services;
- Substance abusers;
- Teenagers needing 24-hour monitoring; and
- Children needing immediate crisis intervention.

In some cases, reaching these children requires access to treatment facilities not available in the community. Teenagers with serious mental illnesses that require a restrictive environment outside the home are often forced to leave their community because locked residential facilities are not available.

## Implementing Best Practices

System of Care (SOC) was the most common response by LMEs when asked about best practices being implemented in their communities. Several of the LMEs are recipients of a five-year federal grant to assist in implementing SOC to treat children and their families. Child and Family Teams (CFT), a critical component of the SOC approach, was cited as an essential part of increasing the quality of care for children in their community. The benefits achieved through properly implementing CFTs include:

- Involving families in their children's treatment decisions and management;
- Providing formal and informal support for children and families to meet the unique needs of each child, including after school care, transportation, and summer camp;
- Engaging community partners in meeting the needs of severely ill children and encouraging efforts to develop individual plans with in-home treatment options when possible; and
- Creating an expectation of service for children and their families that can help benchmark and evaluate treatment outcomes.

Several evidence-based practices such as multi-systemic therapy, therapeutic foster care, and intensive in-home treatment are also being implemented in communities across the state. It is anticipated that the new service definitions will allow for an expansion and greater availability of these treatments for children in North Carolina.

## Increasing Quality through Innovation

Because there will always be more children in need of mental health services than resources available to treat them, LMEs continue to assess the gaps in their service continuum and think creatively about how best to fill them. LMEs and providers are implementing innovative programs to address these needs. The results are an increase in the quality of treatment and a decrease in the number of children placed outside their homes. These strategies generally fall into three categories: working with schools, community collaborations, and decreasing out-of-home placement.

### Working with Schools

- Creating school-based mental health service initiatives to offer an array of mental health services in the school setting, such as day treatment. Schools provide an effective way to reach children whose families may not be able to access treatment due to financial or other constraints.

- Developing and training crisis response teams for schools to respond internally to children who have a crisis while at school.

- Implementing a one-stop clinic at a county high school with high incidences of substance abuse and drop-outs. On-site services include medical, mental health, substance abuse, and women's health services, with substance abuse counselor and clinician available one day a week.

- Establishing school teams to work in collaboration with CFTs in developing informal support networks for children with mental illness and their families.

- Developing a training program for school nurses to identify mental health needs that will result in more children receiving early treatment.

### Community Collaborations

- Hiring a full-time family advocate with blended funding from the LME and county Department of Social Services (DSS). Located in the county's family resource center, this position supports the families of children receiving treatment. In addition, this position is tasked with creating an advocacy network for families throughout the county.

- Hiring a SOC coordinator for a multi-county LME with blended funding from the LME and the county social services, juvenile justice, and school systems. One LME uses the county Smart Start Partnership to staff such a position. This staff person holds a seat on the community mental health collaborative board to assist with management of the effort.

- Hiring a juvenile justice/mental health liaison for a two-county area with funds from juvenile justice and social services to ensure that mentally ill children in the juvenile justice system receive care.

- Establishing a Child Taskforce to develop a strategic plan to meet the gaps in services in the continuum of care and increase the quality of existing care. The taskforce will consider how to allocate available resources based on a prioritization of needs.

Decreasing Out-of-Home Placements

- Establishing crisis intervention facilities that allow for stabilization, assessment, and development of a treatment plan in efforts to prevent hospitalization or out-of-home placement. Several models are being implemented across the state. However, crisis intervention is a service gap in many communities. It is a treatment option that several LMEs have not been able to get a private provider to undertake. They are looking at creative ways to fund such facilities in their community.

- Providing therapeutic foster care. LMEs use this treatment option for children at risk of being hospitalized and as a viable alternative to residential facility placement outside the community. Training for providers and foster parents is critical to the success of this treatment option. One challenge cited was that a change in the service definitions may decrease reimbursement for case management support, which is essential to this treatment option.

- Creating a day treatment program for young children and their families. Working in collaboration with local DSS and juvenile justice stakeholders to provide clinical and case management, this program allows most participating children to stay in their homes.

- Establishing a Care Review system. Several communities have implemented Care Review. This involves committees with representation across multiple agencies serving as a sounding board and accountability partner for CFTs. CFTs are required to come before the Care Review board and share the treatment plan for each child. If they are recommending out-of-home placement, they must show that every other option has been exhausted for that child. The rate of residential placement has decreased in the communities using a Care Review process.

## Challenges to Providing High Quality Services

In spite of these positive achievements, there are still significant challenges to providing a continuum of care to children with mental illness. In some cases these challenges threaten the ability of LMEs to continue the innovative programs that are working to keep children in their homes and communities. Several challenges stem from reform and the changes in roles and responsibilities of LMEs. Others stem from geographic constraints and human resource limitations. Commonly voiced challenges include:

- Implementing a SOC model within a large private provider network. Many LMEs expressed concern about their ability to sustain the SOC model they have implemented and are committed to continuing. When LMEs were providing direct services under the previous system, the training, oversight, and service could be managed and quality could be ensured. Working with a large network of providers and limited authority to hold providers accountable,

makes it more difficult for LMEs to ensure that SOC values and principles are maintained, and that CFTs are being properly trained and used in treatment planning.

- Providing best practice programs in rural communities. LMEs in rural counties expressed difficulty in attracting providers and professionals trained in best practices and willing to implement those services in rural communities. In some cases, providers will offer services only in urban parts of the catchment area. Issues of cost and low population densities are cited as barriers to rural service availability.

- Offering prevention services. Little funding is available for prevention. In some cases, children are recommended for or seek treatment that might have been prevented with earlier intervention. Intervening early helps prevent serious illness and the need for more intensive treatment and out-of-home placement later.

- Changing the cultural mindset. Technical assistance, training, and mentoring for children's mental health service providers is needed to change how people think about treating children with mental illness and successfully implementing a SOC approach. Training and skill development is needed not only for new staff but existing staff, providers, and community partners. In many cases front line staff now provide services that require different skills and a deeper understanding of the complexity of mental illness. Stakeholders (DSS, DJJ, schools) must also begin thinking about a more holistic approach to serving children.

- Aligning incompatible policies. Inconsistencies among state philosophies, mandates, and organizational structure can impede the establishment of an array of community-based services that provide high quality care for children. Issues of local decision making, accountability, standards of care for providers, care coordination, and case management are all areas in which local autonomy plays a critical role in providing quality and cost-effective care.

## Lessons Learned

Across LMEs there have been key lessons learned and insights gained in working to meet the needs of children with mental illness and their families. Two that were common among the LMEs who shared their stories are:

- **System of Care.** SOC has shown positive outcomes in the communities that have implemented it. LMEs cite SOC as an effective approach for children in danger of losing their home, failing in school, or in trouble with the law. To implement it well, providers need formal, hands-on training. A greater investment of time, information, and state resources to LMEs for is needed to support implementation of SOC. In addition, each community would benefit from a staff person dedicated to SOC who can bring people together, develop and work with the network of providers, and support front line staff. This would assist in making SOC the expectation for serving all children with mental illness.

- **Community Collaboration.** Community collaboration is critical to changing community culture and mindset. It takes time, leadership, and commitment from all stakeholders. This is hard work and communities need training and guidance to be successful. More importantly there must be a commitment from community stakeholders to come together to create a shared vision and prioritize needs and resources to be most effective in meeting the needs of mentally ill children and their families.

# APPENDICES

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## Appendix A

# North Carolina Target Populations for Mental Health Services

From the *Child Mental Health Plan 2005: Blueprint for Change*, NC Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services.

The North Carolina *State Plan 2005: Blueprint for Change* states that the primary focus of the re-designed mental health, developmental disabilities, and substance abuse system is to "provide services to individuals with the most severe disabilities in communities of their choice." To meet this goal, the NC Department of Health and Human Services established target populations that meet specified diagnostic and functional criteria along with unique individual circumstances.

*Note: Acronyms contained in this document are identified in Appendix F.*

**1. Child with early childhood disorder (CMECD)**

Children, from 3 years through 5 years of age who demonstrate significantly atypical behavioral, socio-emotional, motor or sensory development such as:

- Diagnosed hyperactivity, attention deficit disorders, autism spectrum disorders, severe attachment disorders, other pervasive developmental disorders, or other behavioral disorders.
- Have indicators of emotional and behavioral disorders such as:
  a. Delay or abnormality in achieving emotional milestones, such as attachment, parent-child interaction, pleasurable interest in adults and peers, ability to communicate emotional needs, or ability to tolerate frustration;
  b. Persistent failure to initiate or respond to most social interactions;
  c. Fearfulness or other distress that does not respond to comforting by caregivers;
  d. Indiscriminate sociability, for example, excessive familiarity with relative strangers, or
  e. Self-injurious or other aggressive behavior.
- Have substantiated physical abuse, sexual abuse, or other environmental situations that raise significant concern regarding the child's emotional well-being.

**OR**

- Have documented presence of one or more of the following indicators associated with patterns of development, which have a high probability of meeting the criteria for developmental delay or atypical development as the child matures:
  a. Parental substance abuse: Birth mother during pregnancy or primary care giving parent has been a habitual abuser of alcohol and/or drugs;
  b. Parental mental retardation: Either parent has been diagnosed with mental retardation or developmental disability; or
  c. Parental mental illness: Either parent has a diagnosed illness such as severe depression, bipolar illness, schizophrenia, or borderline psychotic conditions.

**2. Child with serious emotional disturbance who requires out-of-home placement (CMSED)**

Child, under the age of 18, with atypical development (up to age 5) or serious emotional disturbance (SED) as evidenced by the presence of a diagnosable mental, behavioral or

emotional disturbance that meets diagnostic criteria specified in ICD-9;

**AND**

Functional impairment that seriously interferes with or limits his/her role or functioning in family, school or community activities as indicated by one or more of the following:

- CAFAS score of at least 90; **OR**
- Total CAFAS score is greater than or equal to 70 and it is determined that appropriate functioning depends on receiving a specific treatment and withdrawal would result in a significant deterioration in functioning; **OR**
- In need of specialized services from more than one child-serving agency (e.g. mental health provider(s) and DSS, DPI/schools, DJJDP, DPH, DCD or health care).

**AND**

Placed out of the home or at risk of out-of-home placement, as evidenced by any of the following:

- Utilizing or having utilized acute crisis intervention services or intensive wraparound services in order to maintain community placement within the past year;
- Having had three or more psychiatric hospitalizations or at least one hospitalization of 60 continuous days within the past year;
- Having had DSS substantiated abuse, neglect or dependency within the past year;
- Having been expelled from two or more daycare or pre-kindergarten situations within the past year;
- Having been adjudicated or convicted of a felony or two or more Class A1 misdemeanors in juvenile or adult court or placed in a youth development center, prison, juvenile detention center or jail within the past year; or
- Situation exacerbated by special needs (e.g. physical disability that substantially interferes with functioning).

*NOTE: This target population was designed to cross walk with Level D in the Child Levels of Care document (March, 2002). An individual determined eligible for this target population has priority for funding if identified as: sexually aggressive, and/or, deaf, and/or having co-occurring disorders.*

### 3. Child with serious emotional disturbance (CMMED)

Child, under the age of 18, with atypical development (up to age five) or serious emotional disturbance (SED) by the presence of a diagnosable mental, behavioral or emotional disturbance that meets diagnostic criteria specified in ICD-9;

**AND**

Functional impairment that seriously interferes with or limits his/her role or functioning in family, school or community activities as evidenced by one or more of the following:

- CAFAS score of at least 60; **OR**
- Total CAFAS score greater than or equal to 40 and it is determined that appropriate functioning depends on receiving a specific treatment and withdrawal would result in a significant deterioration in functioning.

*NOTE: This target population was designed to cross walk with Level C in the Child Levels of Care document (March, 2002).*

### 4. Child who is deaf or hard of hearing (CMDEF)

Child, under the age of 18, who is assessed as deaf or as needing specialized mental health services due to social, linguistic or cultural needs associated with individual or familial deafness or hearing loss;

**AND**
The presence of a diagnosable mental, behavioral or emotional disturbance that meets diagnostic criteria specified in ICD-9.

*NOTE: Children who are deaf will be dually enrolled as both Deaf/HH and in their appropriate population category, in order to receive a full array of services. Where this funding is available, it will be depleted before other funding sources pay for the eligible service.*

### 5. Child who is homeless – PATH (CMPAT)

Child, under the age of 18, who has serious emotional disturbance (SED) and has an ICD-9 diagnosis(es) and is;

Homeless, as defined by:

- Lacks a fixed, regular, adequate night-time residence; **OR**
- Has a primary night-time residence that is:
  a. Temporary shelter; or
  b. Temporary residence for individuals who would otherwise be institutionalized; or
  c. Place not designed/used as a regular sleeping accommodations for human beings.

**OR**

At imminent risk of homelessness as defined by:

- Due to be evicted or discharged from a stay of 30 days or less from a treatment facility

**AND**

- Who lacks resources to obtain and/or maintain housing.

*NOTE: There is no specific requirement regarding functioning as measured by a CAFAS score. Assertive outreach can be provided to homeless persons who have a deferred diagnosis.*

## Appendix B

# North Carolina Local Management Entities
# Contact Information as of May 1, 2006

| Counties served | Contact information | Agency director |
|---|---|---|
| Alamance<br>Caswell<br>Rockingham | Alamance-Caswell-Rockingham Area MH/DD/SA Authority<br>www.acmhddsa.org<br><br>319 N. Graham-Hopedale Road, Suite A<br>Burlington, NC 27217<br>(336) 513-4200<br>(336) 513-4203-FAX<br>(336) 513-4444 Emergency Phone Number | Daniel Hahn<br>Chief Executive Officer |
| Camden<br>Chowan<br>Currituck<br>Dare<br>Pasquotank<br>Perquimans | Albemarle MH Center and DD/SAS<br>www.albemarlemhc.org<br><br>305 E. Main Street, Elizabeth City, NC 27909<br>(252) 335-0803<br>(252) 335-9143-FAX<br>888-627-4747 Emergency Phone Number | Charles Franklin, Jr.<br>Area Director |
| Catawba | Mental Health Services of Catawba County<br>www.co.catawba.nc.us<br><br>1985 Tate Boulevard, SE, Suite 529, Hickory, NC 28602<br>(828) 327-2595<br>(828) 325-9826-FAX<br>911 Emergency Phone Number | John Hardy<br>Area Director |
| Davie<br>Forsyth<br>Stokes | CenterPoint Human Services<br>www.cphs.org<br><br>4045 University Parkway, Winston-Salem, NC 27106<br>(336) 714-9100<br>(336) 714-9111-FAX<br>888-581-9988 Emergency Phone Number | Betty Taylor<br>Area Director/ CEO |
| Iredell<br>Surry<br>Yadkin | Crossroads Behavioral Healthcare<br>www.crossroads.bhc.org<br><br>200 Elkin Business Park Drive, Elkin, NC 28621<br>(336) 835-1000<br>(336) 835-1002-FAX<br>888-235-HOPE (4673) Emergency Phone Number | David Swann<br>Area Director/ CEO |

| | | |
|---|---|---|
| Cumberland | Cumberland Area Program<br>www.ccmentalhealth.org<br><br>PO Box 3069, Fayetteville, NC 28302-3069<br>(910) 323-0601<br>(910) 323-0096-FAX<br>(910) 323-0601 Emergency Phone Number | Hank Debnam<br>Director |
| Durham | The Durham Center<br>www.durhamcenter.org<br><br>200 N. Mangum Street, Durham, NC 27701<br>(919) 560-7100<br>(919) 560-7216-FAX<br>800-510-9132 Emergency Phone Number | Ellen S. Holliman<br>Director |
| Duplin<br>Lenoir<br>Sampson<br>Wayne | Eastpointe<br>www.eastpointe.com<br><br>PO Box 599, Kenansville, NC 28349-0599<br>(910) 296-1851<br>(910) 296-1731-FAX<br>800-513-4002 Emergency Phone Number | Ken Jones<br>Area Director |
| Edgecombe<br>Nash | Edgecombe-Nash MH/DD/SAS<br><br>500 Nash Medical Arts Mall, Rocky Mount, NC 27804<br>(252) 937-8141<br>(252) 443-9574-FAX<br>888-893-8640 Emergency Phone Number | Karen Salacki<br>Area Director |
| Franklin<br>Granville<br>Halifax<br>Vance<br>Warren | Five County Mental Health Authority<br>www.fivecountymha.org<br><br>134 South Garnett Street, Henderson, NC 27536<br>(252) 430-1330<br>(252) 430-0909-FAX<br>(877)619-3761 Emergency Phone Number | Foster Norman<br>Area Director |
| Alexander<br>Burke<br>Caldwell<br>McDowell | Foothills Area MH/DD/SA Program<br>www.foothills-bhc.org<br><br>306 S. King Street, Morganton, NC 28655<br>(828) 438-6230<br>(828) 438-6238-FAX<br>866-327-4968 Emergency Phone Number | Steve Corley<br>Area Director |

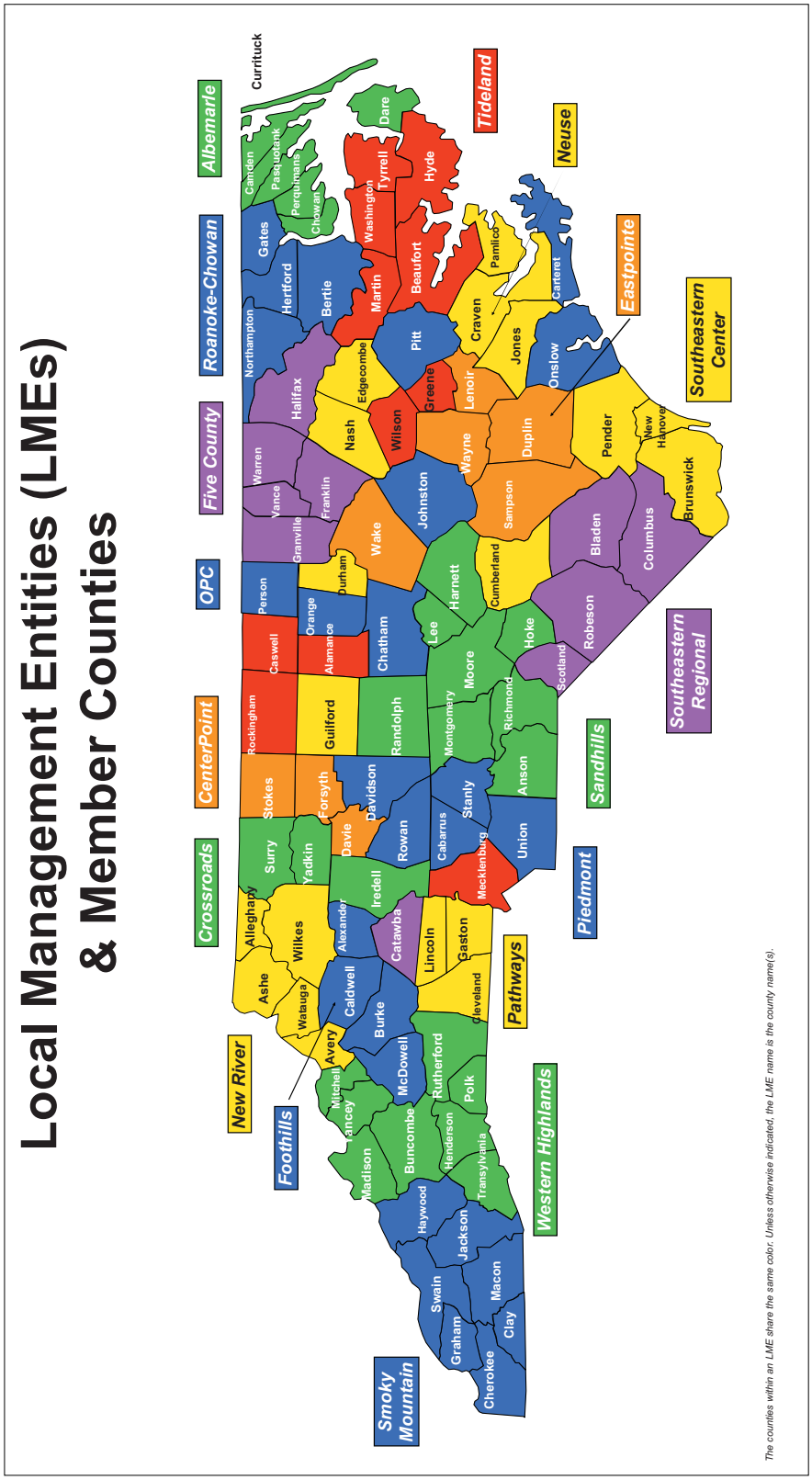
| | | |
|---|---|---|
| Guilford | Guilford County Area MH/DD/SA Program<br>www.guilfordcenter.com<br><br>232 N. Edgeworth Street, 4th Floor, Greensboro, NC 27401-2221<br>(336) 641-498<br>(336) 641-7761-FAX<br>800-853-5163 Emergency Phone Number | Billie M. Pierce<br>Area Director |
| Johnston | Johnston County Area MH/MR/SA Authority<br>www.johnstonnc.com/mainpage.cfm?category_level_id=553&content_id=604<br><br>PO Box 411, Smithfield, NC 27577-0411<br>(919) 989-5500<br>(919) 989-5532-FAX<br>911 Emergency Phone Number | Janis Nutt<br>Area Director |
| Mecklenburg | Mecklenburg County Area Mental Health Authority<br>www.charmeck.org<br><br>429 Billingsley Road, Charlotte, NC 28211-1098<br>(704) 336-2023<br>(704) 336-4383-FAX<br>(704) 358-2800 Emergency Phone Number | Grayce Crockett<br>Area Director |
| Craven<br>Jones<br>Pamlico | Neuse Center for MH/DD/SAS<br>www.neusecenter.org<br><br>PO Box 1636, New Bern, NC 28563-1636<br>(252) 636-1510<br>(252) 633-1237-FAX<br>911 Emergency Phone Number | Roy P. Wilson, Jr.<br>Area Director |
| Alleghany<br>Ashe<br>Avery<br>Watauga<br>Wilkes | New River Behavioral HealthCare<br>www.newriver.org<br><br>895 State Farm Road, Suite 508, Boone, NC 28607-4996<br>(828) 264-9007<br>(828) 264-9468-FAX<br>866-333-8545 (toll free) Emergency Phone Number | Don Suggs<br>Area Director |
| Carteret<br>Onslow | Onslow Carteret Behavioral Healthcare<br>www.ocbhs.org<br><br>165 Center Street, Jacksonville, NC 28546<br>(910) 219-8000<br>(910) 219-8072-FAX<br>(910) 353-5118 Emergency Phone Number | Daniel M. Jones<br>Area Director |

| | | |
|---|---|---|
| Chatham<br>Orange<br>Person | O-P-C MH/DD/SA Authority<br>www.opcareaprogram.com<br><br>100 Europa Drive, Suite 490, Chapel Hill, NC 27517<br>(919) 913-4000<br>(919) 913-4001-FAX<br>800-233-6834 Emergency Phone Number | Judy Truitt<br>Interim<br>Area<br>Director |
| Cleveland<br>Gaston<br>Lincoln | Pathways MH/DD/SA<br>www.pathmhddsa.org<br><br>901 S. New Hope Road, Gastonia, NC 28054<br>(704) 867-2361<br>(704) 854-4809-FAX<br>(704) 867-4357 Emergency Phone Number | Rhett<br>Melton<br>Area<br>Director |
| Cabarrus<br>Davidson<br>Rowan<br>Stanly<br>Union | Piedmont Behavioral Healthcare<br>www.pbhcare.org<br><br>245 LePhillip Court, Concord, NC 28025<br>(704) 721-7000<br>(704) 721-7010-FAX<br>800-939-5911 Emergency Phone Number | Dan<br>Coughlin<br>Area<br>Director |
| Pitt | Pitt County MH/DD/SA Center<br>www.pittcountync.gov<br><br>203 Government Circle, Greenville, NC 27834-7706<br>(252) 902-2100<br>(252) 413-1606-FAX<br>888-791-1667 Emergency Phone Number | Melonie<br>Bryan<br>Interim<br>Area<br>Director |
| Bertie<br>Gates<br>Hertford<br>Northampton | Roanoke-Chowan Human Services Center<br>www.hertfordcounty.com/roanoke_human_resources.htm<br><br>144 Community College Road, Ahoskie, NC 27910-9320<br>(252) 332-4137<br>(252) 332-8457-FAX<br>(252) 332-4442 Emergency Phone Number | Joy Futrell<br>Area<br>Director |
| Anson<br>Harnett<br>Hoke<br>Lee<br>Montgomery<br>Moore<br>Richmond<br>Randolph | Sandhills Center for MH/DD/SAS<br>www.sandhillscenter.org<br><br>PO Box 9, West End, NC 27376-0009<br>(910) 673-9111<br>(910) 673-6202-FAX<br>800-256-2452 Emergency Phone Number | Michael<br>Watson<br>Chief<br>Executive<br>Officer |

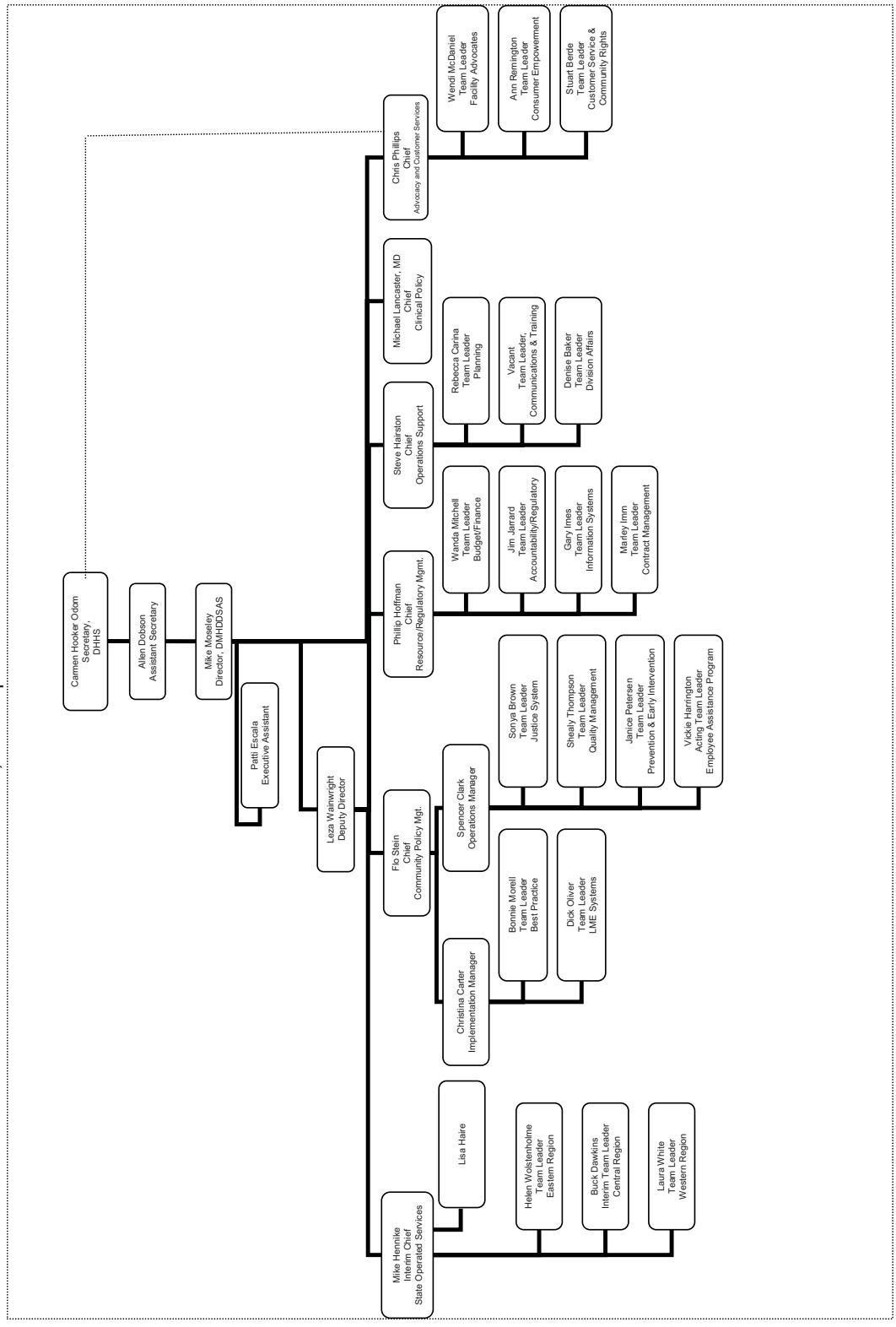
| | | |
|---|---|---|
| Cherokee<br>Clay<br>Graham<br>Haywood<br>Jackson<br>Macon<br>Swain | Smoky Mountain Center for MH/DD/SAS<br>www.smokymountaincenter.org<br><br>PO Box 127, Sylva, NC 28779<br>(828) 586-5501<br>(828) 586-3965-FAX<br>800-849-6127 Emergency Phone Number | Tom McDevitt<br>Area Director |
| Brunswick<br>New Hanover<br>Pender | Southeastern Center for MH/DD/SAS<br>www.secmh.org<br><br>PO Box 1230, Wilmington, NC 28402-1230<br>(910) 251-6440<br>(910) 796-3133-FAX<br>(910) 251-6551 Emergency Phone Number | Arthur Costantini<br>Area Director |
| Bladen<br>Columbus<br>Robeson<br>Scotland | Southeastern Regional MH/DD/SAS<br>www.srmhc.org<br><br>2003 Godwin Avenue, Suite A, Lumberton, NC 28358-2901<br>(910) 738-5261<br>(910) 738-8230-FAX<br>800-672-8255 Emergency Phone Number | Sharen Prevatte<br>Area Director |
| Beaufort<br>Hyde<br>Martin<br>Tyrrell<br>Washington | Tideland MH Center<br>www.tideland.org<br><br>1308 Highland Drive, Washington, NC 27889-3494<br>(252) 946-8061<br>(252) 946-1537-FAX<br>800-682-0767 Emergency Phone Number | Barbara Moore<br>Area Director |
| Wake | Wake County Human Services<br>www.wakegov.com/humanservices<br><br>PO Box 46833, Raleigh, NC 27620-6833<br>(919) 250-3100<br>(919) 250-3194-FAX<br>(919) 250-3133 Emergency Phone Number | Crystal Farrow<br>Director |
| Buncombe<br>Henderson<br>Madison<br>Mitchell<br>Polk<br>Rutherford<br>Transylvania<br>Yancey | Western Highlands MH/DD/SAS<br>www.westernhighlands.org<br><br>356 Biltmore Avenue, Asheville, NC 28801<br>(828) 225-2800<br>(828) 252-9584-FAX<br>800-951-3792 Emergency Phone Number | Arthur D. Carder, Jr.<br>Area Director |

| | | |
|---|---|---|
| Greene<br>Wilson | Wilson-Greene Area MH/MR/SAS<br>www.wgmhc.com<br><br>PO Box 3756, Wilson, NC 27895-3756<br>(252) 399-8021<br>(252) 399-8151-FAX<br>888-399-8021 Emergency Phone Number | Nancy Dean Hunt<br>Area Director |

# Appendix C
## Local Management Entities and Member Counties



# Appendix D
# Organizational Chart for NC Division of Mental Health, Developmental Disabilities, and Substance Abuse Services



# Appendix E
# Children's Mental Health Resources and Entities Represented in this Report

## North Carolina Resources

**The ARC of North Carolina**
www.arcnc.org
The ARC of North Carolina provides individually designed support services to assist people with developmental disabilities live successful, meaningful lives.

**Cecil G. Sheps Center for Health Services Research**
www.schsr.unc.edu/
The Sheps Center seeks to improve the health of individuals, families, and populations by understanding the problems, issues and alternatives in the design and delivery of health care services. Accomplished through an interdisciplinary program that focuses on timely and policy-relevant questions concerning the accessibility, adequacy, organization, cost, and effectiveness of health care services, and the dissemination of this information to policymakers and the general public.

**Center for Child and Family Policy, Duke University**
www.childandfamilypolicy.duke.edu
The Center for Child and Family Policy at Duke brings together scholars from many disciplines with policymakers and practitioners to address problems facing children and families in contemporary society. The Center's current research and policy interests include, but are not limited to, the development and prevention of chronic youth violence, adolescent substance abuse prevention, early childhood adversity and abuse prevention, and education policy analysis and reform.

**Duke University Services Effectiveness Research Program**
serp.mc.duke.edu/
The Services Effectiveness Research Program (SERP) integrates psychiatric and psychological research into clinical practice. SERP researchers conduct mental health services research in the following four areas: Clinical Intervention Development, Mental Health Services/Policy, Law and Mental Health, and Dissemination/Training.

**Great Smoky Mountains and Caring for Children in the Community stud**ies
devepi.duhs.duke.edu/GandCpub.html
This site includes publications from both of these studies on children's mental health in North Carolina.

**Jordan Institute for Families**
ssw.unc.edu/jif/aboutins_index.htm
The Jordan Institute for Families at the University of North Carolina at Chapel Hill, School of Social Work brings together researchers, organizations, communities, and families to engage in research, train practitioners and community leaders, and collaborate with policymakers and legislators. The Jordan Institute's vision is to strengthen families and engage communities.

**Mental Health Association in North Carolina**
www.mha-nc.org
The Mental Health Association in North Carolina is a non-profit mental health organization addressing advocacy, education, and service. The mission of the organization is to promote mental health, prevent mental disorders, and eliminate discrimination against people with mental disorders through community advocacy, education, and service.

**NAMI North Carolina**
www.naminc.org
The mission of NAMI North Carolina (part of the National Alliance on Mental Illness) is to improve the quality of life for individuals and their families living with the debilitating effects of severe and persistent mental illness. NAMI works to protect the dignity of people living with brain disorders through advocacy, education, and support.

**NAMI North Carolina Consumer Council**
www.naminc.org/ConsumerCouncil/ConsumerCouncil.html
NAMI-NCCC is a group of people with a range of interests and talents who have been diagnosed with a mental illness. NAMI-NCCC's members are committed to NAMI's mission to improve the lives of those with mental illness and their families. NAMI-NCCC's hope is that consumers will improve their lives by speaking out for their rights, as well as following their own unique personal dreams within their individual lives and their local communities.

**North Carolina Council of Community Programs**
www.nc-council.org/
The North Carolina Council of Community Programs is committed to improving the health status of North Carolina's communities by promoting effective, efficient, and sufficient mental health, developmental disabilities, and substance abuse care through support and technical assistance to LMEs.

**North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS)**
www.dhhs.state.nc.us/mhddsas
The Division of MH/DD/SAS oversees prevention, intervention, treatment, services, and support for people in North Carolina with or at risk of mental illness, developmental disabilities, and substance abuse problems. Available on the website are the state's Child Mental Health Plan, map of the state's LMEs, and the State Blueprint report to the legislature on the reform efforts.

**North Carolina Division of Social Services**
www.dhhs.state.nc.us/dss
DSS assists individuals and families in need of basic support and provides family-focused services and opportunities to enable their well-being.

**North Carolina Families United, Federation of Families for Children's Mental Health**
www.ncfamiliesunited.org
NC Families United's mission is to link families of children with serious emotional, behavioral, or mental health challenges to state and community partners for the purpose of improving the lives of these children and their families.

**North Carolina Medical Journal**
www.ncmedicaljournal.com
This journal is for those with an interest and involvement in improving the health and health care available to North Carolinians. Its primary vision is to make the journal a major vehicle for health policy communication among all stakeholders in the state. Through an arrangement with the North Carolina Medical Society, the journal is published bimonthly by the North Carolina Institute of Medicine and The Duke Endowment.

**North Carolina Psychiatric Association (NCPA)**
www.ncpsychiatry.org
The North Carolina Psychiatric Association is a professional medical organization that supports and promotes access to and delivery of quality psychiatric services to the citizens of North Carolina. It provides information about the psychiatric profession and mental illness and it provides referrals.

**UNC-CH Division of Rehabilitation Counseling and Psychology**
www.alliedhealth.unc.edu/rpc/
The Division of Rehabilitation Counseling and Psychology is developing a curriculum for rehabilitation counselors with specialty tracks in providing community-based services to individuals with mental illness and developmental disabilities.

## National Resources

**The American Academy of Child and Adolescent Psychiatry (AACAP)**
www.aacap/org
The AACAP is a membership-based, non-profit organization that provides information on child and adolescent psychiatry including current research. Its members actively research, evaluate, diagnose, and treat psychiatric disorders, giving direction to and responding quickly to new developments in addressing the health care needs of children and their families. The AACAP widely distributes information in an effort to promote an understanding of mental illnesses and remove the stigma associated with them, advance efforts in prevention of mental illnesses, and assure proper treatment and access to services for children and adolescents.

**Bazelon Center for Mental Health Law**
www.bazelon.org
The mission of the Judge David L. Bazelon Center for Mental Health Law is to protect and advance the rights of adults and children who have mental disabilities. Bazelon Center attorneys provide technical support on mental health law issues and co-counsel selected lawsuits with private lawyers, legal services programs, ACLU chapters, and state protection and advocacy systems (PandAs).

**Center for the Advancement of Children's Mental Health (CACMH)**
www.kidsmentalhealth.org/index.html
CACMH, a joint effort among Columbia University, the NY State Psychiatric Institute, and the NY State Office of Mental Health, works to broaden the acceptance and use of science and evidence-based treatments through research, training, and ensuring that interventions are family and user friendly.

**Center for Innovative Practices**
www.cipohio.org
The mission of the Center for Innovative Practices is to increase access to and availability of evidence-based and best practice mental health interventions for youth and their families. The Center's objective is: to integrate evidence-based/promising practices with System of Care development; to identify, promote, and coordinate the use of other evidence-based/promising practices and interventions for multi-need youth and their families; to participate in the discussion and exploration of related policy, financing, and program issues; to be complementary to/supportive of other initiatives; and to establish and maintain a partnership agreement with multi-systemic therapy services to serve as a dissemination site.

**Child and Adolescent Health Measurement Initiative (CAHMI)**
www.cahmi.org
The CAHMI ensures that children, youth, and families are at the center of quality measurement and improvement efforts in order to advance a high quality consumer-centered health care system.

**Children's Resource Center (CRC)**
www.wcnet.org/~crckids/
The CRC provides evaluation, treatment, and guidance to families of children with behavioral and/or emotional problems. CRC specializes in services to preschool children and services to older children with multiple problems. CRC assesses and plans for social, psychological, medical, financial, educational, and recreational needs of the child.

**Federation of Families for Children's Mental Health**
www.ffcmh.org
FFCMH is a national, family-run organization dedicated to helping children with mental health needs and their families achieve a better quality of life.

**Human Services Research Institute**
www.hsri.org/
In the fields of developmental disabilities, physical disabilities, mental health and child welfare HSRI works to assist human service organizations and systems to develop support systems for children, adults, and families; enhance the participation of individuals and their families to shape policy and service practices; improve the capacity of systems, organizations, and individuals to cope with the changes in fiscal, administrative, and political realities; expand the use of research and evaluation to guide policy and practice.

**National Advisory Mental Health Council**
www.nimh.nih.gov/council/advis.cfm
The National Advisory Mental Health Council (NAMHC) advises the Secretary of Health and Human Services; the Director, National Institutes of Health; and the Director, National Institute of Mental Health (NIMH), on all policies and activities relating to the conduct and support of mental health research, research training, and other programs of NIMH.

**National Alliance on Mental Illness (NAMI)**
www.nami.org
NAMI is the nation's largest grassroots mental health organization dedicated to the eradication of mental illnesses and improving the lives of persons living with serious mental illness and their families through advocacy, research, support, and education.

**National Association of State Mental Health Program Directors (NASMHPD)**
www.nasmhpd.org
NASMHPD membership includes commissioners/directors of the 55 state and territorial mental health departments. NASMHPD members play a vital role in the delivery, financing, and evaluation of mental health services within a rapidly evolving healthcare environment. The principal programs operated, funded and/or regulated by NASMHPD members serve people who have serious mental illnesses, developmental disabilities, and/or substance use disorders.

**National Conference of State Legislators (NCSL)**
www.ncsl.org
NCSL provides research, technical assistance, and opportunities for policymakers to exchange ideas on the most pressing state issues. NCSL is governed by a 60-member executive committee composed of legislators and legislative staff members who are elected annually.

Publications include:

*Mental Health Services for Children: An Overview.* This article includes background, financial, and service delivery information on children's mental health services for policymakers.

**National Governors Association (NGA)**
www.nga.org
NGA provides governors and their staff with services ranging from representing states on Capitol Hill to developing policy reports on innovative state programs and hosting networking seminars for state government executive branch officials. The National Governors Association Center for Best Practices is a consulting firm for governors and their key policy staff. The Center's mission is to develop and implement innovative solutions to public policy challenges.

Publications include:

*Funding for Children's Mental Health Services: Making the Most of Medicaid.* This article provides information and examples of how states are using Medicaid to broaden the reach and breadth of services available to children with mental illness.

**National Initiative for Children's Health Care Quality (NICHQ)**
www.nichq.org
NICHQ is a national education and research organization dedicated to improving the quality of health care provided to children. Its mission is to eliminate the gap between what is and what can be in health care for all children by raising awareness through stories of success that demonstrate care can be improved to produce better outcomes, helping clinicians and private practice improve care, and undertaking research to identify best practices in pediatric care.

**National Institute for Health Care Management (NIHCM)**
www.nihcm.org/finalweb/default.htm
The NIHCM Foundation is a non-profit, nonpartisan organization dedicated to improving the effectiveness, efficiency, and quality of America's health care system by conducting research, policy analysis, and educational activities on a range of health care issues. In addition, it fosters dialogue between the private health care industry and government to find workable solutions to health system problems.

Publications include:

*Children's Mental Health: An Overview and Key Considerations for Health System Stakeholders. T*his report was written for a forum on children's mental health sponsored by the NIHCM. It provides overview of the key issues surrounding children's mental health, information on efforts being implemented at the state level to meet the mental health needs of children, and

information on financing mechanisms and resources for children's mental health.

**National Institute of Mental Health (NIMH)**
www.nimh.nih.gov
The NIMH is actively involved in strategic planning and priority-setting for the Institute as a whole as well as for specific research areas. NIMH solicits input from patients and their advocates, scientists, Congress, the public, and the National Advisory Mental Health Council. Workgroups of the Council and staff review the portfolio to recommend areas for future investment, with respect to relevance to the mission, traction (capacity for rapid progress), and innovation. NIMH is working to improve mental health through biomedical research on mind, brain, and behavior.

**National Mental Health Association (NMHA)**
www.nmha.org
The NMHA is the country's oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. NMHA has more than 340 affiliates and works to improve the mental health of all Americans, especially the 54 million people with mental disorders, through advocacy, education, research, and service.

**National Technical Assistance Center for Children's Mental Health**
gucchd.georgetown.edu/programs/ta_center/index.html

The Technical Assistance Center assists states and communities in developing comprehensive, community-based, family-centered, and culturally competent systems of care for children and adolescents with serious emotional disturbances and to play a leadership role for system change.

**Ohio Consumer Outcomes System**
www.mh.state.oh.us/oper/outcomes/outcomes.index.html
The Ohio Consumer Outcomes System is an ongoing endeavor to obtain outcome measures for consumers served by Ohio's public mental health system.

**Ohio Department of Mental Health (ODMH)**
www.mh.state.oh.us/
Ohio's public mental health system includes the Ohio Department of Mental Health (ODMH), 50 county and multi-county boards, and nearly 500 community mental health agencies. The boards do not directly provide services but oversee both mental health and addiction services. They act as local mental health authorities, funding, planning, monitoring and purchasing services provided by private agencies and the Behavioral Healthcare Organizations operated by ODMH. This approach which emphasizes local management and control, generates strong citizen involvement and local financial support for mental health services.

**President's New Freedom Commission on Mental Health**
www.mentalhealthcommission.gov
President George W. Bush established the Commission in April 2002. The Commission's 15 subcommittees examined specific aspects of mental health services and offered recommendations for improvement in July 2003.

**Research and Training Center for Children's Mental Health**
www.rtckids.fmhi.usf.edu
This center, located at the University of South Florida, was initiated to address the need for

improved services and outcomes for children with serious emotional/behavioral disabilities and their families. Building on previous investigations, the Center's six integrated research projects are designed, in the short run, to enhance knowledge about effective implementation of system of Care, and, in the long run to make it possible for children with serious emotional disturbances to live, learn, work, and thrive in their own communities. The Center's annual conference has become the principal national forum for exploring research and evaluation findings related to the implementation of system of care.

**The Research and Training Center on Family Support and Children's Mental Health**
www.rtc.pdx.edu/
Located at Portland State University, this center is dedicated to promoting effective community-based, culturally-competent, family-centered services for families and their children who are, or may be affected by mental, emotional, or behavioral disorders. This goal is accomplished through collaborative research partnerships with family members, service providers, policymakers, and other concerned persons.

**Substance Abuse and Mental Health Services Administration**
www.samhsa.gov
The United States Department of Health and Human Services, Substance Abuse, and Mental Health Services Administration works to build resilience and facilitate recovery for people with or at risk for substance abuse and mental illness. The site has information including federal grants, programs, resources, information, and links dealing with substance and mental health services.

*NOTE: Significant portions of these descriptions were taken directly or adapted from the organization websites listed above.*

## Appendix F
## Acronyms Related to Children's Mental Health and Represented in this Report

| | |
|---|---|
| AACAP | The American Academy of Child and Adolescent Psychiatry |
| ACLU | The American Civil Liberties Union |
| ACT | Assertive Community Treatment |
| ACTT | Assertive Community Treatment Teams |
| ACYF | Administration for Children, Youth, and Families |
| ADHD | Attention Deficit Hyperactivity Disorder |
| ADM | Alcohol, Drug Abuse and Mental Health Block Grant |
| AHEC | Area Health Education Center |
| AMI | Alliance for Mental Illness |
| AOI | Assessment and Outcome Instrument |
| AP | Area Program |
| AT | Assistive Technology |
| BD | Behavioral Disorder |
| BED | Behavioral/Emotional Disorder |
| BGSU | Bowling Green State University |
| BH | Behavioral Health |
| BIP | Behavioral Intervention Plan |
| BP | Behavioral Problem |
| CACMH | Center for the Advancement of Children's Mental Health |
| CAFAS | Child and Adolescent Functional Assessment Scale |
| CAHMI | Child and Adolescent Health Measurement Initiative |
| CAP | Community Alternatives Program |
| CAP-C | Community Alternatives Program for Children |
| CAPE | Cluster Analytic Planning and Evaluation |
| CASSP | Child and Adolescent Services System Program |
| CBS | Community-based Services |
| CBT | Cognitive Behavior Therapy |
| CCCS | Caring for Children in the Community Study |
| CCOE | Coordinating Centers of Excellence |
| CFP | Child and Family Plan |
| CFS | Child and Family Services |
| CFT | Child and Family Teams |
| CHIP | Children's Health Insurance Program |
| CHSH | Children's Special Health Services |

| | |
|---|---|
| CMECD | Children with Early Childhood Disorder |
| CMDEF | Deaf or Hard of Hearing Child |
| CMH | Children's Mental Health |
| CMHC | Community Mental Health Center |
| CMHS | Center for Mental Health Services |
| CMI | Chronic Mental Illness |
| CMMED | Seriously Emotionally Disturbed Child |
| CMPAT | Homeless child - PATH |
| CMSED | Seriously Emotionally Disturbed Child with Out-of-Home Placement |
| COI | Client Outcome Instrument |
| CRC | Children's Resource Center |
| CYSED | Children and Youth with Serious Emotional Disorders |
| DCD | Division of Child Development (NC DHHS) |
| DD | Developmental Disability |
| DFS | Division of Facilities Services (NC DHHS) |
| DHHS | Department of Health and Human Services |
| DJJDP | Department of Juvenile Justice and Delinquency Prevention |
| DMA | Division of Medical Assistance (NC DHHS) |
| DMH/DD/SAS | Division of Mental Health, Developmental Disabilities, and Substance Abuse Services |
| DPI | Department of Public Instruction |
| DPH | Division of Public Health (NC DHHS) |
| DSM III R | Diagnostic and Statistical Manual of Mental Disorders (3rd Ed. Revised) |
| DSS | Division of Social Services (NC DHHS) |
| DYS | Division of Youth Services |
| EBD | Emotional or Behavioral Disorder |
| EBP | Evidence-based Practice |
| ECU | East Carolina University |
| ED | Emotional Disability or Disorder |
| EPSDT | Early Periodic Screening, Diagnosis and Treatment |
| FAST$05 | Family and System Team Dollars 2005 |
| FCFC | Family and Children First Council |
| FFCMH | Federation of Families for Children's Mental Illness |
| GSMS | Great Smoky Mountains Study |
| GUCCHD | Georgetown University Center for Child and Human Development |
| HCBS | Home and Community-based Services |
| I & R | Information and Referral |
| ICC | Interagency Coordinating Council |
| ICD-9 | International Classification of Diseases – 9th Revision |
| ICF | Intermediate Care Facility |

| | |
|---|---|
| IDEA | Individuals with Disabilities Education Act |
| IEP | Individualized Education Plan |
| IFSP | Individualized Family Service Plan |
| ILC | Independent Living Center |
| IPRS | Integrated Payment and Reporting System |
| IST | Individual Service Team |
| LCSW | Licensed Clinical Social Worker |
| LICC | Local Interagency Coordinating Council |
| LME | Local Management Entity |
| LOC | Level of Care |
| LRE | Least Restrictive Environment |
| MACSIS | Multi-Agency Community Service Information System |
| MCH | Maternal and Child Health |
| MED | Mental or Emotional Disability or Disorder |
| MHA/NC | Mental Health Association in North Carolina |
| MH/DD/SAS | Mental Health, Developmental Disabilities, and Substance Abuse Services |
| MR | Mental Retardation |
| MST | Multi-Systemic Therapy |
| MSW | Masters of Social Work |
| NAMI | National Association for Mental Illness |
| NASMHPD | National Association of State Mental Health Program Directors |
| NCAHEC | North Carolina Area Health Education Centers Program |
| NCAMI | North Carolina Alliance for the Mentally Ill |
| NCAMI-CAN | North Carolina Alliance for the Mentally Ill – Children & Adolescents Network |
| NCATP | North Carolina Assistive Technology Project |
| NCCC | North Carolina Consumer Council |
| NCCDD | North Carolina Council on Developmental Disabilities |
| NCPA | North Carolina Psychiatric Association |
| NCSL | National Conference of State Legislatures |
| NC-SNAP | North Carolina Support Needs Assessment Profile |
| NCTSN | National Child Traumatic Stress Network |
| NGA | National Governors Association |
| NICHQ | National Initiative for Children's Health Care Quality |
| NIHCM | National Institute for Health Care Management |
| NIMH | National Institute of Mental Health |
| NMHA | National Mental Health Association |
| ODMH | Ohio Department of Mental Health |
| OJJDP | Office of Juvenile Justice and Delinquency Prevention |
| OT | Occupational Therapy |

| | |
|---|---|
| OTF | Outcomes Task Force |
| PAC | Parent Advisory Council |
| PATH | Projects for Assistance in Transition from Homelessness |
| PCP | Person-centered Plan |
| PDD | Pervasive Developmental Disorder |
| PL 99-660 | State Comprehensive Mental Health Services Plan Act of 1986 |
| POS | Purchase of Service |
| PPO | Preferred Provider Organization |
| PT | Physical Therapy |
| PTI | Parent Training and Information Centers |
| R &T | Resource and Training Centers (on children's mental health) |
| ROLES | Residential Living Environment Placement Stability Scale |
| RRC | Regional Resource Centers |
| RRTC | Rehabilitation Research and Training Center |
| SAMSHA | Substance Abuse and Mental Health Services Administration |
| SDDA | State Developmental Disability Authority |
| SED | Serious Emotional Disturbance |
| SERP | Services Effectiveness Research Program |
| SILC | State Independent Living Council |
| SMHA | State Mental Health Agency |
| SMHRCY | State Mental Health Representative for Children and Youth |
| SMI | Serious Mental Illness |
| SOC | System of Care |
| SPMI | Severe and Persistent Mental Illness |
| ST | Speech Therapy |
| T/HP | Treatment/Habilitation Plan |
| UCR | Unit Cost Reimbursement |
| UM | Utilization Management |
| UR | Utilization Review |
| VR | Vocational Rehabilitation |
| WCF&CFC | Wood County Family and Children's First Council |

*Note: Significant portions of this document were taken from the Research and Training Center on Family Support and Children's Mental Health, Glossary of Acronyms webpage and the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services Acronyms and Glossary webpage.*

## Appendix G

# Glossary of Children's Mental Health Terms

**Accessible Services:** Services that are affordable, located nearby, open during evenings and weekends and do not require people to be placed on a long waiting list. Services that consider individual and cultural values as well as barriers that might keep a person from getting help.

**Appropriate Services:** Services, usually provided in the child's community, that are designed to meet the specific needs of each individual child and family based on the best treatment options.

**Appropriate Education:** An individual education program specially designed to meet the unique needs of a child who has a disability.

**Assessment:** A professional review of child and family needs done when they first seek services. The assessment of the child includes a review of physical and mental health, intelligence, school performance, family situation, and behavior in the community. The assessment identifies the strengths of the child and family and is used to determine the most appropriate treatment.

**Behavioral Disorder:** Characterized by the display of behaviors over a long period of time that significantly deviates from socially acceptable norms for the individual's age and situation.

**Capitated Rates**: Reimbursement rates by insurance companies to care providers that have a predetermined amount (cap) of dollars for rendered services.

**Care Coordination**: Brokering services for an individual to ensure that their needs are met and their services are not duplicated by the organizations involved in providing care.

**Case Management**: A service that assists clients to obtain and coordinate appropriate services and community resources such as income assistance, education, housing, medical care, treatment, vocational preparation, and recreation.

**Case Manager:** An individual who organizes and coordinates services and supports for children with mental health problems and their families.

**Child Psychiatrist:** A medical physician qualified to prescribe medications, with a specialization in mental, emotional, or behavioral disorders in children and adolescents.

**Child Psychologist:** A mental health professional with a Ph.D. in psychology who studies and evaluates the social and mental development of children and treats children's emotional disorders, but cannot prescribe medicine.

**Child Welfare:** A social service field that focuses on the basic needs and well-being of children.

**Clinical Social Worker:** A mental health professional trained to provide services to individuals, families, and groups.

**Community-based Services:** An approach to mental health service provision that locates the management, decision-making responsibility, and treatment at the community level.

**Conduct Disorder:** Repetitive and persistent patterns of behavior that violate either the rights of others or age appropriate social norms or rules.

**Children and Adolescents At Risk for Mental Health Problems:** Children who are at greater risk for developing mental health problems due to certain factors in their lives or environments: physical abuse, emotional abuse, neglect, harmful stress, discrimination, poverty, loss of a loved one, frequent relocation, alcohol and other drug use, and exposure to violence and other traumas.

**Continuum of Care:** Provision of multiple services for children over time. The term has recently become interchangeable with comprehensive services. Also see *system of care* and *wraparound services.*

**Coordinated Services:** Children's service agencies and the child's family working together to develop and agree on a plan of care to meet the child's needs. Agencies can include mental health, education, juvenile justice, and welfare, among others.

**Crisis Residential Treatment Services:** Short-term, round-the-clock help provided in a nonhospital setting during a crisis - such as if a child becomes aggressive and uncontrollable. This care is used to a*void inpatient hospitalization,* help stabilize the child, and determine the next appropriate step.

**Cultural Competence:** An awareness and acceptance of cultural differences, an understanding of how cultural dynamics play a role in determining the best treatment options and service needs of a child and family, and the ability to adapt skills to fit the client's cultural context.

**Custody Relinquishment:** The practice of requiring parents to surrender their child into state custody to receive services at public expense.

**Day Treatment:** Community-based, non-residential program of intensive services for children with emotional disorders that allows the child to remain in the home.

**Developmental Disorders:** Disorders that predominantly affect the normal development of language, motor, cognitive and/or motor skills.

**Deviant Behavior:** Breaking formal or informal rules or laws relative to social customs or norms, including sexual behavior.

**Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV):** The official manual of mental health problems developed by the American Psychiatric Association. This reference book is used by psychiatrists, psychologists, social workers, and other health and mental health care providers as well as insurance companies to understand, diagnose and discuss mental health problems.

**Early Intervention:** Services for young children (typically birth to five-year-olds) that address developmental disabilities or child development more generally.

**Emergency and Crisis Services:** Services that are available 24 hours a day, 7 days a week, to help during a mental health emergency. Examples include telephone crisis hotlines, suicide hotlines, crisis counseling, *crisis residential treatment services*, crisis outreach teams, and crisis respite care.

**Emotional Disorder (or Disability):** Behavior, emotional, and/or social impairment exhibited by a child or adolescent that consequently disrupts the child's or adolescent's academic and/or developmental progress, family, and/or interpersonal relationships.

**Evaluation:** A process conducted by mental health professionals which informs an opinion about a child's mental or emotional capacity, and may include recommendations about treatment or placement.

**Exceptional Children:** Children whose performance deviates from the norm (either above or below) and requires special programming.

**Family-centered Services:** Services that are designed to meet the needs of each individual child and family. Also see *appropriate services, coordinated services, wraparound services, and cultural competence.*

**Family Support Program:** Programs to assist children and their families in their community so children can remain in their homes, and families can live balanced, healthy lives.

**Family Support Services:** Services designed to keep families together while seeking and receiving treatment for mental health problems. Services may include consumer information workshops, in-home supports, family therapy, parenting training, crisis services, and respite care.

**Family Therapy:** A treatment model that involves interaction with family members and family interactions as well as with the individual.

**Federation of Families for Children's Mental Health:** A parent-run organization focused on the needs of children and youth with emotional, behavioral or mental disorders and their families.

**Home-based Services:** Treatment or services provided in a family's home in efforts to prevent the child from being placed outside the home. Services can be for a defined period of time or for as long as it takes to address a mental health problem. Examples include parent training, counseling, and working with family members to identify, find or provide other necessary help.

**Independent Living Services:** Support for a young person living on his or her own that helps teach skills to meet daily living needs (financial, medical, transportation). Services include *therapeutic group homes*, supervised apartment living, and job placement.

**Individualized Education Plan (IEP):** A federally mandated written individual plan of services developed by parents and school personnel for all children with disabilities who qualify for special education.

**Individualized Services:** Services designed to meet the unique needs of each child and family based on needs and strengths, ages, and stages of development of the child and individual family members. Also see *appropriate services* and *family-centered services.*

**Inpatient:** Services received while residing in the hospital or residential care facility.

**Inpatient Hospitalization:** Mental health treatment provided in a hospital setting 24 hours a day. Inpatient hospitalization provides: (1) short-term treatment in cases where a child is in crisis and possibly a danger to his/herself or others, and (2) diagnosis and treatment when the patient cannot

be evaluated or treated appropriately in an outpatient setting.

**Least Restrictive Environment:** Appropriate educational, treatment or living situations or programs for a child with disabilities with as few limitations or constraints as possible.

**Managed Care:** A health care service delivery model which may specify which service provider the insured family can use as well as set a limit on the number of visits and kinds of services covered by insurance.

**Mental Health:** How a person thinks, feels, and acts when faced with life's situations. *Mental health* is how people look at themselves, their lives, and the other people in their lives; evaluate their challenges and problems; and explore choices. This includes handling stress, relating to other people, and making decisions.

**Mental Health Problems:** Mental health problems affect one's thoughts, body, feelings, and behavior. Mental health problems can be severe, seriously interfere with a person's life, and cause a person to become disabled. They include depression, bipolar disorder (manic-depressive illness), attention-deficit/hyperactivity disorder, anxiety disorders, eating disorders, schizophrenia, and conduct disorder.

**Mental Illness**: General term applied to severe emotional problems or psychiatric disorders.

**Outpatient:** Treatment available in the community at a local mental health clinic or from private therapists that allows children to live at home.

**Pervasive Developmental Disorder:** Extreme distortions or delays in the development of social behavior and language.

**Post-Traumatic Stress Disorder (PTSD):** Anxiety disorder following a traumatic event.

**Psychiatric Nurse:** A registered nurse specializing in the care of patients with emotional or psychiatric disorders.

**Psychiatric Social Worker:** Social worker specializing in work with psychiatric patients and their families.

**Psychiatrist:** A medical physician qualified to prescribe medication that specializes in mental, emotional, or behavioral disorders.

**Residential Treatment:** Live-in facilities that provide treatment and care for children with emotional disorders who require continuous medication and/or supervision or relief from environmental stresses.

**Serious Emotional or Behavioral Disability/Disorder:** Diagnosable disorders in children and adolescents that severely disrupt their daily functioning in the home, school, or community.

**Support Services:** Transportation, financial help, support groups, homemaker services, respite services, and other specific services to support children and families.

**Systems of Care:** A comprehensive spectrum of mental health and other services organized into a coordinated network to meet the multiple and changing needs of children with emotional disorders.

**Systems Change:** Making modifications in the way policy and procedures are made or services are delivered across multiple programs or agencies.

**Transition Services**: Services needed by youth in transition, such as independent living skills, career education, interpersonal relationship skills, leisure time training, vocational training, job placement, on-site supervision, and supervised apartment living.

**Wechsler Scales:** A series of IQ tests widely used in school systems. Three versions are used:

1. WPPSI: The Wechsler Preschool and Primary Scale of Intelligence;
2. WISC or WISC-R: The Wechsler Intelligence Scale for Children (Revised); and
3. WAIS-R: The Wechsler Adult Intelligence Scale (Revised).

**Wraparound Services**: A coordinated delivery of individually tailored services to children and their families with the goal of keeping the family together in the community and being included in normalized school settings.

*NOTE: Significant portions of this document were taken from the Substance Abuse and Mental Health Services Administration's National Mental Health Information Center Glossary of Terms on Child and Adolescent Mental Health webpage and the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services' Acronyms and Glossary webpage.*

## Selected Family Impact Seminar Briefing Reports

Each seminar is accompanied by a briefing report that summarizes research on a topic and identifies policy options. Copies of this and future briefing reports are available at: www.childandfamilypolicy.duke.edu/fisindex.html

**Family Impact Seminar Briefing Reports on Children's and Family Health Issues**

| State | Seminar Title |
|---|---|
| **NC** | **Medicaid Cost Containment Strategies**<br>www.childandfamilypolicy.duke.edu |
| **DC** | **Do School-based Mental Health Services Make Sense?**<br>www.ncemch.org/dcfps/pdf/11_1999.pdf |
| **DC** | **Substance Abuse Prevention and Treatment Programs: A Family Approach**<br>www.ncemch.org/dcfps/pdf/02_1995.pdf |
| **CA** | **Understanding and Preventing Family Violence**<br>www.library.ca.gov/CAFIS/reports/96-03/96-03.pdf |
| **CA** | **Diverting Children from Crime: Family-centered, Community-based Strategies for Prevention**<br>www.ncemch.org/dcfps/pdf/05_1997.pdf |
| **NM** | **Saving Lives, Saving Dollars: Mitigating the Impact of Child Maltreatment**<br>www.familyimpactseminars.org |
| **NY** | **A Comprehensive, Community-based Approach to Preventing Child Abuse and Youth Violence** |
| **DC** | **Fundraising for Family-centered Organizations in the District**<br>www.ncemch.org/dcfps/pdf/07_1996h.pdf |
| **NY** | **Making Social Indicators Useful for Policy and Program Management in New York State** |
| **NY** | **Healthy Communities: Concepts and Collaboration Tools** |
| **NY** | **Community-based Health Planning** |

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Kenneth A. Dodge, Director

# Center for Child and Family Policy

The **Center for Child and Family Policy** brings scholars from many disciplines together with policymakers and practitioners to address problems facing children in contemporary society. The Center is a national leader in addressing issues of early childhood adversity, education policy reform, and youth violence and problem behaviors. The Center bridges the gap between research and policy by assisting policymakers in making informed decisions based on sound evidence and research.

The Center supports a variety of research studies in child and family policy and also provides comprehensive program evaluation services to local, state and federal policymakers, nonprofits organizations and foundations.

The interdisciplinary Center for Child and Family Policy is led by Kenneth A. Dodge, Ph.D. and housed within the Terry Sanford Institute of Public Policy at Duke University in Durham, North Carolina.

*Center for Child and Family Policy publications and policy briefs are available at www.childandfamilypolicy.duke.edu.*

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